# Respect for the right to health for older prisoners?
# Analyzing the challenges and opportunities in correctional settings in Switzerland

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**Table of Contents**

# Abbreviations

AAAQ: Availability Accessibility Acceptability and Quality

BfS: Bundesamt für Statistik

BGE: Bundesgerichtsentscheid

CoE: Council of Europe

CPHS: Committee for the Protection of Human Subjects

CSC: Correctional Services Canada

CPT: European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment

EPR: European Prison Rules

FMH: Foederatio Medicorum Helveticorum

HoNOS: Health of the Nation Outcome Scales

ICESCR: International Covenant on Economic, Social and Cultural Rights

KKJPD: Konferenz der Kantonalen Justiz- und Polizeidirektorinnen und –direktoren

KNMG: Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst

LGBT: Lesbian, gay, bisexual and transgender

MAID: Medical Aid in Dying

MINI: Mini International Neuropsychiatric Interview

MR: Mandela Rules

PHQ-9: Patient Health Questionnaire

SAMW: Schweizer Akademie der medizinischen Wissenschaften

SCC: Swiss Criminal Code

UN: United Nations

UNODC: United Nations Office on Drugs and Crimes

WHO: World Health Organization

WMA: World Medical Association

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# Contributions

This thesis consists of a general introduction and the first chapter outlining the current situation of this particular population. Four more chapters follow, each constituting a journal article on a specific challenge for this population. In the end, a general discussion and conclusion summarize the findings. For the general introduction, the general discussion and the conclusion of this thesis and for one journal article, I was the sole author.

Haesen S, Merkt H, Imber A, Elger B, Wangmo T (2019). Substance use and other mental health disorders among older prisoners. Int J Law Psychiatry. 2019 Jan - Feb;62:20-31. doi: 10.1016/j.ijlp.2018.10.004. Epub 2018 Nov 11
In this systematic literature review, I analysed publications on empirical research on prevalence and co-occurrence of substance use and other mental health disorders. Helene Merkt and Arnaud Imber contributed to the data collection and analysis. Dr. Tenzin Wangmo reviewed the first draft and together we decided on the final structure. Dr. Wangmo also reviewed the subsequent drafts. Prof. Bernice Elger gave helpful comments on later drafts of the manuscript.

Haesen S, Wangmo T, Elger BS (2017). Identity as an older prisoner: findings from a qualitative study in Switzerland. Eur J Ageing. DOI 10.1007/s10433-017-0443-2
For this publication, Prof. Bernice Elger, Dr. Tenzin Wangmo and I conceptualized the paper. I drafted the manuscript based on research data that had been collected in the context of the first Agequake project and had remained unused. These data were co-analyzed by Dr. Tenzin Wangmo. who also critically reviewed and commented on the several drafts of this publication, and Prof. Bernice Elger gave helpful comments on the structure.

Haesen S, Merkt H, Elger B, Wangmo T (2019) Chains, trains and automobiles. Medical transport for prisoners in Switzerland. Submitted September 2nd, 2019 to Journal of Correctional Health Care, manuscript ID JCHC-19-09-0070
I conceptualized and drafted the manuscript for this publication together with Dr. Tenzin Wangmo. Some information had been gathered in the context of the first Agequake project; most research data had been collected by Helene Merkt and myself. Dr. Tenzin Wangmo critically reviewed and commented on the several drafts of this publication, and Prof. Bernice Elger provided helpful comments on the final version of this paper.

Haesen S, Shaw D (2018). Directing citizens to create advance directives. Swiss Med Wkly 2018;148:w124628. Published 16 May 2018. doi:10.4414/smw.2018.14628
This paper was based on a short manuscript written for a methods course taught by Dr. David Shaw in the context of the Institute for Biomedical Ethics' PhD program. My knowledge on and interest in the subject of advance directives provided a good foundation for this publication. I drafted the manuscript, and Dr. Shaw contributed helpful comments on content and structure. I decided to include this paper in my thesis as advance directives are becoming more important in the correctional context due to the increasing number of older prisoners.

Haesen S (2018). How People Traveling Abroad to Die Came to be Called “Death Tourists”, and Why They Shouldn’t. Journal of Social Work in End-of-Life & Palliative Care, DOI: 10.1080/15524256.2018.1528934

This single-authored publication resulted from my interest in the end of life. Assisted suicide is legal in Switzerland under certain conditions, for Swiss residents as well as for non-residents. It became evident that individuals who are not residents of Switzerland are stigmatized by the media. I conceptualized and wrote the manuscript that was not in direct connection with the research project but covers a topic that is also relevant for older prisoners in Swiss correctional institutions, as both these groups are vulnerable and marginalized. For this reason, I chose to include it in this thesis.

# Summary

Penal institutions in Switzerland differ by their size, their location, their type of detention and by many other factors. One aspect that is common for all of them is that they have to provide healthcare for the detained persons who may already arrive with illnesses or disorders, or who develop health problems during detention. Older individuals, suffering both from chronic diseases and from health problems linked to old age, can be particularly vulnerable. The concept that "prison health is public health" means that taking care of prisoners' health does not only benefit the individual but that prison healthcare influences a whole country's health situation. Released individuals in good health can contribute positively to society, but the public healthcare system can also be burdened by prisoners who are released in bad health.

Both for prisoners and for persons in free society, the right to health – or the enjoyment of the highest attainable standard of physical and mental health, as the WHO puts it – is a fundamental human right. On a global scale, this right is not always respected for prisoners who suffer a high burden of health problems and whose health needs often remain unmet. The aim of this thesis is to examine if this is the case also for older prisoners in Switzerland.

The introduction offers general information on the right to health. It also presents data on demographic changes of the Swiss prison population, on the penal system and on the organization of prison health care in Switzerland.

Chapter 1 provides an introductory overview on older prisoners with mental health disorders and specifically substance use disorders.

Chapter 2 explores the availability of "healthy" models for identity formation in prison which may positively contribute to mental health. Choices and role models available in a correctional institution may differ from the choices a person in free society has.

The topic of chapter 3 is the accessibility of healthcare services for prisoners, especially physical accessibility. Not all necessary services can be offered in prison so that transportation to other locations can be necessary. This can bring along a special set of challenges.

Chapter 4 discusses advance directives in the general population. This topic can be extended to the prison population .as the acceptability and availability of advance directives in correctional institutions need to be discussed. Also prisoners should be encouraged to draft advance directives (and donate organs, an area which is only fleetingly mentioned in the chapter).

Chapter 5 covers an aspect of assisted suicide that is especially pertinent for Switzerland, as the legislation here is more liberal towards residents of other countries than elsewhere. These persons can be vulnerable due to their health status and age, similar to prisoners. In this context, the availability and acceptability of assisted dying for prisoners need to be mentioned. The question if assisted dying should be available to prisoners has been discussed in other countries where this option for the end of life is legally possible, with differing results.

The last part of the thesis provides a general discussion of the presented work and summarizes the findings. The implications for research and practice are briefly outlined. The fact that chapters 1, 2, 4, and 5 have been published in various European and American journals explains a possible overlap between the description of background and methodology. All five chapters together examine the situation of older prisoners in the Swiss correctional system from various aspects and aim to answer the question if they can exercise the right to health without obstacles.

# General Introduction

## Background: The right to health

The notion that health is a human right is a modern development and has been stated in various international documents and declarations, the most known being the World Health Organization's Constitution (WHO, 1946) and the Universal Declaration of Human Rights (UN, 1948). These documents have been ratified by a considerable number of member states of the respective body, and they contain numerous obligations for member states to generate conditions in which "everybody can be as healthy as possible" (United Nations, 1966).

Grad (2002) delineates how the United Nations had initiated the creation of a world health organization, which came into existence two years later, in 1948. In the same year, the United Nations adopted and proclaimed the Universal Declaration of Human Rights (United Nations, 1948). The right to health has for the first time been stated in the World Health Organization's Constitution stemming from 1946. Here, health is defined as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity", and the "enjoyment of the highest attainable standard of health" is called "one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (WHO, 1946).

The term "right to health" is thus referring to the "right to the highest attainable standard of health". The UN's Universal Declaration of Human Rights states in Article 25 that everyone "has the right to a standard of living adequate for the health and well-being of himself and of his family, including (…) medical care (…) and the right to security in the event of (..) sickness, disability (…), old age" (United Nations, 1948). This principle has been reiterated in the International Covenant on Economic, Social and Cultural Rights or ICESCR (United Nations, 1966). Gruskin et al. (2007) show how the responsibility that a government holds extends beyond providing essential health services to addressing general determinants of health, for example education, favorable working and social conditions or adequate housing, all of which are human rights in themselves and necessary for wellbeing and health. The strong relation between the right to health and other human rights is thus evident.

It is worth noticing the difference between the right to health and the right to be healthy. This difference has for example been pointed out in the General Comment No.14 on the ICESCR of the UN Committee on Economic, Social and Cultural Rights (2000). Although, according to this document, "the right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life", it "is not to be understood as a right to be healthy", as "good health cannot be ensured by a State, nor can States provide protection against every possible cause of human ill health". Additionally, the "adoption of unhealthy or risky lifestyles may play an important role with respect to an individual's health".

The same Comment No. 14 gives an overview over the four pillars of the right to health: accessibility, availability, acceptability and quality what would later be known as the AAAQ framework (UN Committee on Economic, Social and Cultural Rights, 2000). This framework provides general considerations to assess if all four elements of the right to health are present in a given country. In the following, each of these four elements will be described in brief.

**Availability**: The respective State party that has signed the covenant is responsible for providing a sufficient quantity of "(f)unctioning public health and health-care facilities, goods and services, as well as programmes" (UN Committee on Economic, Social and Cultural Rights, 2000, paragraph 12a). According to the economic possibilities of the State, the scope of these facilities and services may differ but in any case they include underlying determinants of health such as hospitals, trained medical personnel "receiving domestically competitive salaries", medication, water and sanitation.

**Accessibility**: Everyone, without discrimination, must be able to access health facilities, goods and preventive, curative and palliative health services. Accessibility can be divided into the following four overlapping components:

Non-discrimination means that said health facilities, goods and services have to be accessible to everyone, and above all "the most vulnerable or marginalized sections of the population" (UN Committee on Economic, Social and Cultural Rights, 2000, paragraph 12b). This must be "in law and in fact", and discrimination - for example on the grounds of race, sex, language, social status, health status and other factors as stated in paragraphs 18 and 19 of the General Comment - is prohibited.

Physical accessibility signifies that all sections of the population must be able to physically access health facilities, goods and services. Again, this concerns especially vulnerable parts of the population such as children or older persons, persons with disabilities or ethnic minorities. Not only the medical services must be safely reachable but also underlying determinants of health, such as water and sanitation. Physical accessibility includes "adequate access to buildings for persons with disabilities".

Economic accessibility, or affordability, means that health facilities, goods and services must be affordable for everyone, and payment for health services and services that are in connection with the underlying determinants of health must be based on the principle of equity. This principle implies that the services must be affordable for everybody, no matter if they are provided by public or private furnishers. Compared to richer parts of the population, poorer parts of the population "should not be disproportionally burdened with health expenses". This is in line with UN guidelines stating that in prison, "medical care and treatment (…) shall be provided free of charge" (United Nations, 1988).

Information accessibility means that everybody has the right to "seek, receive and impart" ideas and information related to health issues. The right of individuals that their personal health data be treated with confidentiality should not impaired by this right.

**Acceptability**: The health facilities, goods and services must respect principles of medical ethics and confidentiality. They must also respect individuals, minorities, communities and people and their culture and choices, and be committed to improving the health status of the concerned patients.

**Quality**: Health facilities, goods and services must be culturally acceptable, scientifically and medically appropriate, and of good quality. This includes well-trained staff, "scientifically approved and unexpired drugs and hospital equipment", adequate water and sanitation facilities.

For all these four components, a non-exhaustive catalogue of examples is listed in the General Comment for illustration. These examples include concrete situations like scientifically approved and unexpired drugs or adequate access to buildings for persons with disabilities, but also concepts like equity so that poorer households will not be disproportionately burdened with health expenses in comparison to richer households. It must be noted that paragraph 34 of the General Comment states specific legal obligations. Here, it is explicitly noted that "States are under the obligation to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, including prisoners or detainees, minorities, asylum-seekers and illegal immigrants" to preventive, curative and palliative health services (UN Committee on Economic, Social and Cultural Rights, 2000, paragraph 34).

Core obligations of State parties include ensuring "the right of access to health facilities, goods and services (…) especially for vulnerable or marginalized groups", and "equitable distribution of those health facilities, goods and services, and giving particular attention to vulnerable or marginalized groups and subpopulations" (UN Committee on Economic, Social and Cultural Rights, 2000, paragraph 43ff). .

## Vulnerability and prison

According to Ruof (2004), the term "vulnerable" is applied in clinical research to individuals unable to give informed consent, or who are susceptible to being coerced, for example prisoners, children or handicapped or economically disadvantaged persons. In health policy and medical research, vulnerability is an abstract concept without official consensus how to measure or define it. This means that researchers, healthcare professionals and ethicists use different approaches on whom they consider as vulnerable, without always making clear their criteria to include or exclude groups or individuals. Although the concept of vulnerability is important to determine who qualifies for extended health or social services, or for special protection, this classification may also imply labeling. Stating that a certain subpopulation is vulnerable may be seen as paternalistic and alienating because members of that subgroup may not feel disadvantaged, or even feel empowered (Ruof, 2004).

Wrigley and Dawson (2016) describe vulnerability as the idea that an individual (or a group) has a special status that can have a negative impact on his or her well-being, with the implication that the individual cannot safeguard his or her well-being adequately, and must be assisted to do so. They point out that this "special status" is not characterized more precisely so that "almost everyone can be classified as vulnerable in some way and, in turn, that almost every activity now requires this additional attention" (Wrigley and Dawson 2016, p. 204). This can lead to the devaluation of the concept.

The General Comment No. 14 frequently mentions "vulnerable or marginalized groups" and explicitely refers to prisoners and detainees in article 34. Based on historical precedents, in the literature the vulnerability of prisoners has traditionally been stated in relation to research, as "the constraints of incarceration may affect an individual's ability to give voluntary, informed

consent" (CPHS, 2018). An example of abusing prisoners' vulnerability was a part of the Guatemala syphilis experiment where hundreds of adult Guatemalan prisoners were infected with syphilis without them being informed or having the possibility to refuse to participate (Spector-Bagdady and Lombardo, 2019).

In the context of health policy, vulnerabilities can arise both through socioeconomic status and through individual characteristics and diseases (Waisel, 2013). Prisoners are doubly concerned because they often stem from populations with a low socioeconomic status and are often subject to infectious diseases such as tuberculosis, hepatitis or HIV/AIDS, psychiatric disorders such as drug use, sexual deviance or personality disorders.

Researchers and practitioners state that among the population of detainees, certain individuals may be especially vulnerable from a psychosocial perspective. These individuals can be defined as "prisoners at risk of bullying, suicide or self-harm" (UK Government Digital Office, n.d.). Other researchers are distinct, for example the UNODC which defines eight groups of particularly vulnerable prisoners, namely "Prisoners with mental health care needs; Prisoners with disabilities; Ethnic and racial minorities and indigenous peoples; Foreign national prisoners; Lesbian, gay, bisexual, and transgender (LGBT) prisoners; Older prisoners; Prisoners with terminal illness and Prisoners under sentence of death" (UNODC, 2009). Other publications also count prisoners sentenced on the grounds of sexual crimes as a vulnerable group, due to the increased stigmatization and risk of bullying (van den Berg et al., 2017).

According to rules 39 and 40 of the European Prison Rules, the state has a special duty of care towards prisoners because it has the power to deprive them of their liberty. Rule 4 clearly states that "(p)rison conditions that infringe prisoners' human rights are not justified by lack of resources" (Council of Europe 2006), and a member state cannot justify breaching this duty because of insufficient allocation of means. The elements of this duty concern the physical conditions of imprisonment as well as the prison health services. Physical conditions include satisfactory accommodation and sanitary facilities, clothing and heating that are appropriate for the climate, and adequate nutrition that is appropriate for the individual's requirements. Prison health services must be characterized, among others, by professional independence, confidentiality, equivalence of care, access to a doctor at any time without undue delay, and professional competence (UNODC 2013). However, somatic and mental healthcare in prison are subject to particular challenges, especially to equivalent care and dual loyalty (Niveau, 2007; Pont et al., 2012).

Because of their vulnerability, prisoners deserve special protection (Shaw & Elger, 2015). The United Nations' Basic Principles for the Treatment of Prisoners explicitely state that '(p)risoners shall have access to the health services available in the country without discrimination on the grounds of their legal situation" (United Nations 1990, paragraph 9). This notion is widely known in prison healthcare as equivalence of care. Discussions have arisen whether this equivalence can be measured via equivalence of process (which services are provided, how they are funded and who provides them) or if other parameters such as equivalence of outcomes need to be taken into account. The latter view of equivalence

concentrates on the health outcomes that result from the care that is being delivered (Charles & Draper, 2011). Jotterand and Wangmo (2014) underline that equivalence of outcome is more appropriate for the prison context due to its specific characteristics, such as lack of autonomy of patients or the special therapeutic relationship. However, they note that the principle of equivalence "compares two different settings and two distinctive populations" (ibid., p.10), and stress the need for more conceptual clarity.

Because of their imprisonment, prisoners are not able to choose treatments and healthcare providers. This dependency increases their vulnerability. In many cases, the healthcare professionals working in prison cannot solely be loyal to their patient (the prisoner) as they act at the same time as "personal confidential caregiver" and as "forensic or public health officer accountable to the authorities" (Pont et al., 2012). This ethical dilemma for healthcare practitioners is known as dual loyalty and is defined by Pont and colleagues (2012) as a "clinical role conflict between professional duties to a patient and obligations, express or implied, to the interests of a third party such as an employer, an insurer, or the state". This definition expands a former one of the International Dual Loyalty Work Group (2003) of "simultaneous obligations, express or implied, to a patient and to a third party, often the state". Dual loyalty problems include, among others, "(s)ubordinating independent medical judgment, in therapeutic or evaluative settings, to support medical conclusions favorable to the state" or "(l)imiting or denying medical treatment or information related to treatment to an individual to effectuate policy of the state in a manner that violates the patient's human rights" (International Dual Loyalty Work Group, 2003). It is important to note that dual loyalty conflicts are not limited to authoritarian societies but can also occur in countries that are generally qualified as liberal and democratic.

## Older prisoners as a doubly vulnerable population

It is notable that the exact age cut-off for an older prisoner has changed over time from reaching retirement age (e.g. Farragher & O'Connor 1995 and later Hunt et al., 2010) to cut-off ages as early as 45 years under certain conditions (Sodhi-Berry et al., 2015). According to Forsyth and colleagues, the, most common cut-offs to define an "older" prisoner are currently 50 and 55 years, with the age of 50 being an appropriate age to start preventative measures to improve the prisoners' health (Forsyth et al., 2017). Another reason for this choice is the concept of "accelerated aging" which means that prisoners at age 50 present a health status that is comparable to non-imprisoned persons of 60 to 65 years due to lifestyle and limited access to preventive care and health services (Mitka, 2004).

As stated earlier, the UNODC categories list "older prisoners" and "prisoners with terminal diseases" as particularly vulnerable. Both notions imply the perspective of nearing the end of life. These two distinct categories can overlap if older prisoners suffering from chronic or terminal diseases stay in prison because of various reasons (compassionate release may not be possible; or places in nursing homes or other long-term care facilities may be lacking). This overlap leads to this subpopulation as particularly, or doubly, vulnerable. Depending on the

particular situation, certain individuals who are in prison, are female and old and suffer from a terminal disease can be vulnerable in even more ways..

All older prisoners in Switzerland can thus be qualified as at least doubly vulnerable, because they are imprisoned and because they approach the end of life. Literature shows that these prisoners argue in favor of extended possibilities for compassionate release (Handtke et al., 2017). Although a legal framework for compassionate release exists in Switzerland, it does not happen often: from 1997 to 2017, the Swiss federal assembly received ten petitions for pardon and granted two (Bundesversammlung, n.d.). More frequently, conditional release is granted if justified by reasons inherent to the prisoner, as stated in article 86 of the Swiss Criminal Code (Schweizerisches Strafgesetzbuch vom 21. Dezember 1937, SR 311.0). The execution of a sanction can be interrupted "for important reasons", but precedents have only occurred if treatment according to general medical standards cannot be offered in prison (cf. Bérard et al., 2015). Cantonal laws can state conditions for a temporarily granted release, for example for a medical appointment, or for a long-term release on compassionate grounds, for example a stay in a nursing facility or hospital for a terminally ill person. Intercantonal agreements mention extraordinary conditional release if the prisoner's health has deteriorated so much during detention that the health status makes committing further crimes at least very improbable (Strafvollzugskonkordat Nordwest- und Innerschweiz, 2018, paragraph 3). For granting or refusing temporary release, the prison authority always has the final decision. Temporary release from an open institution is usually allowed as a matter of routine, but in a secure institution, temporary release is only approved after precise plans have been put in place (Swiss Confederation, 2010, p. 12).

## Penal law in Switzerland

In Switzerland, article 123 of the Federal Constitution defines the criminal law laid down in the Swiss Criminal Code (SCC) as a matter of the federal government (Bundesverfassung der Schweizerischen Eidgenossenschaft vom 18. April 1999, SR 101), and article 372 of the SCC states that the cantons are responsible for the execution and enforcement of the criminal law, unless stated otherwise This includes the operation of prisons and prison health services and is laid down in cantonal laws (see for example Verordnung über den Justizvollzug des Kantons Basel-Stadt vom 11.2.2014, SG 258.210). In order to fill the gap between federal and cantonal legislation and to facilitate inter-cantonal collaboration, three regional arrangements (concordates) were established (Swiss Confederation, 2010).

The SCC is divided into three sections. The general provisions define the application of the SCC and terminology), articles on procedural questions (e.g. powers of courts) and specific provisions which classify sanctions into sentences and measures. This was first proposed by Carl Stooss who in 1893 distinguished sentences from "preempting safeguard measures" and introduced internment for persons being "of unsound mind" (Stooss, 1893). Finally, the third section of the SCC contains articles on procedural questions.

According to article 40.2 SCC, custodial sentences usually last from six months to 20 years, although they can be pronounced for life. Measures differ from sentences in the fact that their duration is not fixed but depends on its intended purpose, as they should only last as long as necessary to eliminate the risk of reoffending, and only when there is a high probability of success (articles 56 and 59 SCC). Measures mentioned in the Swiss Criminal Code can be therapeutic measures, indefinite measures or other measures like prohibitions from practicing a profession or forfeiture of dangerous objects. They are usually ordered in addition to a sentence but can also be ordered by themselves.

To decide on therapeutic and indefinite measures, the court must consider reports by experts with specialized psychiatric qualification and professional experience. Expert reports and the opinion of a commission consisting of a psychiatrist and several representatives of penal authorities are also required for the yearly review or conditional release of so-called "serious cases" (Swiss Confederation, 2010).

Therapeutic measures are regulated in articles 59 to 63. For the stationary treatment of psychiatric disorders (article 59), the felony or misdemeanor must be in direct relation to a psychiatric disorder, and treatment can reduce the risk of further offences due to the disorder. Therapeutic measures should be executed in a psychiatric institution, or in an institution for the execution of measures. If there is a risk of escape or of committing further offences, the prisoner is treated in a secure institution. A measure according to article 59 may last 5 years at maximum, although a five-year extension can be ordered by the court several times, if necessary, for life as the law provides no maximum cumulative length.

Article 64 of the SCC describes "secure care and treatment", i.e. internment. While the aim of therapeutic measures is to treat the offender and thus reduce the risk of repeat offence, the aim of internment is to ensure public safety by excluding the offender from society. Ordering this type of sanction can only happen if two conditions are fulfilled. The sanction must be a serious felony as defined in the article, and the expert legal assessment of the offender must state that the risk remains that the offender will commit further similar acts. Indefinite detention must always be preceded by a therapeutic measure. Even a sanction according to article 64 is not of indefinite length but can be changed into an article 59 under certain conditions (Swiss Confederation, 2010).

A popular initiative introduced lifelong incarceration of "incurable, highly dangerous sexual and violent offenders" into article 123a of the Federal Constitution in 2004, only one request of a Prosecutor's Office has been legally binding; it is unknown how many requests were made in total (Bundesrat, 2016). This is mainly due to the notion that it is not possible for experts to diagose untreatability for life. Although cantonal courts ruled that untreatability during the coming 20 years would mean untreatability for life, the Federal Court did not agree with this reasoning and stated that these cantonal decisions conflicted with federal law (BGE 140 IV 1, S. 6). The notion of untreatability is unclear for other reasons. If an offender does not suffer from a mental health disorder, he cannot be treated and thus qualifies as untreatable. Untreatability may also occur if suitable treatment options, such as specialized institutions, are missing. Untreatability must be directly related to criteria that are structurally, durably and closely linked to the offender's personality. Criteria that can potentially change over time are

not sufficient to qualify for this sanction. A lack of treatment institutions or lacking motivation of the offender to start therapy are not sufficient. (BGE 140 IV 1, S. 6)

An internment according to article 64 is served in a secure penal institution. Switzerland has not yet designed specific institutions limited to offenders with this sentence.

As is shown in table 1, the number of offenders in general, and especially the number of older offenders in Switzerland is increasing (Bundesamt für Statistik 2018, 2018a, 2018b).

| **Sanctions** | **Year** | **Total** | **Male** | **Swiss** | **Age 50 and more** | **Age 60 and more** |
|---|---|---|---|---|---|---|
| All offenders with sentences | 2010 | 3202 | 3042 | 910 | 313 | 92 |
| **All offenders with sentences** | **2017** | **4390** | **4125** | **1131** | **585** | **161** |
| Internment art. 64 SCC | 2010 | 156 | 151 | 113 | | 18 |
| **Internment art. 64 SCC** | **2017** | **143** | **140** | **100** | | **43** |
| Stationäre Massnahme | 2010 | 723 | | | 150 | 33 |
| **Stationäre Massnahme** | **2017** | **887** | | | **242** | **96** |
| Freiheitsstrafe | 2010 | 2210 | | | 272 | 80 |
| **Freiheitsstrafe** | **2017** | **2586** | | | **368** | **108** |
| | | | | | | |

Moschetti and colleagues (2015) mention that 80 % of the sample population in the canton of Vaud were non-Swiss citizens, although it is not clear how many may have been residents of Switzerland. This is higher than for Switzerland over all cantons, with currently 72.1 % of all prisoners being non-Swiss citizens (BfS, 2018c). They also report that the proportion of Swiss detainees was much higher among older prisoners (starting at age 50), namely 51 % of this group.

## Broader application of the right to health

As mentioned earlier, the principle of equivalence of care means that health services in a prison environment must at least correspond to the level of care that is accessible for the population

outside prison. Handtke and colleagues (2012) mention that Switzerland faces not only the task of ensuring that this principle is accepted, but the additional challenge that all 26 cantons have autonomy concerning judicial authority, execution of sanctions and health-related laws which leads to great diversity in prison systems and the organization of prison health services. They note two major problems in achieving equivalence of care in Switzerland, namely independence of prison health care services and prison healthcare workers who are specifically trained (Handtke et al., 2012).

While the principle of equivalence is usually discussed for acute and chronic care, it can be extended to two topics that have been less discussed until now: advance directives and assisted suicide. Just as advance directives are becoming more important for older people outside prison, they merit closer discussion in the penal context, at least for prisoners of a certain age or suffering from health problems. Regarding assisted suicide, a topic of special consideration in Switzerland due to its legal feasibility, health reasons constitute the most frequent reason to ask for an assisted death in occidental countries (Wiebe et al., 2018, Snijdewind et al., 2015, Fischer et al., 2009).

### Advance directives

Advance directives are often discussed in the context of advancing age, although they also come into play in the context of terminal illness or organ donation (Goffin 2012). In the penal context, advance directives have been broadly described by Elger (2014), particularly for the Swiss canton of Geneva. Overall, research on advance directives in prison is scarce and usually focuses on three distinct constellations: prisoners nearing the end of life, prisoners on hunger strike, and prisoners with mental disorders.

For prisoners on hunger strike, article 6 of the World Medical Association's Declaration of Tokyo states that if a prisoner refuses nourishment and is considered by the physician (and at least one other independent physician) as capable of forming an unimpaired and rational judgment concerning the consequences of such a voluntary refusal of nourishment, he or she shall not be fed artificially. The physician must explain to the prisoner the consequences of the refusal of nourishment. (World Medical Association 1975).

The Preamble to the World Medical Association (WMA)'s Declaration of Malta states that an ethical dilemma arises when hunger strikers who have issued clear instructions not to be resuscitated reach a stage of cognitive impairment: The principle of beneficence calls to resuscitate the prisoner but respect for individual autonomy restrains physicians from intervening if a valid and informed refusal has been made. (World Medical Association 1991).

It is necessary to make sure that the prisoner's decision was formed without pressure and while knowing all possible consequences. For the Swiss context, the Swiss Academy of Medical Science has issued guidelines on so-called "long-term fasting", stating that physicians must objectively and repeatedly inform the prisoner about possible risks and consequences of a hunger strike. The guidelines state that if the hunger striker lapses into a coma, physicians must proceed in accordance with their conscience and professional ethics unless the hunger striker

has left explicit instructions to be followed in the event of a life-threatening loss of consciousness. (Swiss Academy of Medical Sciences, 2018)

Another context where advance directives are important is the situation of a prisoner who is nearing the end of his life. Like in free society, topics to be considered range from directives to not resuscitate the person to the use of antibiotics or special care instructions depending on a specific illness or ailment.

The WMA state in the Montevideo declaration on the end of life that patients should be encouraged to express preferences regarding care, that "physicians should discuss a patient's preferences with the patient and/or the patient's substitute health care decision maker and should encourage patients to formally document their goals, values and treatment preferences (WMA, 2011). This indicates that dealing with advance directives is part of medicine and thus also included in the right to health.

The Swiss context gives rise to particular considerations regarding advance directives. Article 372 of the Swiss Civil Code stipulates that doctors have to respect the content of the advance directives unless they violate legal regulations or if there are reasonable doubts that they still reflect the presumed will of the patient (Schweizerisches Zivilgesetzbuch vom 10. Dezember 1907, SR 210).The Swiss Academy of Medical Sciences has issued guidelines on advance directives. They declare that the drawing-up of an advance directive requires personal engagement with disease, accident, the process of dying and death. In healthy phases of life it is only to a limited extent possible to transpose oneself into the situation of a serious illness or death, and basically it is difficult to imagine, in advance, which medical measures one would accept in borderline situations and which not. Special weight is therefore attached to the informed expression of a person's wishes and the careful drawing-up of an advance directive (SAMW, 2013).

### Assisted dying

The WMA spoke out against physicians taking part in euthanasia in the declaration of Madrid (World Medical Association, 1987). The national medical associations of the Netherlands and Canada, where assisted dying and especially euthanasia is legally possible, left the WMA (KNMG, 2019; Owens, 2018).While medical aid in dying is accepted and demanded by members of free society in these countries, assisted dying in prison is a new phenomenon. In the Netherlands, no cases of prisoners demanding assisted suicide or euthanasia have happened yet. In Belgium, the interned prisoner Frank van den Bleeken asked for transfer to a specialized institution in the Netherlands - as none was available in Belgium- or otherwise euthanasia in 2014 because of unberarable suffering in prison (The Guardian, 2014). In Canada the *Guideline 800-9, Medical Assistance in Dying* has been passed to regulate the conditions for medical aid in dying to inmates of Canadian correctional institutions. While of the total number of Canadian prisoners requesting and receiving medical assistance in dying (MAID) is unknown, the Correctional Investigator Ivan Zinger describes the case of an inmate suffering from terminal illness who was on palliative care for over a year, and whose request to receive MAID at a

regional hospital under the authority of Correctional Services Canadawas granted (Zinger, 2018) In Switzerland where assisted dying but not euthanasia is legal, an interned prisoner has requested assisted dying in 2018 (SRF online, 2018).

## The somatic and mental health of ageing prisoners

The somatic health care situation for older prisoners has been described by various authors, often for a certain disorder or a certain geographic or administrative subpopulation. For example, the situation of older female prisoners was described by Revière and Young (2004) and later by Handtke and colleagues (2015), with the conclusion that this subgroup was vulnerable in various contexts, being female, older and imprisoned. Fazel and colleagues have researched larger populations of older prisoners through meta-analyses (Fazel et al., 2001**)**. They found that psychiatric problems are much higher among older prisoners than among younger prisoners or elderly persons in the community**.** In Switzerland, older prisoners utilize health care more often than younger prisoners (Wangmo et al., 2016, Moschetti et al., 2017), but barriers exist for older prisoners to access health care services (Heidari et al., 2017). Researchers also examine interventions to improve the health status of older prisoners (Wangmo et al., 2018).

For mental health problems of older prisoners, various researchers have looked at specific disorders like depression or schizophrenia (Koenig et al., 1995; Rautanen & Lauerma, 2011), or at certain subgroups like victimized offenders or prisoners with dementia (Blitz et a., 2008; Cipriani et al., 2017), but comprehensive research on general problems in mental healthcare is still sparse. For the last two decades, Franke and colleagues (2019) describe an increase of almost 20% of prisoners with a generally high risk of mental disorders, and the increase of groups with specific treatment needs, such as female prisoners or older prisoners who seem to be at greater odds of having depression, depressive symptoms, or dementia, next to specific somatic problems (Franke et al., 2019).

Concerning the situation in Switzerland, most research is done on a regional level. Eytan and colleagues (2011) reported associations between psychological symptoms or substance use and physical health problems for the canton of Geneva. Moschetti and colleagues (2015) described specific disease profiles of a prisoner sample in the canton of Vaud. Mental health problems were frequent, as more than a third of the sample suffered from some form of mental health problem, substance use excluded, and 27 % of the sample suffered from serious mental health problems substantially interfering with major life activities (definition: National Institute of Mental Health, n.d.). Moschetti and colleagues note that although substance use was less common among older prisoners in comparison to prisoners younger than 50 years of age, the prevalence for psychiatric disorders was higher (as 42.6 % of them suffered from at least one psychiatric disorder), mostly personality disorders (26 %), neurosis (13%), schizophrenia (6.6%) and mood disorders (4%). Wolff and colleagues found that mental health problems were frequent for a remand prison in Geneva, with almost one third of detainees suffering from

mental health problems and more than 40 % from illicit drug use even though this population was rather young and did not present disorders typical for an older age (Wolff et al., 2011).

## Mental health care in Swiss correctional institutions

As stated above, prison health in Switzerland is a cantonal matter. Several cantons have decided to place the organization of prison health services under the responsibility of the department of health, while others opted for the department of justice or police. Cantons offer various mental health care services in their correctional institutions, which range from acute and supportive psychiatric care in prisons to forensic care and measure centers.

Brägger (2014) states that only half of the persons needing psychiatric care due to a therapeutic measure have access to appropriate therapy while the other half is placed in prisons without suitable treatment, especially in the Latin concordate. Treatment approaches vary in that most German-speaking cantons treatment happens in a public context between therapists, patients, justice, public stakeholders and the general public, while French-speaking cantons tend to emphasize doctor-patient confidentiality (Brägger 2014).

## Research aims

Few empirical data is available on health and healthcare of older persons in Swiss correctional and forensic institutions. While the SNF-funded project "Agequake in prisons: Reality, policies and practical solutions concerning custody and health care for ageing prisoners in Switzerland" from 2011 to 2015 has shed some light on somatic healthcare in prisons, information on mental health has been sparse, and possible problems of mandatory treatment have predominantly been looked at from a legal perspective.

The aims of this thesis are to provide general information on the current provision of mental health care for older prisoners in the Swiss correctional system, and look at them from the overarching principle of the right to health.

In order to reach this goal, this thesis focuses on four main objectives:

1. Development of an overview about substance use and mental health problems among older prisoners.
2. Examination of ways to build an identity under conditions that may in many ways be different from conditions in free society.
3. Exploration of access to somatic and mental health care services that are not offered in prison but that need transportation to other locations and institutions.
4. Analysis of the question if access to advance directives and assisted dying qualify as parts of healthcare and if access to them affects the reality of older prisoners in Switzerland.

## Methodology

### The Agequake projects: general overview

The work presented here evolved from the project "Agequake in prisons – second part". This project is funded by the Swiss National Science Foundation and started in October 2011. The first part lasted from 2011 to 2015. While it was originally intended to give an overview of somatic and mental health care in Swiss prisons, the scope of the project was subsequently limited to somatic health care due to resources and logistics. This project focused on ethical, medical, legal and economical aspects of somatic health care of older prisoners in the Swiss correctional system.

This multi-centre study covered 14 cantons in Switzerland and combined qualitative and quantitative research. Qualitative and quantitative data were collected starting from November 2011. For the qualitative part, semi-structured interviews were held with prisoners and with stakeholders working in prison or in areas related to prison. The quantitative part consisted in

data extraction from the medical records of an equal number of older and younger prisoners in the German and French speaking parts of Switzerland.

The second part of the Agequake project started in February 2017, following again a multi-center study design with a mixed methods approach. A literature review was done to assess the state of research on the burden of mental health disorders among older prisoners. The data collection began in April 2017 for the qualitative part and was followed by the quantitative part starting in July 2018.

## Qualitative data collection

The qualitative part of the study consisted of semi-structured interviews with stakeholders and prisoners which took place in 13 French and German speaking cantons of Switzerland. Out of a total of 37 prisons and correctional institutions in the participating cantons, 33 corresponded to the inclusion criteria which were: prisons and correctional institutions in both German and French speaking regions of Switzerland with more than 20 places, and housing prisoners who were at least 50 years old and convicted to a sentence or a measure. Of the 33 contacted institutions, 19 agreed to participate in this study.

### *Prisoner interviews*

Participants had to be at least 50 years old, speak German, French or English, be convicted to a measure or a sentence (in this case with at least one contact with a prison psychiatrist), and a mental health expert had to conform that their mental health state permitted participation. Participants came from prisons in 7 French and German speaking cantons. We interviewed 40 male and 10 female participants whose age ranged from 50 to 75 years. All participants were interviewed in the respective institution they were staying in, usually in medical examination rooms or in visiting rooms.

### *Stakeholder interviews*

In total, 30 stakeholder interviews were conducted in eleven cantons of Switzerland, 35 in Canada, and 10 in the Netherlands. These two countries were chosen because of possible best practices concerning older prisoners and prisoners with mental health problems. For Switzerland and the Netherlands, stakeholders consisted of psychologists, psychiatrists and nurses; for Canada, the spectrum of professions was broader and also included occupational therapists**.** The aim was to focus on professions knowledgeable about the situation of mental health care in prisons and forensic institutions. We wanted to see if there were country- or region-specific approaches to topics such as mental health care facilities, diagnosis, or treatment.

## Quantitative data collection

The quantitative part of the study took place in ten French and German speaking cantons of Switzerland. The quantitative data collection consisted of four elements: the extraction of health-related data from medical records, and psychiatric measures (see appendix). For the quantitative data collection, comparison groups of younger participants (less than 50 years old) from the same prisons were included.

### *Medical records*

From the participating prisons, medical records were obtained and relevant data were extracted with a data extraction sheet (cf. appendix). Consent for insight into the medical records was obtained either with opt-out or opt-in approaches, as decided by the institutions. With the opt-out approach, information notices were shown in places accessible to the prisoners such as notice boards, refectories, or medical offices. Two institutions decided on an opt-in approach instead, so explicit approval of the prisoners whose medical records were analyzed had to be collected.

### *Psychiatric Measures*

Three instruments for psychiatric assessments and screenings were used to estimate the burden of certain mental health disorders and the treatment success in prison. The PHQ-9 is a patient questionnaire that can be used as a screening tool but also to assess the severity of an existing depression. The participant completed the PHQ-9 in the presence of a research team member.

The MINI is a validated short structured interview that is used to assess the 17 most common psychiatric disorders through a relatively short and structured diagnostic interview done by a mental health care professional (cf. Sheehan et al., 1998). Members of the project team carried out the MINI.

### *HoNOS*

This instrument consists of the 12 questions of the HoNOS completed by seven additional questions (scales) on security in order to take into account the special considerations of care in secured institutions such as prisons or forensic clinics. These security scales concern for example the “risk of harm to adults or children”, the “need of building security to prevent physical escape” or the “risk to individual from others”. It is important to note that the HoNOS-Secure is not a tool for risk assessment, but that it allows to rate the outcome of a risk assessment (which usually has already been done by clinicians or other professionals) to determine clinical risk management procedures and the need for care.

In Switzerland, article 58 of the Health Insurance Act of 1994 obliges healthcare institutions to review periodically effectiveness, expediency and cost-effectiveness of their services in order to guarantee quality assurance (Bundesgesetz über die Krankenversicherung vom 18. März 1994, SR 832.10) .

To measure treatment success, the HoNOS is used by all mental health institutions in Switzerland, including forensic clinics. Health care services in prisons - even those with psychiatric wards - are not included in these measurements. In order to assess readiness of prison health professionals and acceptability of this instrument, and to train health care professionals working in a correctional environment, the project team organized and carried out two training events, one in the German speaking part (Bern) and one in the French speaking part (Lausanne).

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# Chapter 1: Substance use and other mental health disorders among older prisoners

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**Substance use and other mental health disorders among older prisoners**


## Abstract:

The goal of this study is to explore the status quo of mental health and substance use problems among older prisoners. Our review presents the prevalence as well as co-occurrence of substance use and other mental health disorders in older prisoners. We conducted a systematic review of literature following the PRISMA statement. The search was carried out in four databases and supplemented with manual screenings of bibliographies from all retrieved articles. Publications were included if they met specific inclusion criteria. A total of 17 articles were included and in half of them, older offenders were the main study population. Older inmates have higher prevalence of mental health disorders than younger prisoners and are more likely to use alcohol. Several studies mentioned an association between substance use and other mental health disorders. Access to treatment was a concern with several studies providing recommendations to improve this. Most studies were done on older male prisoners, confirming that older female prisoners constitute a subgroup of a subgroup which is even more vulnerable and under-researched. It is important to carry out more research on both older male and female prisoners to ensure optimal delivery of appropriate mental health care for older prisoners and to prepare for a currently younger population that will age with different and distinct mental health problems and substance use patterns


## Introduction

The worldwide number of older prisoners has increased over the past few decades, mirroring the growing ageing population outside prisons (Fazel et al 2016; Nowotny et al 2016; Aday & Krabill 2012; Cloyes & Burns 2015; Pro & Marzell 2017). Causes for this increase, such as changes in the legal system leading to quicker incarceration and longer prison stays, have been described elsewhere (Loeb & Abudagga 2006; Vogel et al 2013). Loeb and Abudagga (2006) stated that prisoners 50 years and older constituted the most rapidly increasing age group of prisoners in the United States. They also noted that this minimum age was most often used to describe the term "older inmates" after it had been coined by Wiegand and Burger in 1979. Almost 20 years ago, Beitchman (1998) found an increasing number of incarcerated individuals over 50 who were at the same time diagnosed with a major mental illness. It is reported that older prisoners with mental illness are not only the fastest-growing sub-population among those incarcerated but also the one with the worst health (Chodos et al. 2014, Pro & Marzell 2017). It has also been shown that older inmates have a higher number of somatic (Moschetti et al., 2015; Wangmo et al 2015) and mental disorders (Nowotny et al 2016; Aday 1994; Baillargeaon et al 2009) when compared to younger prisoners.

However, the population of older prisoners is not homogeneous. Aging and aged prisoners can be divided into distinct groups such as offenders who were incarcerated at a younger age and grow old in prison as they are serving a long sentence; offenders who have been incarcerated multiple times throughout their lifetime; and offenders who commit their first crime after 50 years of age (cf. Glaser et al, 1990; Nowotny et al 2016; Kakoullis et al 2010). Sodhi-Berry and colleagues (2015) mentioned that the third group constitutes more than half of all 'old' prisoners and they experience relatively more adjustment problems with imprisonment

compared to the other groups. Additionally, a study from Canada revealed that the third group accounted for the majority of older prisoners (72.8%), with 17.1% belonging to "repeat offenders", and only 10.2% being "long term offenders" (Uzoaba, 1998).

There is lack of specific research that examines the different mental health needs of older prisoners. Such evaluations are critical since the definition of mental health disorders has changed over time. For instance, substance use has not always been considered a mental health problem. Also, from the literature, we know that older prisoners are less likely to use illicit drugs, but more likely to use alcohol before incarceration (Gallagher, 1990). A study in Iowa showed substance use problems in 71% of inmates over the age of 55, with alcohol being the primary drug of use (Arndt et al., 2002). Surprisingly, they were significantly less likely to receive treatment for substance use in comparison to younger inmates.

Mental health issues affecting older offenders comprise, among others, substance use, anxiety disorders, psychotic disorders, mood disorders, neurodevelopmental disorders and personality disorders with an onset that often starts at a younger age, but the additional disease burden of old age includes age-related neuropsychiatric disorders like dementia or depression (Davoren, 2015; Fazel & Grann 2002; Hayes, 2012). Mental health could also be affected due to the prison environment and experiences that are traumatic and stressful. A survey of a US prison system revealed that 20% of 1,800 prisoners (of whom 8% were aged 48 or above) were pressured or forced to have at least one unwanted sexual contact. Half of these prisoners reported unwanted intercourse, and 25% had experienced gang rape (Struckman-Johnson et al. (1996), as cited in Haugebrook et al (2010)).

According to Arndt and colleagues (2002) only little systematic research has been conducted on the mental health and substance use treatment needs of older prisoners. A thorough and transparent investigation of what should be provided to prisoners in terms of mental healthcare may be required for legal reasons such as the obligations contained in disability discrimination laws to the principle of equivalent care (Kakoullis et al 2010). For psychiatric care, treatment needs are even less clear than for somatic care (Sodhi-Berry et al 2015, Hayes et al. 2012, Fazel et al. 2004). A few scholars have sought to provide recommendations that would improve the overall mental healthcare provided to older prisoners. One suggestion forwards the expansion of both somatic and psychiatric prison healthcare services or an increased use of medical parole in order to transfer older prisoners to community-based health care (Di Lorito et al., 2017; Williams & Sudore, 2011; Pro & Marzell, 2017). As it is known that prisoners who are relatively healthy and well-prepared to function adequately in the community are less likely to reoffend and will probably cost society less in terms of health care and in light of lack of information on the status quo for mental health and substance abuse among older prisoners, our study wants to shed more light on the scope and possible dynamics of the co-occurrence of substance use and other mental health disorders in older prisoners by reviewing the available data on this topic. Literature on this is scarce and data are not always comparable, as older prisoners are not always listed as a distinct category of prison population. A critical synthesis of all available information on this topic could help to tailor available resources for this growing prison sub-group with distinct mental health burden and mental health needs.

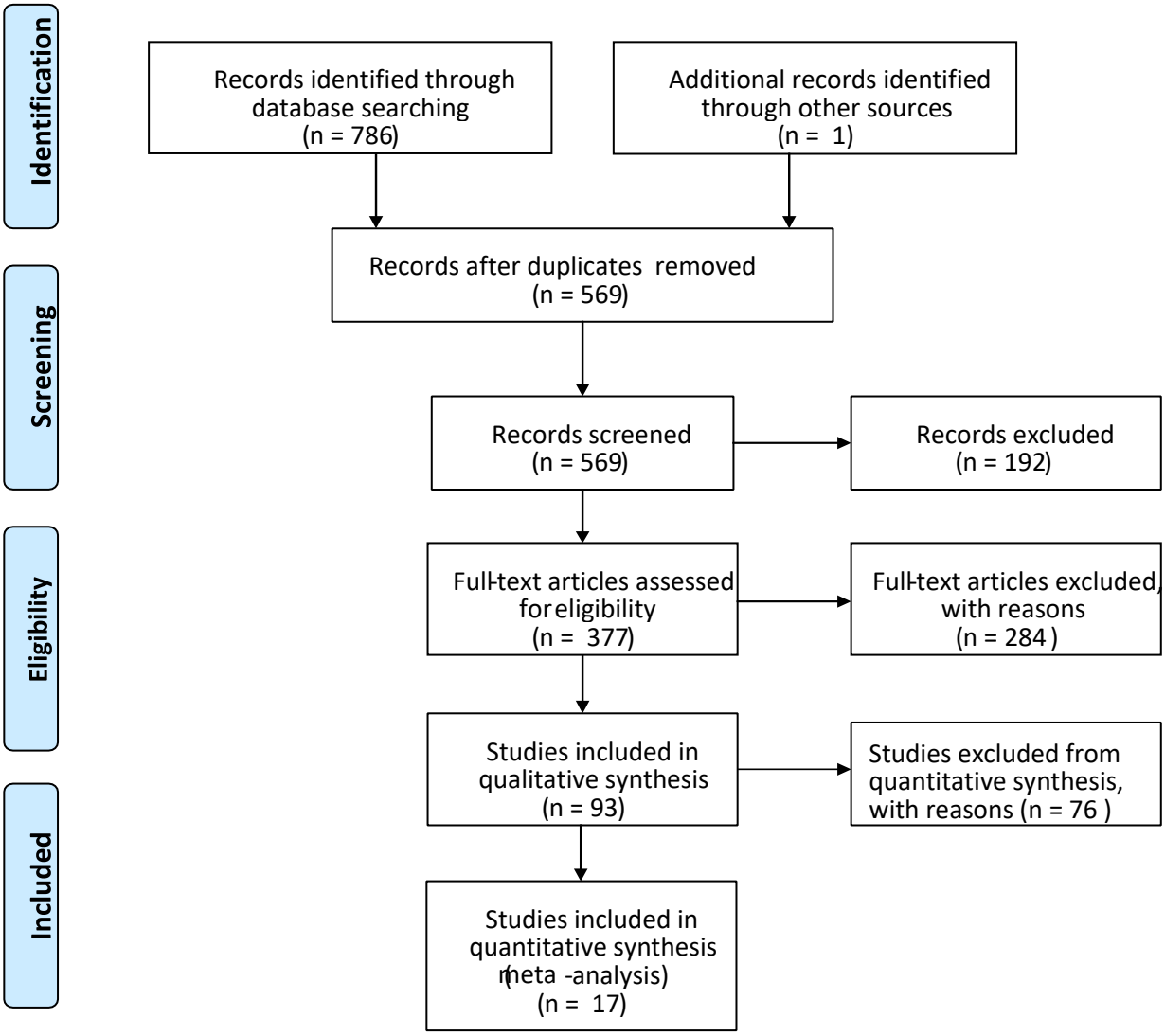
## Methods

### *Search strategy*

The present review follows the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher, Liberati, Tetzlaff & Altman, 2009) to ensure rigor. The authors discussed the formulation of search terms and strategies based on their experience as well as based on published literature. The search was carried out in PubMed/MEDLINE, PsycINFO, EMBASE and CINAHL between the date of database conception and April 2017. The search teams included: [“geriatr*” or “older”or “elder*”] AND [“jail”or “offender”or “correctional”or “prison*”or “inmate”or “sentence*”or “remand”or “detaine*”or “felon”] AND [“mental*”or “psychiatr*”or depress*”or “personality”or “disorder”or “retardation”] AND [“drug*”or “substance*”or “psychotropic”or “alcohol]. This resulted in a total of 786 citations, of which 209 were from PubMed/MEDLINE, 200 from PsycINFO, 308 from EMBASE and 69 from CINAHL.

The above search of the literature was supplemented with manual screenings of bibliographies from all retrieved articles which led to the addition of one article. All literature identified were then subject to the article inclusion/exclusion criteria that are listed below (see PRISMA flowchart, Figure 1).

**Figure 1: PRISMA 2009 Flow Diagram**




*From:* Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

**For more information, visit www.prisma-statement.org.**

## Article inclusion/exclusion criteria

Publications were included if they met specific inclusion or exclusion criteria. To reduce bias, the criteria were specified before conducting the literature search. To be included in our review, a publication had to meet the following criteria: Studies published in English, German or French with a focus on a specifically defined group of older prisoners (cut-off age defined by the authors of the respective publication) in remand prison or after conviction. In cases where a study focused on a broader prison population, it could be included if it had a separate category of older participants (in remand prison or after conviction).

Excluded articles were those publications that dealt with temporary incarceration, ex-prisoners or older people in forensic settings without being convicted. In addition, we excluded publications that only treated substance use without mentioning other psychiatric disorders. Also excluded were articles presenting systematic reviews or meta-analyses, conference abstracts, book chapters, and dissertations.

The authors did not categorically exclude qualitative publications from the start because we hypothesized that using a mixed research technique might help to summarize the extant literature, as opposed to drawing on findings of quantitative studies only. However, the final step consisted in the analysis of exclusively quantitative publications.

## Study selection and appraisal

Title and abstract screening of all initial results was carried out by the main author (SH) who dismissed the papers that were clearly ineligible for the review (see Figure 1). The remainders (n=93) were checked for eligibility against the inclusion/exclusion criteria by two authors (SH and HM or AI). Specific reasons for rejections at this point were recorded. Differing results during these steps were discussed between the readers, and remaining disagreements were resolved by another author, TW. Only 17 quantitative papers met the standards for inclusion.

# Results

## Study characteristics

In 9 of the 17 the studies, older offenders were the main study population. The 17 studies were conducted in Western countries, mostly in the United States, but also the UK, Ireland, Sweden, Switzerland and Australia. The total population of prisoners included was 49855 of which "older" prisoners numbered 8081. Table 1 provides further information on study characteristics.

The definition of an "older offender" varied considerably across studies. The range of age cut-offs arches from 45 years which came from the most recent publications (Gates et al, 2017; Sodhi-Berry et al., 2015) to 65 years, with 60 years being the most chosen cut off age (see Table 1). Twelve out of the 17 studies included older female prisoners. However in six studies, they only appeared in the demographic information without further discussion of gender-specific findings, and one study did not differentiate between older and younger female prisoners (Table 2).

**Psychiatric disorders among older male prisoners**

Main results concerning mental health disorders among older male prisoners are shown in table 3 and specific prevalences are presented in table 4. Our review indicates that older inmates have a higher prevalence of psychiatric disorders than younger prisoners (Hunt, 2010; Moschetti et al., 2015; Sodhi-Berry et al., 2015). Almost half of the older inmates suffered from at least one psychiatric disorder such as personality disorders, neurosis, schizophrenia or mood disorders (Moschetti et al., 2015). Comorbid mental illnesses such as dementia, depression, psychoses or dependence disorders appeared very often even when the focus was on somatic illness (Sodhi-Berry et al., 2015).

There were differences in the rates of mental health disorders among offenders aged 50 years and over (Hayes et al., 2012). That is, the group aged 50–54 years was more likely to have a psychotic disorder and personality disorders than those 55 years and older, but. Offenders aged 50 to 59 years were more likely than those over 60 years to suffer from mental disorder including mental illness, major depression, substance use and personality disorders. Although remand prisons may have generally higher psychiatric morbidity than other prisons, older offenders showed comparable rates of psychosis as younger ones (2% v 4 %) but higher rates of affective disorders (38% v 17%) (Davoren et al., 2015). Here the difference between age groups was much more significant among older male than among older female remand prisoners, namely 40% versus 32%. Fazel and Grann (2012) concluded that almost a third of their study population aged 60 and over were suffering from a psychotic illness, a fifth manifested personality disorder, 8% of them had a depressive or anxiety disorder, and 7% had a diagnosis of dementia.

Proportionally more prisoners aged 65 years and older suffered from mental illness (mostly depression) at the time of the offence (Overshott et al., 2012). Almost half of that sample had been on psychiatric medication, and the same amount of offenders showed a family history of mental illness (Koenig et al., 1995). In most cases there was considerable overlap of diagnoses (addiction, dementia, and antisocial personality disorder) so that it was difficult to associate specific diagnoses with violence. Finally, while rates of drug/alcohol dependence were similar among prisoners irrespective of age, Williams and colleagues (2014) reported that participants with severe persistent pain (who were older prisoners) were more likely to receive opioids than those with less severe pain.

**Substance use among older male prisoners**

Table 5 shows main results concerning mental health disorders among older male prisoners, specific prevalence data are given in table 6. A total of 15% of forensic psychiatric evaluations with individuals aged 60 revealed substance abuse or dependence problems **(**Fazel & Grann, 2002). Older and younger male remand prisoners had similar rates of substance use, but older prisoners were more likely to use alcohol while younger prisoners were more likely to misuse illicit drugs (Davoren et al., 2015). Only a small minority of older prisoners used illegal drugs, alcohol and pharmaceuticals at the same time (Moschetti et al., 2015). Among older prisoners, the group aged 50–54 years were more likely to abuse substances such as alcohol and illicit drugs than those in the group aged 65–69 years (Hayes et al., 2012). However, reported rates

of substance use varied widely in the cited studies which were conducted among older offenders in state forensic units (Lewis et al., 2006), remand prisons and correctional facilities.

Several studies mentioned an association between substance use and other psychiatric disorders. For instance, Haugebrook and colleagues (2010) stated that older prisoners of both genders "have psychosocial problems and needs, particularly unaddressed trauma and stress histories, and health, mental health, and substance use issues" (p. 223) and the inherent stressfulness of a prison environment may contribute to even more somatic and mental health problems for older adult prisoners. Older perpetrators who had committed homicide were more likely to suffer from depression while younger perpetrators rather showed psychotic disorders and alcohol/drug problems at the time of the offence (Overshott et al., 2012). Another research mentioned an unexpectedly low proportion of older offenders with MHS contacts and comorbid substance use. This may be explained by a possible under-treatment of substance use disorders or under-reporting of these in administrative databases (Sodhi-Berry et al., 2015).

The relation between general alcohol use/ dependence and alcohol use at the time of the offense was linked to violent crime both for older and for younger offenders (Lewis et al., 2006). Older offenders with a history of alcohol or drug use were found to be at higher risk for current psychiatric disorders and substance use (Koenig et al., 1995). This in turn may hide underlying psychiatric problems.

**Mental health and substance use among older female prisoners**

Since female prisoners compose an important segment of the "older prisoner" group, we sought to analyze them separately. These studies are summarized in Table 2. Specifically, older female remand prisoners suffered more from affective disorders than their younger prisoners, but the difference was not statistically significant. Women in general had higher prevalence of psychiatric problems than men, especially for personality and mood disorders and "reaction to severe stress" (Moschetti et al., 2015), and greater odds for suffering from dementia, depression or depressive symptoms, but there were no gender differences for the association of age and prevalence or number of mental health diagnoses (Gates et al., 2017). Likewise, Davoren and colleagues (2015) noted no significant difference between older and younger female remand prisoners was found when alcohol use and history of neurological disorders were compared. As noted previously, they also found that older female remand prisoners were less likely to use illicit drugs than younger female prisoners.

**Older prisoners vs older persons in the community**

The comparison of prevalence rates of mental illness among older individuals in prison and in the community led to differing results. In one study, rates of serious mental illness in older prisoners are comparable to older persons in the community although a possible underdiagnosis and consequent undertreatment of mental health problems among the prison population was mentioned (Nowotny et al., 2016). Comparing the elderly forensic and general psychiatric populations, a possible link between psychotic symptoms (especially paranoia) and violent crime may exist in both populations (Lewis et al., 2006). Elsewhere, around 14% of older offenders were reported to suffer from at least one serious mental illness, a result comparable to a prevalence of 15 to 20% in older adults in the community, but the authors cautioned that

PTSD was excluded from this category leading to underdiagnosis (Williams et al., 2010). Diagnostic instruments pointed to drug dependency in 25% of cases and to alcohol dependency in almost half of the sample. Another study mentions a higher prevalence of mental health issues in prisons compared to the community (56% compared to 10.6 %) underlining that "the health status of prisoners in their 50s is viewed as equivalent to the health status of community members in their 70s" (Haugebrook et al., 2010). Although studies about the general population mention prevalence of mental disorders reducing with age, high psychiatric morbidity is reported in older offenders (Sodhi-Berry et al., 2015). Compared to both younger prisoners and older people in the community, older prisoners show significantly higher rates of major illnesses and functional impairment, with alcohol misuse, underdiagnosed depression, and liver diseases as particular problems (Fazel & Baillargeon, 2011).

**Older prisoners' access to mental health care**

As early as 1995, low treatment rates for psychiatric conditions were reported in a prison context (Koenig et al., 1995). Likewise, Fazel and colleagues (2004) confirmed that only 18% of older male prisoners with a recorded problem were receiving psychotropic drugs. In comparison to younger prisoners, older offenders were found to be significantly less likely to be diagnosed with schizophrenia or a personality disorder, but more likely with dementia or an affective psychosis (Fazel & Grann, 2002). Another study pointed out that none of the prisoners aged 65 years old or older had ever been in contact with psychiatric services, although more than two-thirds of this group was suffering from a mental illness, mostly depression (Overshott et al., 2012). For the prisoners 60 to 64 years old, 35% had had previous lifetime contact, and almost half of that group had a diagnosis of mental illness when committing the offence.

**Improving mental health for older prisoners**

Included studies also provided further recommendations to address the limited access to mental health services provided to older prisoners. Arndt and colleagues (2002) cautioned that the release of elderly inmates at a time when they need more medical and social support may conflict with effective rehabilitation strategies. Numerous authors recommended better age-sensitive detection and treatment of mental disorders within the prison context and advocated special forensic and therapeutic services (Sodhi-Berry et al., 2015; Fazel and Grann, 2002; Davoren et al., 2015). For individuals with substance use and/or mental health disorders, efficient pain management can be hindered by clinicians' fears of misuse or diversion of medication or overdosing. For appropriate therapy and medication, developing a specific approach to assessment and management of pain in older inmates is recommended (Williams et al., 2014). Further recommendations consisted of ensuring an assessment by geriatric psychiatrists for all offenders above "pension" age and revising "traditional" age cut-offs to become more inclusive in terms of who is an "older" person in prison. Reasons for this are to correct possible underdiagnosis of depression in particular and to take into account "the specific issues of old-age psychiatry" in a comprehensive way during cognitive assessments (Overshott et al., 2012).

## Discussion

This paper examines the association between substance use and other psychiatric disorders for older offenders. It seeks to be comprehensive by ensuring that all data relevant for older female prisoners are also highlighted. Therefore, the best available data to date allows us to underline the increased burden of mental illness that occurs within the aging offender population, which is often neglected. As only 17 studies fulfilled our inclusion criteria, the sheer number in and of itself may be depicting the limited knowledge that is available on this topic. Further, that no studies were captured from regions such as Eastern Europe, Asia, and Africa depicts disinterest in this issue in particular and prisoners in general. We could therefore conclude that our work is preliminary and much needs to be done to understand the overall burden of mental health illness among prisoners worldwide. Finally, with respect to who is an "older" prisoner, we find that the included studies used varying age "cut-offs". Such varied usage (45 to 65 years) has several implications of who would receive access to mental health care.

From our analysis, we first find higher prevalence of psychiatric disorders among older prisoners compared to younger inmates noted. This finding confirms previous results such as Anno et al. (2004), Binswanger et al. (2009) and Binswanger et al. (2010). Second, our research finding that alcohol is the most common substance among older offenders mirrors the patterns of substance abuse among older individuals in the general population where alcohol is the most widely used substance as well (Kuerbis et al., 2014). The fact that drug use prevalence among offenders is much higher than among the general population has been stated since a long time (cf. Lintonen et al., 2011), and we hypothesize possible changes in substance use patterns due to demographic changes. Third, older female offenders differ from older male offenders both for substance use and for mental health issues. Forth, regarding substance use among older prisoners, studies differed considerably in the substances that were mentioned. Only two recent publications included tobacco smoking which might show the growing focus on health hazards due to smoking in prison. Most studies named alcohol as a separate category, and one of the oldest publications focused on alcohol alone. Two studies only indicated "substance use" without explaining if alcohol was considered a psychoactive substance or not and included in this. Ideally, in further studies substance use could be coded according to internationally used ICD or DSM classification because differing degrees of detail and random choices of substances make comparisons difficult.

Underdiagnosis and undertreatment of pain, which is associated with mental disorders, can severely reduce quality of life for older individuals. Reasons for this may be limited resources for prison health services, but also other factors like fears of misuse and diversion of pain medication or overdosing may play a role here, just as in the general population (O'Brien et al., 2017). However, this should not be a barrier to efficient and appropriate treatment. Medical staff needs to decide about treatment options based solely on state-of-the-art, evidence-based guidelines.

### Comparison of older and younger male prisoners

As is obvious from the results of our study, the high prevalence of mental disorders among older prisoners is a phenomenon that needs to be addressed. High rates of specific psychiatric

disorders were found for older perpetrators, who were also more likely to have a lifetime history of severe mental illness. Symptoms of mental illness at the time of the offence increased with age. Offenders over 64 suffered particularly from affective disorder. The age segment between 25 and 64 includes "older" offenders according to some cut-off ages, which is a problem that is discussed below. For these "middle age groups", alcohol dependence was common in addition to schizophrenia. More than half of offenders aged 65 and over were mentally ill at the time of the homicide (mostly depression and possible psychosis), with even some cases of dementia. Proportionally, fewer perpetrators aged over 64 had been in contact with mental health services before committing the offence. However, Hunt and colleagues (2010) describe perpetrators aged 65 and over as having significantly more symptoms of mental illness at the time of the offence and also at later evaluation. They describe this group as a distinct population, having high rates of affective disorder, often showing symptoms of mental illness at the time of the offence, but using less drugs and having less personality disorder and criminal histories.

An important finding was that several studies show drug use to be more common among younger offenders than among older individuals, although rates and populations differed considerably. Rates were 87.5% against 30.7% (Arndt et al., 2002) or 18% against 3.7 % (Moschetti et al., 2015) for a general prison population, 40% against 52% for alcohol use and 61% against 51% for drug use among homicide perpetrators ((Hunt et al., 2010), 12.5% against 14.8% for prisoners with forensic evaluation (Fazel & Grann, 2002), and 39% against 46% for remand prisoners (Davoren et al., 2015). One study did not differentiate by gender but showed that younger offenders differed from older offenders mainly for cannabis consumption (21.4% vs 6.4%) while consumption of other substances was comparable (Arndt et al., 2002). Substance use patterns are thus likely to shift when currently young or middle-aged offenders will age.

**Definition of "older offenders" and age cut-off**

As alluded previously, clarity and consistency in using a "correct" cut-off age is important. Several studies note 50 years (Loeb & AbuDagga 2006; Wangmo et al 2015), while others use 55 (Williams et al (2014), 60 (Davoren et al., 2015) or even older. The Australian Institute of Criminology recommends different thresholds to define older non-Indigenous and Indigenous offenders, 50 (for non-Indigenous) and 45 years (for Indigenous) because of the latter group's decreased life expectancy and poorer health status (Sodhi-Berry et al., 2015). Similarly, extensive discussion concerning the definition of the 'older prisoner' and the different cut-off ages that have been applied especially in UK-based research (50, 60 and 65 years) (Hayes et al., 2012). Pointing out the lack of scientific evidence for a cut-off at age 50, they chose a cut-off at 60 in order to make their research comparable with other studies but also included a random sample of prisoners aged 50 and older to examine the utility of this cut-off. They confirmed the utility of a cut-off age of 50 because the health needs of this group proved to be very similar to offenders aged 60 and older.

The choice of a cut-off age may have important consequences. A greater likelihood to be diagnosed with diminished responsibility may also be influenced by 65 years being "the traditional age limit for old-age psychiatry services in the UK" (Overshott et al., 2012) and consequently examination and diagnoses done by geriatric specialists.

**Gender in prisons**

Most studies for a prison context are done on men. Although excluding women from the study population was justified with ethical arguments and accompanied by acknowledging their "constitutively different" needs, it confirms the fact that older females constitute the subgroup of a subgroup and are thus even more vulnerable and neglected, as previous research has shown (cf. Aday & Farney, 2014; Handtke et al., 2014).

The finding that females in remand prison were overrepresented in the older prisoner group was explained by the fact that older women live longer than men and the global population of older persons is thus predominantly female, as older women live longer than older men (Davoren et al., 2015). However, it is known that women commit far less crimes than men and that the population of a remand prison is not representative of a population of sentenced prisoners; for Ireland, a third to half of incarcerated women were said to be on remand (Quinlan, 2006). More research might elucidate this overrepresentation. Although the percentage of women was indicated in those studies that included female offenders, not all authors subdivided them into older and younger females, so that the ratio of men and women among "older adults" was not always obvious.

The specific challenges of older woman prisoners – such as a higher prevalence of smoking, drug use, psychiatric problems and severe pain – may partly be explained by the different type of offences they commit, which went beyond the scope of this literature review.

**Limitations of the study**

Our keyword search may not have included every search term designed to find all possible results. We only looked at articles with at least an abstract in English, so a language bias cannot be completely excluded.

Several studies did not differentiate between older males and females, and due to the much higher proportion of male than of female offenders, we decided to put them under prevalence rates for male offenders. However, they may not reflect the accurate prevalence rates.

Diagnostic criteria were not always clear. In studies where data are copied from charts and medical records it was not always evident how diagnoses and observations contained there were generated. Misdiagnoses and bias may thus not be excluded, and we may have interpreted possibly different things to mean the same. On the other hand, relying on self-reports can be problematic because prisoners may fear stigmatization for mental health problems and tend to underreport current or past problems. This may lead to unmet health needs (Fazel et al., 2004; Hunt et al, 2010; Koenig et al., 1995). Another consequence of relying solely on self-reports could be malingering and inflation of certain prevalence rates (Sodhi-Berry et al., 2015; Hayes et al., 2012).

Due to the mentioned differences and the variety for the choice of a "correct" age cut-off (between 45 and 65 years), subgroups that were defined as "middle aged" in one publication could have been included in the "older" category of other studies, with possible changes of the

results, but it is beyond the scope of this review to see which change in prevalence may stem from this.

## Conclusion

As far as we know, the present study is the first to systematically review a possible link between substance abuse and other mental disorders occurring in the population of older prisoners. The lack of reliable data on this group is evident, and findings of the different studies are not always consistent. Mental health problems occurring in older prisoners do not differ in scope from younger prisoners' disorders but occur at different rates. Neurodegenerative disorders that are typical for an aging population, such as dementia, are not reflected in these studies yet and will require specific approaches. Also the prison administrations and health services will need new strategies in order to tackle issues related to mental health problems including substance use. Case managers or other liaison persons could facilitate a more seamless transition from prison to the outside world by not only making sure that all relevant information on mental health and substance use issues from prison records is not only passed on but also by proactively requesting appointments or assessments.

Although research has clearly shown that the group of older offenders has distinct needs for somatic as well as for mental health care, limited resources and lacking political will can make it difficult to provide adequate possibilities for diagnosis, treatment and accommodation. Given recommendations range from small steps that can be easily implemented in daily practice (like making geriatric assessments a standard part of health service provision, or changing clinicians' fear of adequately prescribing pain medication) to resource-intensive changes like constructing new units for vulnerable prisoners or adapting healthcare provision given in the community to the needs of older prisoners that have been released. Recommendations made in the various publications are still valid, no matter the publication date. Ignoring the problem that has become more obvious over the years will not result in making it go away but in higher morbidity and possibly mortality among this population. More research – on both genders - is urgently needed to plan the optimal delivery of appropriate mental health care for the currently older prisoners and prepare for a currently younger population that will age with different and distinct mental health problems and substance abuse patterns.

## Conflict of interest:

None

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**Table 1: Overall characteristics of studies included in the review (N=17)**

| Author(s) | Year | Country | Population | All offenders N = 60335 | Older offenders N = 8081 | % older offenders (Older/ All offenders) | Cut-off age (in years) | Average age of older offenders (in years) | Study design[a] |
|---|---|---|---|---|---|---|---|---|---|
| **Arndt et al.** | 2002 | USA | All offenders in Iowa Medical and Classification Center | 10952 | 180 | 1.6 | 55 | 61.3 | 1 |
| **Davoren et al.** | 2015 | Ireland | All older persons in two Irish remand prisons | 22608 | 213 | 0.9 | 60 | 63.1 | 1 |
| **Farragher & O'Connor** | 1995 | Ireland | All older persons referred to National Forensic-Psychiatric service | 42 | 42 | 100.0 | 65 | 70.0 | 1 |
| **Fazel & Grann** | 2002 | Sweden | All persons referred to a forensic psychiatric evaluation | 7297 | 210 | 2.8 | 60 | 64.0 | 1 |
| **Fazel et al.** | 2004 | England and Wales | All older sentenced men in selected prisons | 203 | 203 | 100.0 | 60 | 66.0 | 3 |
| **Gates et al.** | 2017 | USA | All adult offenders in Kentucky | 10988 | 2940 | 26.8 | 45 | 52.8 | 1 |
| **Haugebrook et al.** | 2010 | USA | Older adults drawn from database of New Jersey department of correction | 114 | 114 | 100.0 | 55 | 55.5 | 1 |
| **Hayes et al.** | 2011 | England | All male prisoners in 13 of the 14 prisons in North Western prison service area | 165 | 165 | 100.0 | 50 | - | 3 |
| **Hunt et al.** | 2010 | England and Wales | All persons convicted of homicide as notified by Home Office | 2478 | 54 | 2.2 | 65 | - | 1 |
| **Koenig et al.** | 1995 | USA | All older prison inmates in North Carolina | 95 | 95 | 100.0 | 50 | 57.0 | 3 |
| **Lewis et al.** | 2006 | USA | All older persons referred to a Psychiatric Institute in South Carolina | 99 | 99 | 100.0 | 60 | 66.8 | 1 |
| **Moschetti et al.** | 2015 | Switzerland ( Vaud) | All prisoners in closed facilities in the canton of Vaud | 1664 | 136 | 8.2 | 50 | 57.0 | 1 |
| **Nowotny et al.** | 2016 | USA | Data from Bureau of Justice | 1160 | 1160 | 100.0 | 50 | 56.3 | 1 |
| **Overshott et al.** | 2012 | England and Wales | All persons convicted of homicide as | 47 | 47 | 100.0 | 60 | 65.8 | 1 |

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | | | notified by Home Office | | | | | | |
| **Sodhi-Berry et al.** | 2014 | Australia | All older offenders in Western Australia | 1853 | 1853 | 100.0 | 45 | 53.2 | 1 |
| **Williams et al. (a)** | 2010 | USA | All older persons from Survey of Inmates in State Correctional Facilities | 360 | 360 | 100.0 | 55 | 61.0 | 2 |
| **Williams et al. (b)** | 2014 | USA | All older prisoners in one county jail | 210 | 210 | 100.0 | 55 | 59.4 | 2 |

[a)]1 = retrospective cross-sectional quantitative data collection, 2 = prospective cross-sectional quantitative data collection, 3 = both retrospective and prospective quantitative data collection

**Table 2: Characteristics of older female offenders and key findings (N=12)**

| Author(s) | Older female offenders as main study population or subgroup | Number of females offenders | % female offenders (among all prisoners)* | Number older females offenders * | % older females (among all older offenders) | Key findings older female prisoners |
|---|---|---|---|---|---|---|
| **Arndt et al.** | Subgroup | 1213 | 11.1 | 11 | 6.1 | - |
| **Davoren et al.** | Main | 56 | 26.3 | 56 | 26.3 | • Female remands had more affective disorder than younger female controls but not statistically significant.<br>• No significant difference in rates of alcohol misuse or history of neurological disorder between younger and older females.<br>• Older females were less likely to misuse illicit drugs than younger female prisoners. |
| **Farragher & O'Connor** | Main | 2 | 4.8 | 2 | 4.7 | - |
| **Fazel & Grann** | Subgroup | 657 | 9.0 | 16 | 7.6 | • Types of mental disorders in this sample of men and women aged 60 and over were: psychotic illnesses in 32%, personality disorder in 20%, substance abuse or dependence in 15%, depressive or anxiety disorders in 8%, and dementia in 7%. |
| **Haugebrook et al.** | Main | 9 | 7.9 | 9 | 7.9 | - |
| **Hunt et al.** | Subgroup | 319 | 12.8 | 7 | 3.8 | • More female perpetrators in those aged 45-64 compared to other age-groups. |
| **Lewis et al.** | Main | 12 | 12.1 | 12 | 12.1 | - |
| **Moschetti et al.** | Subgroup | 140 | 8.5 | 14 | 10.0 | - |
| **Overshott et al.** | Main | 4 | 8.6 | 4 | 8.6 | - |
| **Sodhi-Berry et al.** | Main | 351 | 18.9 | 351 | 18.9 | • Older men were twice as likely to use MHSs for substance use disorders after sentence than older women. |
| **Williams et al. (a)** | Main | 22 | 6.2 | 22 | 6.2 | - |
| **Williams et al. (b)** | Main | 10 | 4.9 | 10 | 4.9 | • Older persons with severe pain were more likely to be female (9% vs 2%).<br>• Incarcerated older women use more health care services than older men; and community-dwelling older women report pain at higher rates than older men. |

*Please refer to Table 1 for the following denominators.

**Table 3: Mental health concerns among older male prisoners: Main results (N=17)**

| Author(s) | Methods used in the study to categorize MH concerns among older prisoners | Main results related to mental Health |
|---|---|---|
| **Arndt et al.** | Chart review | • 22.5% of older offenders suffered from a psychiatric illness. |
| **Davoren et al.** | Chart review | • A higher rate of affective disorder was found among older offenders.<br>• Older prisoners have a greater need for general medical and psychiatric services than younger prisoners. |
| **Farragher & O'Connor** | Chart review | • Two thirds of the sample of older offenders had a past psychiatric or forensic history. |
| **Fazel & Grann** | ICD-9 from 1988; DSM-IV from 1997 | • Older offenders were more likely than younger offenders to be diagnosed with an affective psychosis, less likely to suffer from a personality disorder or schizophrenia.Types of mental disorders in this sample of men and women aged 60 and over were: psychotic illnesses in almost one in 3 cases, personality disorders in one in 5 cases, depressive or anxiety disorders in one in 12, and dementia in one in 14 cases.* |
| **Fazel et al.** | Geriatric Mental State | • Psychiatric medication needs were met only in 18% of all reported cases.<br>• Of those who were defined as having depression, only 14% were being treated with anti-depressants at the time of the interview. |
| **Gates et al.** | ICD-9 classification | • Aging offenders had significantly greater odds for having dementia, depression or depressive symptoms.<br>• There was no association between age groups and the number of comorbid MH disorders.<br>• Of those with MH prescriptions, only one in 6 received medication. |
| **Haugebrook et al.** | Case record review | • MH issues were reported in more than a third of cases. |
| **Hayes et al.** | SCID-I and SCID-II, MMSE | • High rates of MH disorder for those aged 50 years and over.<br>• Prisoners aged 50 to 59 were significantly more likely to have mental disorders than those over 60 years. |
| **Hunt et al.** | Psychiatric reports for occurrence of certain MH disorders ("symptoms of hypomania, depression, delusions, hallucinations and other psychotic symptoms") | • Older perpetrators were more likely to have symptoms of mental illness at the time of the offence (particularly affective disorder in those aged 65 and over).<br>• They had less personality disorder but more often received a diminished responsibility verdict and a hospital disposal. |
| **Koenig et al.** | DSM-III checklist, Diagnostic Interview Schedule | • More than half of older participants met one-month criteria for psychiatric disorder.<br>• Over a third had a previous psychiatric history requiring treatment.<br>• The one-month prevalence of major depression was 50 times higher compared to the community.<br>• Inmates with psychiatric disorders were more likely to show drug abuse or dependence. |
| **Lewis et al.** | Chart review | • Almost a third of older participants had antisocial personality disorder.<br>• Only six subjects had neither Axis I nor Axis 2 diagnosis. Over 2 in 3 subjects had more than one psychiatric disorder.<br>• Almost half had been psychiatrically hospitalized at least once, half of the sample had a family history of mental illness,<br>• Almost 1 in 5 had a history of at least one suicide attempt, more than half had been in outpatient psychiatric treatment immediately before arrest. |
| **Moschetti et al.** | ICD-10 classification | • More than one in four older inmates suffered from at least one psychiatric disorder.<br>• The prevalence of mental disorders was significantly higher compared to younger prisoners. |
| **Nowotny et al.** | Decision to include 2 specific serious mental health problems | • Older veteran inmates had higher rates of PTSD than older nonveteran inmates. |

| | | |
|---|---|---|
| **Overshott et al.** | psychiatric reports (not described in detail) | • At the time of the offence, almost a third of perpetrators suffered from depression.<br>• Older homicide perpetrators had similar proportion of lifetime diagnosis of mental disorder to homicide perpetrators in general.<br>• At the time of the offence, almost of the sample suffered from depression, almost a fifth from personality disorders. |
| **Sodhi-Berry et al.** | ICD-9-CM Classification | • The second most commonly treated disorder in older offenders were neurotic/depressive disorders.<br>• Older offenders with a treated mental disorder had a much higher risk of suffering from a comorbid substance use disorder than non-offenders (1.4% vs. 0.05%).<br>• In the 1-year pre-sentence period, older offenders were six times more likely to have at least one MH service contact for any mental disorder than non-offenders. older |
| **Williams et al. (a)** | Self-report for MH problems using survey | • One in seven older individuals reported at least one "serious mental illness". |
| **Williams et al. (b)** | Definitions of mental health disorders from Bureau of Justice Statistics | • Half of all older participants suffered from a serious mental illness. |

*Results similar as Table 2 since findings for older male and older female prisoners were not distinguishable.

**Table 4: Mental illness among older prisoners**

| Author(s) | Number of older offenders | Any psychiatric problems n (%) | Psychotic disorders n (%) | Affective disorders n (%) | Personality disorders n (%) | Sexual disorders n (%) | Neurological disorders n (%) |
|---|---|---|---|---|---|---|---|
| **Arndt et al.** | 180 | 41 (22.5%) | | | | | |
| **Davoren et al.** | 213 | | 4 | 80 | | | 49 |
| **Farragher & O'Connor** | 42 | | Schizophrenia: 6 (14%) Paranoid disorders: 4 (10%) | 2 (5%) | | | 6 (14%) |
| **Fazel & Grann** | 210 | 172 (82%) | Psychoses: 67 (32%) schizophrenia: 15 (7%) | 16 (8%) | 41 (20%) | 6 (3%) | Cerebral lesions: 10 (5%) Dementia: 15 (7%) |
| **Fazel et al.** | 203 | 61 (30%) | | | | | |
| **Gates et al.** | 2940 | 1321 (44.9 %) | 184 (6.3%) | Depression: 600 (20.4%) Anxiety: 478 (16.3%) | | | Dementia: 59 (2%) |
| **Haugebrook et al.** | 114 | 41 (36%) | | | | | |
| **Hayes et al.** | 165 | 160 (97%) | Psychotic disorder: 8 (5%) Any psychotic features: 12 (7%) | 91 (55%) | 51 (31%) | | |
| **Hunt et al.** | 54 | 29 (54%) | Schizophrenia: 5 (9%) | 27 (50%) | | | |
| **Koenig et al.** | 95 | 51 (54%) | | | | | |
| **Lewis et al.** | 99 | 93 (93.9%) | 25 (25.2%) | 11 (11.1%) | 34 (32.3%) | | Dementia: 44 (44%) |
| **Moschetti et al.** | 136 | 58 (42.6%) | Schizophrenia: 9 (6.6%) | Neurotic, stress-related and somatoform disorders: 18 (13.2%) + mood (affective) disorders 5 (3.7%) | | 35 (25.7%) | |
| **Nowotny et al.** | 1160 | | | | | | |
| **Overshott et al.** | 47 | 20 (42%) | 2 (4%) | 15 (32%) | 8 (17%) | | 5 (11%) |
| **Sodhi-Berry et al.** | 1853 | 220 (11.9%) | 26 (1.4%) | 32 (1.7%) | 15 (0.8%) | | |
| **Williams et al. (a)** | 360 | 49 (13.6%) | Schizophrenia: 11 (3.0%) | Depressive and bipolar disorders: 64 (17.8%) PTSD: 23 (6.3%) | | | |
| **Williams et al. (b)** | 210 | 104 (50%) | | | | | |

**Table 5: Substance use among older male prisoners: Main results (N=17)**

| Author(s) | Methods used in the study to categorize substance use | Main results concerning substance use |
|---|---|---|
| **Arndt et al.** | Abuse defined by DSM-IV criteria | • More than two thirds of older inmates report substance abuse problems at admission to prison (less than younger prisoners).<br>• Older inmates are more likely than younger inmates to have abused one substance only (primarily alcohol).<br>• Older inmates are less likely to have received previous treatments for substance abuse problems. |
| **Davoren et al.** | - | • Less illicit drug use among older prisoners.<br>• Higher rates of alcohol misuse among older prisoners. |
| **Farragher & O'Connor** | Review of prison records | • More than one third of the sample (much higher prevalence depending on the subgroup 10 - 82%) had a history of alcohol abuse. |
| **Fazel & Grann** | ICD-9 from 1988; DSM-IV from 1997 | • Substance abuse or dependence problem in one in 6 older prisoners. |
| **Fazel et al.** | Review of prison records | • Older prisoners have a very low level of drug misuse. |
| **Gates et al.** | ICD-9 classification | • Aging offenders had significantly lower odds for having a history of cannabis and cocaine use disorders. |
| **Haugebrook et al.** | Case records | • Very high reported prevalence of substance use. |
| **Hayes et al.** | Review of prison records | • Substance use disorders were more likely in the age group 50-59 (for both, alcohol and drugs). |
| **Hunt et al.** | Psychiatric reports for occurrence of certain MH disorders | • Rates of previous drug misuse, alcohol misuse and violence were lowest in those aged 65 and over. |
| **Koenig et al.** | DSM-III checklist | • More than half of older offenders were incarcerated on drug charges.<br>• More than half of the sample showed alcohol or drug abuse. |
| **Lewis et al.** | Prison charts | • Alcohol dependence was most common diagnosis (over two thirds of the sample).<br>• 62% of the co-morbidity cases, it included alcohol abuse or dependence. |
| **Moschetti et al.** | ICD-10 classification | • Lower rate of mental illness related to psychoactive substance use.<br>• Less likely to misuse illegal drugs, more likely to abuse alcohol.<br>• Two measures on drug problems revealed differences: 32% declared being active drug users in entry examination with nurse, 18% were diagnosed with drug abuse problems in psychiatric follow-up. |
| **Nowotny et al.** | DSM-IV for substance use | • Among substance users with behavioral issues, there is a high burden of disease related to drug and alcohol use (HIV/AIDS, Hepatitis) and also a high level of behavioral health issues.<br>• Substance users with behavioral health issues have greater criminal justice involvement, higher rate of past incarceration episodes. This group has the highest percentage of black men. |
| **Overshott et al.** | Psychiatric reports | • Rates of alcohol dependence at the time of offence was low. |
| **Sodhi-Berry et al.** | ICD-9-CM classification | • Substance use was the most commonly treated disorder for offenders and non-offenders. |
| **Williams et al. (a)** | TCU Drug Screen, CAGE alcohol dependency questionnaire | • 25.2% had a drug dependency score over 3 on TCU.<br>• 45.6% had a alcohol dependency score over 2 on CAGE. |
| **Williams et al. (b)** | Drug Abuse Screening Test and AUDIT-C | • 56% drug use, 60% problem alcohol use. |

**Table 6 Substance use among older prisoners**

| Author(s) | Number of older offenders | Substances included | Any substance use n(%) | alcohol n (%) | Cannabis n (%) | Other illicit drugs n (%) | Other n (%) |
|---|---|---|---|---|---|---|---|
| **Arndt et al.** | 180 | Alcohol, Cocaine/Crack, Marijuana, Methamphetamine, other substances | 128 (70.9%) | 153 (85.04%) | 3 (1.6%) | Cocaine/ crack: 14 (7.9%) | |
| **Davoren et al.** | 213 | Substances, alcohol, illicit drugs | 83 (39%) | 77 (36%) | | 16 (8%) | |
| **Farragher & O'Connor** | 42 | Alcohol | 15 (35.7%) | 15 (35.7%) | | | |
| **Fazel & Grann** | 210 | Alcohol, substances, drugs | 31 (15%) | - | - | - | |
| **Fazel et al.** | 203 | Substances | 10 (5%) | - | - | - | |
| **Gates et al.** | 2940 | Alcohol, cannabis, cocaine, heroin, IDU, narcotic, tobacco | 2134 (add %) | 542 (18.4%) | 188 (6.4%) | Heroin: 16 (0.7%) IDU: 229 (8%) Cocaine or crack: 160 (5.4%) | Tobacco: 999 (34%) |
| **Haugebrook et al.** | 114 | Substances | 92 (81%) | | | | |
| **Hayes et al.** | 165 | Drugs, alcohol | 83 (50%) | 77 (47%) | | 23 (14%) | |
| **Hunt et al.** | 54 | Drugs, alcohol | | History of alcohol use: 6 (11%) | 0 | 0 | |
| **Koenig et al.** | 95 | Alcohol and drugs | 54 (56.8%) | | | | |
| **Lewis et al.** | 99 | Alcohol, drugs | | 67 (68%) | | 17 (17%) | |
| **Moschetti et al. (self-reported)** | 136 | Drugs, pharmaceutics, alcohol, cigarettes | 26 (19.1%) | 33 (24.2%) | | 8 (5.9%) | Pharmaceuticals: 5 (4.0%) Tobacco:53 (38.9%) |
| **Nowotny et al.** | 1160 | Substances, injecting drugs | 657 (56.6%) | | | IDU: 749 (64.6%) | |
| **Overshott et al.** | 47 | Alcohol | | 3 (6%) | - | - | - |
| **Sodhi-Berry et al.** | 1853 | Substances | 106 (5.7%) | | | | |
| **Williams et al. 2010** | 360 | Alcohol (CAGE), drugs (TCU drug dependence score) | drug dependence : 91 (25.2%), alcohol: 164 (45.6%) | | | | |
| **Williams et al. 2014** | 210 | Alcohol, drugs | | 127 (60%) | | 118 (56%) | |

# Chapter 2: Identity as an older prisoner: findings from a qualitative study in Switzerland

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**Identity as an older prisoner: findings from a qualitative study in Switzerland**


## Abstract:

The increasing numbers of aging prisoners raise the issue of how they maintain their personal identity and self-esteem in light of long-standing detention. This study sought to answer this question since identity and self-esteem could influence mental and physical health. We conducted a secondary analysis of 35 qualitative interviews that were carried out with older inmates aged 51-75 years (mean age: 61 years) living in 12 Swiss prisons. We identified three main themes that characterized their identity: personal characterization of identity, occupational identity, and social identity. These main themes were divided into sub-themes such as familial network, retirement rights or subjective social position. Personal characterization of identity mostly happened through being part of a network of family and/or friends that supported them during imprisonment and where the prisoner could return to after release. Individual activities and behavior also played an important role for prisoners in defining themselves. Occupational identity was drawn from work that had been carried out either before or during imprisonment although in some cases the obligation to work in prison even after reaching retirement age was seen as a constraint. Social identity came from a role of mentor or counselor for younger inmates, and in a few cases older prisoners compared themselves to other inmates and perceived themselves as being in a higher social position. Identity was often expressed as a mix between positive and negative traits. Building on those elements during incarceration can contribute to better mental health of the individual prisoner which in turn influences the chances for successful rehabilitation.


## Introduction

Personal identity, self-concept and self-esteem are closely related concepts (Baumeister 2015), which aid an individual to cope with stress, trauma and misfortune (Baumeister and Leary 1995; Eriksson and Lindström 2007; see Steele 1988 cited in Baumeister 2005). Personal identity—an individual's concept of their self—is often classified using one's belonging to a certain group (Baumeister 2015). Self-concept— the individual's understanding of their self, that is, their interpretation of the self—may evolve with changing goals and ideological beliefs over the span of a person's lifetime.

In contrast, self-esteem—the evaluation of the self—is rather stable over time. Ideally, the aging stage succeeds previous successful and fruitful lifecycle milestones such as creation of a family and completion of a career. To ground our study purpose, we briefly highlight different life events that contribute toward formation of identity for older adults in the community and present how incarceration disrupts this expected aging identity.

For Erikson and Erikson (1998), the eighth stage of psychosocial development, that is, the stage of late adulthood (from 65 years on) is identified with holding on to one's sense of wholeness and the belief of having led a significant life (experiencing integrity), as well as not fearing the idea that there might not be enough time to begin a different life course (avoiding despair). Individuals who succeed in both tasks are able to develop wisdom, including acceptation of the

life lived, pride of past achievements and the fact that death is unavoidable and inescapable. Ideally, the aging stage follows previous successful and fruitful lifecycle milestones such as creation of a family and completion of a career. Graefe (2013) describes aging as a paradox and multidimensional experience, but states that the current ideal of "successful aging" may only be possible for a limited social group who fulfills three criteria: having necessary financial resources to be protected from precarious situations, cherishing autonomy, self-determination and self-regulation, and being in relatively good health until old age. This group may best be represented by urban middle- and upper-middleclass older individuals. In turn, this would mean that "unsuccessful aging" may be the case for individuals belonging to less fortunate social strata. This corresponds to the finding of Westerhof et al. (2011) who note that an individual's approach to aging partly depends on the welfare system he/ she is living in and that it is thus important to also study "the effect of individual perceptions of welfare regimes on the aging process" (p. 59).

Throughout a person's life, the job(s) or career that a person has occupied plays a key role in the formation of their personal identity (Christiansen 1999; Hendricks 2004). The benefits of lifelong occupation in the form of social security and/or pensions as well as health care benefits at old age contribute toward the formation of a social identity as a retired person. Additional positive events that are associated with identity at old age are becoming a grandparent, and when possible, contributing toward caregiving activities for the grandchildren (Kaufman and Elder 2003). That grandparenting is an important identity for older adults is illustrated in the literature that underlines older adults' positive attitudes toward grandparenting and taking up this role when needed (Bordone and Arpino 2016; Di Gessa et al. 2016). Whitbourne (1986) highlighted these two milestones when she stated that "it is the self-appraisals in these areas that permeate all other areas of identities" (p. 3).
According to Weiss and Lang (2012), a "dual age identity"— referring to their generation as well as to their age group—allows individuals to identify with a generation (linked to a certain birth cohort) rather than with a specific age group (for example, "60–70 years of age"). The difference between the two is that generational identity usually represents positive concepts of similarity and interdependence between its members, whereas age group identity implies more age-stereotypical characteristics associated with (rather) negative attributes. Studies on age identity also reveal that it does not conform to personal identity (Sherman 1994). Older individuals regularly report that they feel younger than they actually are, and hence their perceived age, imagined age and desired age are younger than their actual age (Kaufman and Elder 2002, 2003). A youthful age identity is an almost universal phenomenon and may even be associated with older individuals' positive state of health and subjective well-being, whereas poorer health factors seem to be significant predictors of an older age identity among older adults (Macia et al. 2012). Bowling et al. (2005) state that it may also "be a function of perceived years left to live (or of time of death)".

Most of the research on identity at old age is carried out with the general population. Thus, the meaning of being an older person and one's identity has not been captured in the context of imprisonment. Unlike older persons in the community, who can retire once they reach a certain age (e.g., 65 years), older prisoners may have the duty to work indefinitely in prison. This is at

least true in the Swiss prisons where a work obligation remains irrespective of age (Meier c. Suisse 2016). Continued work in prison is geared toward preparing prisoners to integrate work life upon release and counteracting negative effects of detention through structured daily life (X vs. Amt für Justizvollzug des Kantons Zürich 2013; Meier c. Suisse 2016). Hence, all prisoners must work during their stay in prison, the only exceptions being illness, injury and lack of available work opportunities.

Interestingly, a feature of old age that remains common for older prisoners in Switzerland is their right to receive old age income (similar to the social security benefits in the USA). Every person in Switzerland who has worked in his adult life and has contributed to the social insurance system is entitled to old age income, regardless of incarceration (personal communication with the Swiss Social Insurance Office, 01.05.2016). Brogden and Nijhar (2000) even mention this characteristic of prison under the headline "Prison as haven" and state that according to Wiltz, "(n)ot only does the incarcerated older person maintain a work role, he commands a social security income which places him at an economic advantage in relation to younger inmates" (pp. 142–145).

Incarceration is likely to distance them from their family members and friends. Although an aging individual (both in the community and in prison) cannot escape negative experiences such as loss of friends and family or deteriorating health, older adults in the community possess more opportunities to develop coping strategies in order to maintain a healthy personal identity, self-concept, and self-esteem to improve their overall well-being (Levy et al. 2002; Schafer and Shippee 2010; Westerhof and Barret 2005). New friends or acquaintances can be made and cultivated, while unwanted relations can be avoided. But these opportunities may not be freely available to older prisoners. Carstensen (1992) stated that when the aging process and old age are lived out in an institutionalized setting such as nursing homes, assisted living facilities and even prisons, these older persons often do not have the opportunity to make new relations and maintain old relations and may not be able to find people they wish to socialize with. In the case of prisons, since most prisoners are younger (Moschetti et al. 2016; Wangmo et al. 2015a), it may be difficult for an older person to relate to and bond with younger prisoners or those from different backgrounds. At the same time, there is a research underlining the role of older persons as mentors for others, mostly younger prisoners (Loeb and Steffensmeier 2011; NC4RSO 2011; Prison Reform Trust 2016; Wangmo et al. 2017).

Incarceration means that older prisoners may have lived in a closed setting for many years and will continue to do so until their release. We imagine that the long time served in prison would have a different impact for these individuals than for those who enter prison at a later life stage, having spent most of their lives outside prison. We also presume that the construction of identity for older prisoners may be different because the concept of "old age" in prison does not have the same implications as it does in the general community.

The number of older individuals in prison is increasing rapidly (Human Rights Watch 2012; Prison Reform Trust 2016; Walmsley 2013), making them an important group to study. In Switzerland, the population of prisoners aged 50 years and older has more than doubled from

295 persons in 2003 to 663 in 2014 (Bundesamt für Statistik 2015); a similar increase is being witnessed by other countries as well, for example, the USA or the UK (Carson 2015; Prison Reform Trust 2016). Schneeberger Georgescu (2006) reported that the increase in the number of older prisoners in Switzerland was mostly due to a rising number of prisoners serving indeterminate sentences and aging in prison, thereby concluding that most prisoners were aging in prison.

Unfortunately, little is known about identity and aging in the prison context. To our knowledge, only a few studies have captured how older prisoners perceive their identity as an older person in the prison (Aday and Farney 2014; Crawley and Sparks 2013). Understanding how older adults conceive their own selves in prison might prove vital for improving their overall conditions and leading to better mental health and well-being. Therefore, the aim of this paper is to highlight how older prisoners in Switzerland conceptualize their old age and identity. We nevertheless note that the topic of identity before and during imprisonment had not been a part of the original research project (Handtke and Wangmo 2014; Handtke et al. 2017; Wangmo et al. 2017); therefore, the question of how identity changes as a consequence of imprisonment cannot be treated in the scope of this paper.

## Design and methods

The goal of the Swiss national project "Agequake in prisons: Reality, policies and practical solutions concerning custody and health care for ageing prisoners in Switzerland" was to examine the health care of older prisoners in Switzerland.
During the course of this project, both qualitative interview data (see Handtke and Wangmo 2014; Bretschneider and Elger 2014; Wangmo et al. 2017) from older prisoners (50 years and older) and quantitative data from the medical records of older and younger prisoners (see Wangmo et al. 2015a, b) were collected. The secondary data analyzed in this study come from the qualitative part of this project, and the analysis was done in light of gaps in research illustrated above and lack of primary data. Secondary analysis in this case is based on primary data that were collected by researchers of the same institution, so the context is well known to the authors. Also, we agree with scholars such as Zieblandt and Hunt (2014) who have stated that for publicly funded research the value of data for the public good in general and particularly for the populations participating in the research should be maximized.
Since studies with prisoners conclude that due to a mix of prison environment and prisoner population-based factors (Elger 2004; Elger et al. 2002; Ritter et al. 2011), they age faster than their counterparts in the community as shown by the fact that they have higher disease burden and poorer health status (Loeb and Abudagga 2006). Thus, prisoners are considered old (at least in the scientific literature) when they reach 50 or 55 years, although some recent research considers this an oversimplification (Spaulding et al. 2011).

Older prisoners were defined as those who are 50 years and older for this project and both qualitative interview data (see Handtke and Wangmo 2014; Bretschneider and Elger 2014; Wangmo et al. 2017) from older prisoners (50 years and older) and quantitative data from the medical records of older and younger prisoners were collected (see Wangmo et al. 2015a, b).

## Study sample

Thirty-five older prisoners, with an age range of 51–75 years, participated in this study. Time served in prison until the date of the interview ranged from 0.4 to 23.4 years, with an average of 6.1 years. They were imprisoned in open and closed prisons in the German ($n$ = 23) and French ($n$ = 12) language regions of the country. Only five of the older prisoner participants were women. Younger prisoners were not interviewed because the national project was designed with a focus on elderly prisoners, defined as those who are 50 years and older (Loeb and Abudagga 2006; Mitka 2004).

## Data collection

The interviews were carried out by two Ph.D. students at the prisons, with discussions held in German or French languages, based on the preference of the participants. The semi-structured interview guide was designed to explore older prisoner's perceptions of their health and health care, their aging experiences, and the environmental as well as social circumstances in prison. Related to this paper, within the aging experiences and social circumstances in prison, questions related to their family and friends both inside and outside the prisons were posed, their right to retirement, work responsibilities, etc. All interviews took place in person in the prisons and were carried out by two Ph.D. students working on the project. The language of the interviews was either German or French. These interviews were on average 91 min long and were tape recorded. All interviews were transcribed verbatim and anonymized by research assistants. To ensure the quality of transcriptions, they were checked for errors by independent assistants.

## Data analysis

Data analysis was carried out using semantic thematic analysis (Braun and Clarke 2006; Guest et al. 2011) in light of the secondary nature of this work using already collected data with different study goals. In the process of carrying out analysis of the study for primary study goals (Handtke and Wangmo 2014; Wangmo et al. 2017; Handtke et al. 2017), we realized that interesting information was being raised that could not be put together with into the primary study goals of health and aging concerns of older prisoners. Thus, the authors decided to re-analyze the data to find "how is old age identity described and experienced by older prisoners?" SH and BE read the transcripts of all 35 interviews, as they were fluent in German and French languages. TW read the transcripts of the 23 German interviews. All authors met to discuss the collective findings on what main themes are evident in the interviews that could points toward old age identity in prison. Thereafter, SH re-read the interviews to identify relevant data that responded to the research question.
Using semantic thematic analysis, she coded the data related to old age identity into initial categories and subcategories.

These categories and subcategories were presented to TW and BE. After discussion, all authors agreed on three main themes which included three different factors at the level of personal,

institutional, and social levels allowing participants to characterize themselves as an older person in a meaningful way that underscored their belongingness and value (Table 1). All authors discussed and agreed on the interpretations of these sub-themes during the drafting of the manuscript. The analysis took place in the language of the transcripts.
Exemplary quotes presented in the paper were translated from German or French to English by SH. These translations were edited by TW and BE to ensure that the meaning of the context remained clear. Quotes do not provide identifying information of the participants.

**Table 1** Findings from the thematic analysis

| Main theme | Sub-theme 1 | Sub-theme 2 |
|---|---|---|
| Personal characterization of identity | Identity as a family member and a friend | Identity through their actions and behavior |
| Occupational identity | Work responsibilities before imprisonment | Work obligation in prison |
| Social identity | The wise mentor | Subjective social position |

## Results

### Personal characterization of identity

*Identity as a family member and a friend*

Family-based identity formed an important part of the lives of many participants and gave them a sense of belonging.
They thus situated themselves as a grandparent, a parent, a child or a sibling. Moreover, they emphasized the support that they received from their families who came to visit them and with whom they continued to maintain their relationships: “I have my children, my two children, I have my two sisters who come [to visit] very often. And I have my nieces and my nephews.” (P25, female, 3.2 years in prison)
For some participants, family relations were their most important connection to the world outside the prison and family members, especially their descendants, of whom they were very proud of, defined their identity.

> My family, my children, I do not want to live without my family, without my children, definitely not. My family is my children. Yes, I’m so proud of them. Now I’m a grandmother with five grandchildren. (P2, female, 2 years in prison)

However, there were a few prisoners who no longer had a family either because they were dead or because they have been disowned.

> Yes, my friends. I don't have a family. In my case, the whole family is murderer and manslaughter. My mother was [X years old] when she had me, and when she was [X years old], the old man shot her. And my brother hung himself. (P17, male, 2.9 years in prison)

Another prisoner stated: "I don't have a family anymore. Since 8 years I [only] have a girlfriend." (P34, male, 0.5 years in prison) In these cases, they seemed to value their relations with friends and colleagues as much as, or even more, than their family. One participant carefully differentiated between various types of friends, casual and close ones, and underlined his active role in choosing the close friends:

> I have friends, very dear friends. I don't have many but I have very dear ones. Those who come to see me, those with whom I have – I am someone quite – I have always chosen my friends. I have had so many friends – those who have stayed are really – faithful ones. (P06, male, 0.5 years in prison)

Most participants who were likely to be released highlighted that they would return back to their family or friends and seek to live a good life with them and never return to prison. This good life was sometimes conveyed in rather ideal expressions. One participant (P07, male, 1.1 years in prison) stated: "I want to end this sentence and then live together with my wife again until – until death do us part."
Furthermore, this sense of belongingness and having someone to return to was important for their identity in prison which went beyond the current context of incarceration.

> My future, that's to go back to my family, my children and my grandchildren as soon as possible, of course. To live with them, um, for many years still, I still have many projects. (P22, male, 0.4 years in prison)

The idea of being needed underlined the importance of one's individual existence and the impossibility to be replaced, and was expressed by one participant in an almost repetitive way:

> I think once I have completed this I never want to go to prison again, never. Because now my daughter needs me, my wife needs me, my children need me, right. And as long as I live I really want to devote myself to my family. (P20, male, 2.1 years in prison)

*Identity through their actions and behavior*

A few participants described themselves through actions and behavior that can be classified using the personality traits.
They characterized themselves as non-conformist when they voiced disagreement with prison rules that were perceived as discriminatory or when their needs were not properly addressed, as one participant stated:

> After the smoking ban I went on strike and said, I will boycott my visits because nobody from my side will come here anymore [most are smokers], and I will not put up with discrimination. … During one and a half years I fought for my rights, and once our new deputy was here, this worked within a week. (P15, male, 5.6 years in prison)

However, the few participants who sought to voice their concerns were not always successful. One participant noted that meek prisoners are preferred by the prison administrators:

> I learned that the more you defend yourself in prison against anything, that you demand so-called justice, the more they put you down. And they like those who cry, who take drugs to calm themselves, and not those who hold their head high." (P32, female, 8.9 years in prison)

Others described how they utilize and plan to use their time in prison to keep up with their creativity. They mentioned working on cookbooks and memoirs; for example, a participant (P10, male, 2.7 years in prison) reported:

> I also intend to write a cookbook. (…) And also to write down, let's say, my whole life. Especially about the little guy (when I was a child), those things come to my mind.

Another, (P21, male, 10.5 years in prison), discussed how he was preparing for an art exhibition that would occur once he was released:

> I still am in touch with people where I could make art exhibitions with my, with my stuff. (…) And I also want to prepare for an art exhibition as long as I'm still in here. In a year I could go to (name prison unit) for the very compliant ones, the really serious ones. (…) I could even have a room allocated to me. So I could spread my palettes, my paintings a bit, there I could prepare for an art exhibition. (P21, male, 10.5 years in prison)

A small number of participants expressed they sought to isolate themselves from others. After noting she must remain in prison for the duration of her sentence, participant (P01, female, 10.4 years in prison) stated that, "I simply tell you, my friends are my books, my computer and my four walls. (…) This isn't my world." In the case of one participant, this positive self-isolation was described as quasi-monastic.

> I often draw the parallel to a monastery. We have a life a bit like in a monastery. It's roughly the same life: we have daytime activities, afterward we are confined. The week end is confined. So I like this… this monastic life. … I sit down in my cell, I eat, I do something else… It's an infinite time that I gained also for myself. And this gives me the occasion to have, um, personal activities that make me richer than life outside. (P27, male, 3.4 years in prison)

Some participants talked about the guilt of having committed a crime and therefore suffering a punishment. In doing so, they identified themselves as a person who has repentance and is capable of moral reasoning. For instance, one participant (P02, female, 2 years in prison) said, "I have to suffer until the time I will get out of prison." Another (P08, male, 1.8 years in prison), strongly believing that it is right to live the consequences of his actions, noted: "I am not in prison to make friends. I am in prison to serve my sentence."
Different from those who felt that suffering was justified and accepted that role, there were others who reported that their identity was not respected by prison personnel. They resented that they were treated as worthless individuals, were ignored, and not recognized as humans, as one participant expressed:

> Me, I am – sometimes they forget that I am here. They have enclosed me outside of the kitchen, they have forgotten me. Because I am quiet, I am silent, I don't make problems. … There are many here who get upset because we are not respected. In any case we are humans; we are not treated like humans. (P27, male, 3.4 years in prison)

Another participant experienced purposeful negation and compared this to similar situations in early life, being treated like an object or an immature being:

> Well, and the doctors of (hospital in French-speaking Switzerland), you can tell them, and the staff, when we go, we go with guards, and the doctors and them, they speak to the guards, they don't talk to us. It's like we were a child, and then you talk to the mother. Because we are in prison. (P25, male, 3.2 years in prison)

**Occupational identity**

*Work responsibilities before imprisonment*

Many participants defined themselves through the work they had done prior to their incarceration. They held professions such as painters, cooks, journalists, accountants, drivers, businessmen, and translators. Moreover, a few were adept in several languages that they could use in prison as well.
Some participants were even able to continue using their skills and knowledge. They discussed how their skills were in demand and that they were able to contribute something positive and remain useful, all of which feeds into feeling good about themselves.

> Here, there are other prisoners all the time who come to me 'listen, couldn't you quickly translate something into Italian?' and stuff like that (…). I'm always open, and that's why I am constantly overworked, always lots of things. It's really special. (P31, male, 6.2 years in prison)

> When I was in prison X, I painted a lot, many persons; I made portraits of their wives, their children, their mom or dad. So, um, I was paid a bit through that. Many people

> asked me, I had to turn some down because – because it's a lot of work for me. (P27, male, 3.4 years in prison)

*Work obligation in prison*

In addition to their prior employment and ability to help other prisoners, several study participants also identified themselves with the allocated work in prison. For example, a participant who also derived professional pride from his work stated:

> "I have good relations with everybody who works in the kitchen. I am appreciated through my work, they call me 'Doc Salad' [name changed]" (P27, m. 3.4 years in prison).

However, not all participants were working full time in prison, with some reporting working part-time. A few participants felt flexibility is desirable since older persons who tire more easily may not be able to carry out physically demanding work. A participant discussed this flexibility of work obligation for older persons in general.

> That's it, that's it, so he can adapt his hours and let's say be a little freer. I'm not talking about outside the prison, but that he [older prisoner] is a little freer concerning the schedules, so that he can rest when he feels tired because it's true, he must be tired. (P23, male, 1.3 years in prison).

A few older prisoners even reported that they requested to be able to work since it was good for them, that is, working allowed them some level of independence and not working could mean being relegated to their cell. A participant (P09, male, 6.7 years in prison) reported, "I really prefer to go to work than to spend the whole day in my cell. Really, weekends are bad for me." Another (P32, female, 8.9 years in prison) ascribed almost "rescuing" qualities to work in prison:

> I was on sick leave because of my illness. And I pleaded with the prison director, let me work, that's my best therapy. And she let me continue, and I probably survived the whole thing probably thanks to that, thanks to work. Because aftercare in a prison is as bad as you can imagine. Because you're left to your own device, there is no pain medication, no band aids, no dressing. Nothing!

Furthermore, work that they were able to carry out in prison allowed them to not only feel useful, but also be free to some extent since during their work time; they could manage themselves instead of being managed:

> So when they open that big gate for me and they let me go, because they have made a wooden cupboard for me especially to store all the gardening material, so I take good care of it. And when I open my cupboard and I leave with my tools and I pass that gate, I have the impression to find myself as if I was in semi-liberty. I feel privileged because

> I find myself in – maybe it's stupid in your eyes – but I have the impression to be, um, different from the others. (P24, female, 2.6 years in prison)

For their work, they reported receiving some monetary compensation ranging between CHF 250 and 700 per month based on the amount of work as well as which prison they were in. Not all this "salary" was available for personal use, in most cases 2/3 could be used as they wished and was kept in an active account, and 1/3 was kept in a savings account. In any case, having discretionary funds, however, small, means a certain level of independence and decision-making:

> Because I also order from the active account. I just have that amount here that I need for the cafeteria, shopping and small things, which we can buy at the vending machine downstairs and phone cards and so on. (P20, male, 2.1 years in prison)

Although most participants appreciated working in prison, very few reported that the work obligation is constraining if they did not wish to work. One participant mentioned the choice between refusing to work and having to suffer disciplinary measures. Although in his case, he was able to reduce his work load.

> Hmm-I think that- if I didn't have this access to a reduced schedule, it would be a little harder for me nevertheless, to be obliged. And I think I would have refused, and if I had refused I think they would have put me, in the dungeon [isolation cell used for punishment]. So hmm nevertheless it isn't very pleasant for an elderly person to have to go in the dungeon because we don't agree to go work. That's it. That's quite an important problem. (P22, male, 0.4 years in prison)

A few participants reported receiving their old age pension even though they were in prison. For instance, (P11, male, 13.1 years in prison) stated: "Yes, I get a compensation here [for the work I do], that is just-, the standard. And I also get some money from the AHV [old age pension], a subsidy. So I am financially secure." Others who reported receiving old age pension noted that it comes to their account outside the prison.

**Social identity in prison**

*The wise mentor*

Identity in prison was also emulated when a considerable number of older prisoners mentioned their role as a mentor or counselor for younger inmates. One participant (P22, male, 0.4 years in prison) stated:

> I have contact with younger persons, and this is very interesting because you can counsel them, you – you can tell them 'this is what I think of life' and what they should enjoy of it above all, right. (P22).

They were proud that they could provide advice to younger prisoners, support them with their wisdom and experience, and act as "father" figure. They revealed being very satisfied when identified as such: "There was a younger guy, less than 26 years old, and he told me then that if he could choose again he would choose me as a father, and I should not go [and commit suicide], I am still needed." (P10, male, 2.7 years in prison).

*Subjective social position*

A few prisoners were identified with their level of skills or knowledge compared to the rest of the group. They felt that compared to the others, they were in a better social standing because of their higher education, general understanding, nationality, and thus ability to communicate in the local language. This may have served as a way to distinguish themselves through perceived additional attributes and a strategy for themselves to rationalize not fitting in (because of age or different hobbies) and turning it into something positive:

> Well, it is quite… incompetent, to say the least, of the three who are there I would say one is competent. (…) Well, sometimes it is tiring to listen to that brainless rap music. (…) If I look around there are around half a dozen persons with whom I can discuss things at the same level. Because I'm not interested in idiot computer games or action movies. (…) There are few people who read. As I said, except a handful, all the others are in the gym, that macho stuff. (P15, male, 5.6 years in prison)

A female participant used a similar strategy and created perceived identity of "solidarity" with another female inmate through nationality and education levels. Her almost apologetic introduction shows that she is conscious of this strategy and that this rationalizing may be taken for arrogance.

> Well, I have to explain a bit - the woman who works with me is also Swiss. She has – please don't get me wrong. She also has a higher education. (…) I'm really the only one who has nothing with life and limb or a threat to society (…) compared to the others, I never endangered anybody in any way nor tried to endanger anyone. (P01, female, 10.4 years in prison)

## Discussion

Older prisoners drew their identities mainly from three sources. First, the personal characterization of identity included being a member of his or her family and/or being a friend and receiving support through these ties. Identifying oneself based on relationships such as a father, a mother, and a grandparent is an expected finding in light of the importance of role identity, especially as a grandparent (Bordone and Arpino 2016; Di Gessa et al. 2016; Kaufman and Elder 2003). Although this part of identity formation was hindered for these older prisoners as they were unable to carry out their grandparenting roles due to incarceration (Handtke et al. 2015), they took pride in being part of a family tree and having descendants. We hypothesize

that this feeling of belongingness derived from being a member of a close circle of persons may balance out the impression of random and anonymous existence as a prisoner.

Another aspect of personal characterization was viewing their identity through personal actions and behaviors that can be classified as personality traits according to the "Big Five" personality factors (Tupes and Christal 1961). These core factors represent the basic structure behind all personality traits (extraversion, agreeableness, conscientiousness, openness to experience, and neuroticism) and were visible in how our participants described themselves. For example, nonconformity to the prison rules can be seen as a dimension of extraversion; creativity was underscored by those who reported it as a dimension of openness to experience, just like those who enjoyed working a lot; introversion and recluse as a dimension of extraversion; and ideas of guilt or suffering a punishment (expressed through repentance or penance) as dimensions of neuroticism, similar to the feeling of being ignored or lacking a human identity.

The difference between having made actual experiences and merely planning to carry out projects in the future seemed important for the personal narrative. Actions that had taken place and were experienced as positive and constructive, like standing up to the smoking ban, were expressed in a more assertive way and seemed to have a more positive consequence for the individual's identity.

Potential actions such as conducting creative projects in the future were expressed in a more conditional and vague way and did not lead to the expression of an artistic identity.
Being able to see isolation in a constructive way made it easier to cope with the context of imprisonment and view oneself as a person who is able to use even this experience for the best, for example, by feeling "rich" through personal development.
Identifying oneself as suffering or powerless led to resentment.
One participant (P27) reaffirmed the humanness that he felt was denied to him although his way to react to this— remaining silent—differed from the more common reaction of getting "upset." However, it is not clear if this resignation is partly rooted in being older or entirely in general personality traits. The coping strategy of a participant (P25) to deal with the perceived infantilization consisted in searching for help from allies who would serve as intercessors, as in this case the interviewer who was perceived as communicating with doctors and prison staff on a more efficient level than the participant.

The association of these personality dimensions with many other behaviors such as work success, mental ability, life satisfaction, social vitality or resiliency, in addition to personality disorders (Widiger and Costa 2002) and mental disorders (Kessler et al. 2005) indicates that these dimensions may be universal (McCrae and Costa 1997). Srivastava et al. (2003) conclude that these personality traits are not static, but can evolve over an individual's life span. Therefore, it may be possible to put in place interventions in the prison context that addresses the positive dimensions of personality to improve the mental health and life satisfaction of older prisoners.

Second, occupational identity was derived from activities before or during imprisonment. Some prisoners used professional skills that they had acquired prior to imprisonment and could use in prison. Others acquired new skills during incarceration, although it is not clear if this happened in a manner that was formal (like a structured professional training for prisoners) or informal (comparable to training on the job). In both cases, professional pride was derived and with it an identity associated with being needed and appreciated.

We nevertheless do not have data to examine if professional skills acquired in prison had a bigger impact on identity if there had been previous periods of unemployment which might be an interesting topic for further research. Furthermore, work in prison even at old age, in most cases, provided some equilibrium to the prison situation through creating a certain daily routines. In the context of Switzerland, where all prisoners must work irrespective of age (cf. Meier c. Suisse, 2016; X gegen Amt für Justizvollzug des Kantons Zürich 2013), being able to work and not having to retire may also contribute to a (social) identity of the self where one is not different from the others. At the same time, work obligations and lack of knowledge about entitlement to old age benefit takes away an important part of old age identity of deservingness through welfare provision (cf. Fealy et al. 2012), that they would have enjoyed if they were not incarcerated. Not being able to cope with the demands of (physical) work can be a visible indicator of increasing age and vulnerability, forcing the individual to rest when tired and suffering more from disciplinary measures than younger prisoners. The physical or mental tiredness that was perceived by some participants and was associated with the aging process was thus expressed in a rather negative way and may lead to associations of vulnerability and frailty when defining one's identity. We hypothesize that the focus on work and its demands, as well as the constant comparison with younger prisoners, prevents older inmates from reaping the benefits of the subjective perception of feeling younger than they actually are (Bowling et al. 2005; Demakakos et al. 2007).

We can say here that occupational identity means much more for individual participants than just having an occupation that structures the time in prison. Depending on individual character, it can imply a sense of freedom, of reaffirming oneself as someone who can refuse certain work. Third, social identity as an older prisoner was often associated with being a mentor, which was also evident in previous studies that note the positive position of older prisoners (Wangmo et al. 2017; Yates and Gillespie 2000). However, being a mentor is not necessarily the same as being a leader as the type of bonding and interaction is not the same. In a few cases, having a "parental" role was also mentioned, epitomizing their status as "role models." Interestingly, only male participants talked about a mentoring role. In the literature, mentoring is sometimes described as a role for persons who do not have children of their own (NC4RSO 2011), but we were unable to see if this was also the case in our sample. In some cases, social identity was related to the educational skills and other skills that they possessed, which distinguished them from their peers. Such factors derived from comparison with others, also called "external contingencies" (Vonk and Smit 2011), are in contrast to "intrinsic contingencies" and appear to be negatively correlated to personal well-being. Distinction through social identity created alienation although it is not clear if the resulting self-isolation was the consequence of or the reason for this alienation. The need to feel different from the rest of the population may have

given the participants the necessary resilience to endure the time they served, creating a heroic narration of a person who is better than the rest instead of suffering from social isolation without coping strategies.

This strategy may be less sustainable for maintaining a positive identity, but it also may be an individual strategy to turn the perceived weakness of social isolation into a strength, in that way preserving self-worth.

It must be noted that only 5 of the 35 participants were female, and that among female prisoners there was heterogeneity, just as between male prisoners. Therefore, it is difficult to derive differences in identity that can reliably be traced back to gender issues instead of interpersonal differences. All three sources of identity stated above contained "positive" and "negative" characteristics. A "positive" identity stemmed from ties to family or friends, from professional activities before or during prison, from social roles as mentors as well as from positive individual personality traits like creativity and being strong enough to be a non-conformist.
Although Aday et al. (2014) conclude that participation in religious or spiritual activities may provide stability and perspective in later life for older prisoners, the importance of religion for our participants did not rise to the level of a theme and was thus not presented in the results. Similar to the results of other studies (Ardelt 2003; Reker and Chamberlain 2000), for our study participants, frequently mentioned topics related to meaning and purpose in life such as personal relationship was a factor that solidified their identity and thereby the perspective of their later life. It is evident that prison disrupts this relational factor in light of limitations that are placed on those incarcerated. Handtke et al. (2015) state that older female prisoners "were constantly thinking, worrying, and wishing to see and be with their family and friends" and mention the common strategy of elderly female prisoners of keeping "their social relations inside prison superficial and to a minimum, while "exporting" it to the outside and stressing the importance of extramural contact" (p. 5).

In contrast, a "negative" identity—that is, the assumption of a persona which is at odds with the accepted values and expectations of society (Mosby 2009)—comprises, for example worthlessness or guilt, isolation, lack of friends or family. Negative personality traits such as feelings of vulnerability were evident in the voices of some of our study participants. Research has shown that life events such as loss of independence or continuity with the past life, feelings of social isolation or loneliness or loss of autonomy contribute significantly to depression as "the daily living in which they could no longer exert control engendered a sense of helplessness and hopelessness and raised existential doubts" (Choi et al. 2008 p. 545). While this may be said for the general population, it is especially important in the context of an institutionalized setting such as hospitals, nursing homes or—as in the context of this article—prisons. Already in 1977, Reker (1977, p. 691f) revealed how the sense of a purpose in life "may be an insulator against the pressures of a structured prison environment and may be predictive of successful rehabilitation." This sense of a purpose was most clearly expressed by participants who had a family or friends to return to after liberation and fulfill a social role; in cases where this perspective was lacking, we deem that the perceived loss of autonomy may weigh heavier. It would have been interesting to examine the existence of a link between "negative" identity

coupled with diagnosed depression and social isolation and other negative factors mentioned above, but this was beyond the scope of this project and would be an interesting topic for further research.

Not all interviewed older prisoner participants fit clearly into the "positive" or "negative" categories mentioned above. Many participants expressed different strategies to create or maintain an identity. Several "non-conformists" used writing to document perceived injustices, while for certain "family types," writing was a way to pass on memories to loved ones. Being a "mentor" was often associated with identity from work either before or during the sentence and a high level of life experience that is symbolized by older age.

Many older prisoner participants also mentioned a mix of both "positive" and "negative" identities, for example, a feeling of being rooted within a network of family and friends while at the same time suffering from feelings of isolation or inadequacy, which in turn may lead to feelings of emotional ambivalence over time. Research has shown that such ambivalence should not be regarded as something entirely negative (Fong 2006). Larsen et al. (2003) found that coactivation of "positive" and "negative" emotions, rather than suppressing "negative" emotions or accentuating "positive" ones, makes it possible to maintain these emotions longer in the working memory and better organize and integrate them into the individual's personal narrative in order to find meaning and make sense of major life stressors. This can help to transcend traumatic experiences, thus strengthening resilience and healthy coping mechanisms. Hershfield et al. (2010) assessed data from a 10-year longitudinal study and found that increased experiences of mixed emotions were associated with less health decline over time.

Antonovsky's (1979, 1987) salutogenic model explains differences between the formation of a predominantly "positive" or "negative" identity by the presence or absence of the main factors that determine health and disease (e.g., stressors, generalized resistance resources, sense of coherence).

An individual's sense of coherence reflects meaningfulness, comprehensibility, and manageability of life, which has strong connections to positive outcomes like good physical and mental health (Lindström and Eriksson 2005; Piotrowicz and Cianciara 2011). Consequently, the lack of such factors often lead to formation of "negative identity" and result in a reduced state of physical and mental well-being. Lindström and Eriksson (2005) state that the sense of coherence is not a rigid concept and the capacity to develop it is available throughout the lifespan. Ventegodt et al. (2011), when reviewing the literature on interventions that can induce salutogenesis and improve quality of life, cited treatments and actions such as conversation and body psychotherapy, therapeutic touch, physical therapy or general body work, in contrast to therapy through drugs and biomedicine that appeared to rehabilitate the patient's "sense of coherence" and promote existential healing which may involve "a complete reorganization of the patient's personality" (p. 419). The question how far improving quality of life and factors that contribute to positive identity is feasible in an institutionalized context remains open.

## Limitations

Like any other qualitative research, the study is bound with the limitations that plight this type of research methodology: lack of generalizability and social desirability. The latter may seem critical in light of the context of the study. However, since the topic of identity in old age was not the main theme of the project (which intended to understand the health and aging experiences of older prisoners; see Handtke and Wangmo 2014; Handtke et al. 2015; Wangmo et al. 2017), we are certain that social desirability has not affected this topic. This also means that the results on identity and old age in prison represented here are not expansive. Our findings is exploratory at best and thus more research is needed with the aim to evaluate how identity formation and identity continuation affect prisoners' overall quality of life and thereby their physical and mental health. This is important since better health status of older prisoners would translate into more efficient management of the prisoner's health and other needs with the available limited resources. Most of the older prisoner participants (30 out of 35) were older men reflecting the gender variability in prison. This means that the voices of older women in prisons remain unexplored.

In light of the very few female participants in this study, we were not able to distinguish gender-related differences in factors that constitute identity at old age. Future studies that carefully examine older female prisoners would be a worthwhile endeavor.

## Conclusions

For reasons related to respect for human dignity and in order to keep health costs as low as possible, it is desirable to help prisoners find positive identities, as predominantly negative identities risk to increase mental health morbidity and put an additional burden on the individual as well as on society as a whole. Positive identities are linked to have a positive role and a sense in one's live, for example, being a meaningful and respected person in various ways that range from defending the rights of other prisoners or being a reliable part of a social network to seemingly small things like cooking and salad making. These are linked to a "purpose in life" which can serve as a protection against the stressful life under prison conditions and may increase the chances for successful rehabilitation after release. Prison psychologists, nurses, general practitioners, and the prison administration could improve mental health through allowing positive identities by making use of context-dependent factors, situations, and stimuli such as increased creative expression, work that corresponds to the individual's abilities and needs, possibilities to gain knowledge or engaging in favor of other prisoners. As most studies on age identity at old age are carried out among older adults in the community, further research is needed in the prison context to understand old age identify formation, how it changes due to long-term incarceration, and how it could be applied to positively affect the well-being of older prisoners.

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# Chapter 3: Chains, trains and automobiles: Medical transport for prisoners in Switzerland

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## Chains, trains and automobiles: Medical transport for prisoners in Switzerland


### Abstract

Imprisoned persons are transported for several purposes including transfers to a different prison, legal-procedural reasons such as court hearings, and to receive medical treatments. Availability and acceptability of transportation may limit the access to healthcare if health services cannot be provided within the prison grounds. The aim of this paper is to examine the conditions of medical transport for older prisoners in Switzerland and to assess if these practices are in line with international recommendations. Interviews with experts working in the prison context and with older prisoners were conducted. Cantonal differences, administrative constraints and inappropriate conditions can delay access to necessary healthcare and increase suffering.



**Keywords**:

older prisoners, prison, healthcare, access to health


### General Introduction

Imprisonment is a radical shift in a person's life. The prisoner is isolated in a secluded location and subject to severe restrictions, sometimes not only deprived of liberty, but also of other civic or political rights (Mincke & Lemonne 2014). Movement is restricted to the prison space except when prisoners must be moved to another location for several purposes, such as court hearings and to receive medical treatments. Transports provide points of intersection and interaction possibilities between prisons and the outside (Follis, 2015). Movement and mobility during the entire spatio-temporal process of incarceration are important conditions for the functioning of the current penitentiary system and create substantial costs related to the transport itself and security services needed during transport. Medical transports represent only a small fraction of prisoner transports: in 2010, HMP Leeds sent 6777 prisoners to courts, received 9460 prisoners, transferred 1882 prisoners to other prisons and received 480 prisoners from other prisons, and noted 780 hospital escorts for medical treatment and specialized appointments (Follis, 2015). For medical transports, power relations appear in the dynamics of who can order a transfer, who decides on situations important enough to merit transport, and who informs whom about transport schedule and delays (Martin & Mitchelson, 2009). Prisoners' movements through the prison's geographical space – including specialized medical practices or hospitals where healthcare interventions may take place - are intensively controlled by custody policies, routines, economies, and spur-of-the-moment decisions (Stoll, 2003).

Policies and practices following custodial priorities can create significant delays and obstacles to accessing care. Transportation was linked to humiliation, mistreatment, long delays, and precarious means of transport (Souza & Peixoto, 2016). Poor transport conditions may lead to prisoners delaying their needs for outside medical care, or even refusing treatments. Access to medical care is complicated by geographical limitations, as many prison facilities are located

in rural areas, far from community-based services or cities with medical professionals, and healthcare costs and outcomes may depend on the type of healthcare delivery site, like community hospitals or specialized prison medical facilities (Ahalt et al., 2013, Young & Badowski, 2017).

The central powerful position of experts like doctors or psychologists is important in the context of healthcare, when arranging the modes, lengths, and places where sentences are served (Mincke & Lemonne, 2014). If healthcare staff is hired by and reports to prison health services, this power is less ambiguous than if they are hired by public health administration but report to prison or justice administration. The ideal solution is health personnel depending on public health administration, and makes decisions on medical grounds only. International bodies such as the WHO state that "health personnel in prisons should act in their professional capacity completely independent of prison authorities and in the closest possible alignment with public health services, while remaining in effective liaison with prison staff to enable health care to be delivered efficiently" (UNODC/WHO 2013).

## Supranational guidelines and regulations

The main international guiding regulation for imprisonment conditions is the revised Standard Minimum Rules for the Treatment of Prisoners adopted unanimously by the UN General Assembly on December 17, 2015 (UN General Assembly 2016), hereafter called Mandela Rules. Rule 73 describes the removal of prisoners.

The recommendations of the Council of Europe R(98) state general principles for the ethical and organizational aspects of prison healthcare andnote on transportation that "in being escorted to hospital the patient should be accompanied by medical or nursing staff, as required" (Council of Europe 1998). The European Prison Rules - "Recommendation Rec(2006)2" – are another important document drawn by the Council of Europe and adopted by the Committee of Ministers for the first time in 1973 (Council of Europe 2006). The European Prison Rules[1] treat the transfer of prisoners in articles 32.1 to 32.3. Both European Prison Rules and Mandela Rules are legally non-binding but used by international monitoring and inspecting agencies as key principles to assess treatment of prisoners. Although both sets of rules differ in several aspects (Huber, 2006), we present their similarities regarding conditions for prisoner transportation in Table 1.

## National regulation in Switzerland for prisoner transports

The federal organization of Switzerland imply that *inter*cantonal and *intra*cantonal prisoner transports follow different legal settings. Conditions for intercantonal transports of prisoners are stipulated in a treaty between the *Conference of Cantonal Directors of Justice and Police (KKJPD)*

[1] https://www.coe.int/en/web/cpt/-/cpt-factsheet-on-transport-of-detainees

and JailTrainStreet (JTS); intracantonal transportation is managed and executed by the respective canton.

The choice of vehicle depends on the goal of the transport and the individual's dangerousness assessment. Often prisoners are transported in groups using road vehicles. For prisoners considered dangerous, escort vehicles may be used, or the prisoner is asked to sit between police staff or security agents. Transport can happen partly by trains with a special compartment for prisoners (Schneider, 2014). The train operates on weekdays along two connections linking several big Swiss cities[2]. From the railway stations, transport continues by road vehicles called "fourgons" that are outfitted with four single cells and one "family cell" and can easily access the train for prisoner transfer. Train transport conditions have improved since the European Committee for the Prevention of Torture and Inhuman or Degrading treatment or Punishment (short: Committee for the prevention of Torture, or CPT) criticized them in 1996[3], especially the fact that prisoners were transported in the luggage wagon, were neither accompanied by staff nor permitted to use the toilets between stations. An overarching concept was agreed in 2000 between the Department of Police, KKJPD and a workgroup composed of Swiss Federal Railways and a private security firm (Altorfer, 2005).

Medical emergencies are usually handled by calling an ambulance; transports for medical appointments often happen with fourgons, soemtimes with police cars. Transport for medical purposes should be governed by medical criteria and respect ethical standards. If health personnel schedules medical appointments implying transport, type and timing of the transport need to mainly depend on the patient's health condition, not on administrative convenience or cost considerations like a maximum number of allowed outside transportations per day ( Bretschneider and Elger, 2014).

As mentioned by Moran and colleagues (2012), the problem of costs and inconvenience of transport for health reasons has been the topic of few publications, such as Stoller (2003). Empirical and ethical questions related to prisoner transportation merit increased academic attention. To our knowledge, little has been documented on the question how different transport conditions affect prisoners in general, and specifically older prisoners who are in worse health than younger ones (Fazel et al., 2001; Wangmo et al., 2014). Older prisoners may suffer more than younger inmates from "institutional thoughtlessness", that is, "the ways in which prison regimes (routines, rules, time-tables, etcetera) simply 'roll on' with little reference to the needs and sensibilities of the old" (Crawley (2005) p. 16).

We aim to fill this research gap by documenting for the Swiss context who requests, schedules and organizes medical transportation, and how transportation happens. The experience of older prisoners themselves and the viewpoint of experts in prison services must be considered to see if transport conditions are satisfactory, or if improvements are necessary.

[2] Zurich – Basel – Bern and Geneva – Lausanne – Fribourg – Bern

[3] https://www.beobachter.ch/burger-verwaltung/gefangenentransport-scharf-bewachte-zuge-0 retrieved 20190107

## Material and methods

The nationally-funded research project "Agequake in Prisons" on older prisoners' health began in 2011. Ethics committee approval was obtained in 2011 for the first subproject on somatic health and in 2017 for the second subproject on mental health. Qualitative, semi-structured interviews were carried out with 92 persons aged 50 years or older who were detained in Swiss prisons and forensic institutions that participated in the first (N=35) and second (N=57) subprojects. 54 Swiss experts on prison healthcare and administration were interviewed. All interviews were conducted face-to-face and lasted from 30 to 100 minutes. Permission to record the interviews was obtained from all participants after information about study aims and procedure was provided. Interview recordings were transcribed in the original language according to predefined transcription rules.

Transcribed documents were imported into the qualitative analysis software MAXQDA 12, double-checked by independent assistants to ensure data quality, and all identifying information was anonymized. For analysis , data were read several times by SH, HM and TW to gain familiarity and coded in MAXQDA 12. After several introductory coding meetings among the whole research team, SH coded the data by specifically searching for sections regarding medical appointments or transport to medical institutions, as well as related words in the original language like "handcuffs," "guards," "bus," "transport" or "ambulance". TW was included in data analysis to discuss quotes and codes fitting the purpose of this paper. The draft version of the analyzed data was presented to all co-authors . This paper presents the four problems that the authors agreed as being the relevant main themes on this topic. Translation of quotes from French and German to English were carried out by bilingual assistants and researchers and checked for consistency. Where needed, information is added using [ ] to make the sense of the quote more easy to comprehend.

Transportation questions were part of the first study questionnaire and came up spontaneously and repeatedly during the second research project, showing that the issue was important to prisoners and to experts and merits consideration.

## Results

We group our findings into four main categories: (1) Organization of and notification about the transport, (2) transport implementation, (3) use of handcuffs, and (4) exposure to the public and humiliation. These categories are discussed in detail below and further teased into sub-themes where necessary.

### Organization of and notification about the transport:

*Decision making, transport organization and administration*

Both stakeholders and prisoners reported that decisions about the necessity of a transport were usually taken by prison doctors. A prisoner described the administrative complexity (quote 1, table

2). Some prison doctors mentioned that transports were scheduled quickly for the most important cases; persons with less pressing health problems needed to wait (quotes 2 and 3, table 2).

Some stakeholder participants described well-defined, general procedures for transporting prisoners for health matters. In case of emergencies the transport was organized quickly, and parties involved were simultaneously informed. Depending on the patient's state, transport vehicles other than ambulances were used (quotes 4 and 5, table 2).

One prison director underlined that his institution had a clear protocol to follow (quote 6, table 2). For the director of another institution the choice of transportation was variable and depended first of all upon the individual case (quote 7, table 2).

*Cantonal and institutional differences*

This sub-theme was only highlighted by stakeholder participants who mentioned the cantonal variety of rules and regulations that results from Switzerland's federal-state organization leaving execution of sanctions to the canton (quote 8, table 2). Some experts were not sure who organized transportation in their canton after the necessity of a transport was stated, others knew that depending on the cantonal rules, the penitentiary administration needed to approve, or that the decision had to be jointly made by the doctor and cantonal or institutional security services.

Even between institutions, there was considerable variety on resources and management of detainees with chronic illnesses needing regular transport, for example for dialysis. For some this did not pose problems at all. One expert commented "if someone's sick, and if someone needs it, then he needs it" (S4, head of prison health services), and another described the procedure in detail (quote 9, table 2).
Others stated that transport could be organized but was a challenge or a problem. Regular transports for dialysis were sometimes refused by other administrative actors (quote 10, table 2) or considered downright impossible (quote 11, table 2).

*Problems with transport organization*

This sub-theme was only mentioned by prisoner participants. Sometimes transport to a medical institution happened only after several days of discomfort or pain, until the health care professional in charge was convinced that the situation was serious enough to merit a transport (quote 12, table 2). The same prisoner had had a similar experience in another prison (quote 13, table 2).

Prisoners saw this as a general problem of prison health services and felt that some doctors were not diligent enough in diagnoses or differential diagnoses. They complained about long waiting times that they saw as unjustified. In some cases, external physicians criticized these delays saying that there could have been serious consequences (quote 14, table 2).

Some prisoners who insisted in transport to external health facilities assumed that it was easier if the hospital called and asked for a prisoner's transport (quote 15, table 2). They criticized that they were often notified very late about transport to the hospital, sometimes only a couple of hours before, although control visits in hospitals could have been scheduled a long time ahead. Depending on the aim of the appointment, this was counterproductive if a prisoner needed to be

on an empty stomach but had already had breakfast because he had not been informed (quote 16, table 2).

Some participants found the procedure for medical transportation cumbersome and not worth the trouble (quote 17, table 2. They mentioned that due to the obstacles, they were reluctant to access healthcare services (quotes 18 and 19, table 2).

## Transport conditions

*Older prisoners' views on transport conditions*

Although prison and healthcare institution could be geographically close, transportation sometimes took long due to additional prisoner pick-ups that considerably prolonged the time being handcuffed in the fourgon compartment (quote 1, table 3). Sometimes relay stations had to be visited where the prisoner needed to spend the night.

The most frequent means for hospital visits was the fourgon, followed by the ambulance car. Many prisoners complained about the fourgon's restricted space (quote 2, table 3).

For several older prisoners, transport conditions seemed devised for younger, physically active prisoners but were exaggerated and humiliating for older persons who were not in physical shape anymore (quote 3, table 3). One prisoner complained about these conditions at the court for human rights in Strasbourg (quote 4, table 3).

*The need for advocates*

Both participant groups noted the need for advocates to improve transport conditions. One health professional said that 'if the prisoner did not speak up for a specific health problem himself, the team alerted the medical doctor who then organized the transport and the enrolment in a hospital' (S39, head of accompanied housing). Prisoners related that protesting usually was unhelpful but that finding allies among health staff could lead to more appropriate transportation. One prisoner felt afraid of accidents and at the driver's mercy, without any possibility of protection, as the fourgon's transport cages had no safety belt. This prisoner managed to get a "special transport", i.e. a normal road vehicle, because one of the accompanying staff had noticed the prisoner's difficulties to enter and exit the fourgon, and said "we have special vehicles, so you should get one." (P59; 62 years). Another interviewee commented that there was some leeway for transport conditions (quote 5, table 3). Transport conditions could improve if medical services insisted upon a different type of transport (quote 5, table 3). For one prisoner who had collapsed from severe breathing problems and needed an urgent transport to the hospital, the requested ambulance vehicle had to wait at the perimeter, so the prisoner had to walk from the prison building until the gate (quote 6, table 3).

### Use of handcuffs

Prisoners reported that handcuffs, ankle cuffs or other means of movement control like GPS anklets were used before entering the vehicle, during the ride, after exiting the vehicle, and while being transported in hospital in a wheelchair. Many older interviewees felt that this was exaggerated and described their poor state of health due to age and illnesses: “What do you think, I could run away being overweight and out of breath?” (P40; 63 years) For some prisoners who had on other occasions been allowed to take leave for several hours or even days, the unequivocal use of handcuffs was felt as a “lack of trust” (P38; 51 years). Prisoners who suffered from conditions reducing their mobility, such as a bad leg, felt humiliated (quote 1, table 4). Through use of handcuffs some prisoners felt diminished to the status of cattle. Some of them did not want to go to important medical appointments at all; sometimes these were seen as a necessary evil (quote 2, table 4). Stakeholders did not mention this issue.

### Exposure to the public and humiliation

Sometimes, prisoners waiting at the hospital together with other patients felt exposed by wearing prison clothes and being handcuffed (quote 1, table 5).

Stakeholders and prisoners also underlined undignified situations for prisoners seeking care at a hospital (quotes 2 and 3, table 5). Some prisoners felt uneasy and helpless when put in wheelchairs and wheeled through the corridors after accessing a hospital through the basement (quote 4, table 5).

Humiliation was not limited to exposure but also included being ignored (quote 5, table 5).

## Discussion

Our study is important and novel as questions around medical transportation for older prisoners exemplify practical consequences of structural problems but have not yet been researched. According to international soft law, the necessity of a medical transport must be stated by a member of the medical staff, the prisoner’s health needs being “the primary concern of the doctor” (COE, 1998). Our results show that such decisions can collide with administrative limitations as shown for transports to dialysis facilities and for the lack of alternatives to ambulances or compartmentalized vans for elderly and fragile patients. Evident from our results, older prisoners often felt neglected or not taken serious when stating health problems, and complained about delays that they felt were unjustified. Main reasons for the underlying lack of communication were based on security issues and could have negative consequences, such as, not receiving a necessary exam timely because the prisoner was not informed early enough about the medical appointment, and the subsequent cost of such a cancelled appointment. This could be improved by creating clearer communication channels, by limiting the discretionary power of single prison administrations, and by developing binding guidelines on cantonal or federal levels that are in line with international guidelines and regulations.

Transports in train and fourgon created additional suffering for older prisoners who had to comply with the transportation conditions irrespective of their health status. This corresponds to "institutional thoughtlessness" (Crawley, 2005). It sometimes took the advocacy of an attentive person noticing a problem, and intervening, but if no such person was there, the institutional carelessness was not counterbalanced. Older prisoners voicing health problems felt mistrusted and not taken seriously, leading to resentments and resignation. Both the MR and the EPR state that unnecessary hardships must be avoided. We propose that medically-oriented conditions and decisions for medical transports need to be established and widely announced either for every individual penitentiary institution or on a cantonal, concordate or national level instead of depending on random factors such as the presence or absence of a well-meaning individual. Prison health care professionals play an important part in these matters.

Older prisoners complained about exaggerated handcuffing and felt that this happened not based on their dangerousness but out of routine. They cited illness and reduced mobility as an obvious contradiction to security-based fears and noted that handcuffing made their prisoner status unnecessarily visible for the general public, which was humiliating. Here as well, the MR and EPR prohibit any unnecessary exposure to situations that could result in humiliations. Well-documented individual decisions on the use of restraining devices are needed so decision-makers are aware of the importance and consequences of this matter.

Access to health care outside the prison requiring transport was difficult as prisoners felt that they had to unduly justify and insist on their need to see an outside healthcare provider. Sometimes complaints were not taken seriously, treatments were delayed or appointments cancelled, and prisoners experienced unequal power situations. Unlike in free society, possibilities lacked to voice a different opinion or access the desired service. This constitutes a first-order obstacle to healthcare access. Interviewees suffered not only from health problems but also from powerlessness and invisibility. Feelings of frustration provoked disgust in procedures and unwillingness to go through them, which constitutes a second-order obstacle to healthcare access.

The principle of equivalence of care means that health services in prison should be of the same standard and quality as for patients in the community (United Nations 1982; Niveau 2007). In both contexts, older people may constitute a vulnerable population (Harris et al. 2006; Waisel 2013), and imprisonment adds a second layer of vulnerability and powerlessness (Luna 2009). Feelings of powerlessness and frustration may also arise for older people in freedom who are living in institutions that are "total" due to their barriers to social interaction with the outside, such as hospitals or nursing homes (Goffman 1957). The difference with prison is that contacting advocates (family members, friends, lawyers, media) who can access the institution is easier than in prison where contacts are strictly limited and controlled.

The high cantonal level of independence in Switzerland leads to differences in sentence execution, including the way to decide and organized medical transports. Access to healthcare is further influenced by "spatial injustice": the more peripherally a prison is situated, the more difficult it can be to access health services, as described by Young and Badowski (2017) for the US context. Different healthcare delivery sites may also lead to different healthcare costs and outcomes, as mentioned by Ahalt and colleagues (2013). A possible solution could be to assign each penal institution to one peripheral hospital and clearly define procedures to facilitate access, or to create

regional or national prison hospitals big enough to take in acute and chronic cases from all over Switzerland, like the French "interregional secure hospital units" [4] or the Dutch "judicial centers for somatic care" [5].

Although our research centers on older prisoners, our results may be generally valid for younger and older prisoners alike, as suffering related with medical transports does not depend on age. Further research on this topic is necessary.

**Limitations**

Our research's main limitation is that the opinions of stakeholders who agreed to participate may not be representative for all healthcare experts working in prison. Also, not all older prisoners in Swiss prisons were reached, as prison administration had to allow participation, so the findings cannot be generalized to all older prisoners or stakeholders. We only looked at transportation in a medical context, not on other transport situations like transfers to courts or other prisons.

**Conclusions**

Not all aspects of either the MR or the EPR are respected in the context of medical transports for older prisoners, and the principle of equivalence of care (United Nations 1982; Harris et al. 2006; Niveau 2007; Waisel 2013) is not always upheld. Practical solutions for the concrete problems mentioned must be found.

Teleconsultations can reduce the need for medical transports to access specialists, and local pilot projects have started in Switzerland. Other improvements include streamlining and clearly defining procedures on a concordate or nationwide level, and increasing transparency by documenting decisions regarding prisoner transport. Administrative responsibilities and regulations on decisions must be well defined within the Swiss federal context. Centralized prison hospitals should be discussed. The "medical surveillance ward" ('Bewachungsstation' in German) in Bern may have been devised with such a goal in mind but does not have sufficient beds and resources to care for more than a few acute cases overnight, as there are 16 beds, 13 of which are occupied on average (Amt für Justizvollzug 2018, Amt für Justizvollzug 2019). Establishing mobility patterns for older and younger prisoners' medical transports may help to better understand dynamics and limitations of the system. This exceeds the framework of our research project but should be included in a broader research project on drivers of health in detention.

**Conflict of interest:** none

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[4] Unité hospitalière sécurisée interrégionale UHSI, see https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000583783&dateTexte=&categorieLien=id

[5] Justitieel Centrum voor Somatische Zorg JCvSZ, see https://www.dji.nl/locaties/penitentiaire-inrichtingen/pi-haaglanden/justitieel-centrum-voor-somatische-zorg/index.aspx

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**Table 1: Conditions for Prisoner Transportation in Mandela Rules and European Prison Rules**

| Topic | Mandela Rules | European Prison Rules |
|---|---|---|
| Exposure | 73.1 When the prisoners are being removed to or from an institution, they shall be exposed to public view as little as possible, and proper safeguards shall be adopted to protect them from insult, curiosity and publicity in any form. | 32.1 While prisoners are being moved to or from a prison, or to other places such as court or hospital, they shall be exposed to public view as little as possible and proper safeguards shall be adopted to ensure their anonymity. |
| Transport conditions | 73.2 The transport of prisoners in conveyances with inadequate ventilation or light, or in any way which would subject them to unnecessary physical hardship, shall be prohibited. | 32.2 The transport of prisoners in conveyances with inadequate ventilation or light, or which would subject them in any way to unnecessary physical hardship or indignity, shall be prohibited. |
| Responsible entity | 73.3 The transport of prisoners shall be carried out at the expense of the administration and equal conditions shall obtain for all of them. | 32.3 The transport of prisoners shall be carried out at the expense and under the direction of the public authorities. |

**Table 2: Organization of and notification about the transport**

| Quote and participant details | Participant's quote |
|---|---|
| Quote 1: P5; 70 years | If you get an appointment from the hospital or from the respective institution that needs to treat you, a transport order to the security service is issued, the security service informs the healthcare service, and I am also informed when I have to go to the front, to the security service. |
| Quote 2: S6; prison doctor | So you have all this mobilization of efforts around one or two patients, doesn't this create inequalities for the access to health for the others? |
| Quote 3: S7; prison doctor | The correctional administration can only transport one detained person after the other, so obviously there's a threshold effect that cannot be exceeded and is quickly reached. |
| Quote 4: S5, prison director | We have very precise procedures, which are really also well-rehearsed procedures. If the ECG shows that something is not good, is unsafe, then as a rule the management is informed immediately, but if it is obvious that we can't lose any time, we immediately call the ambulance, inform the management, and at the same time police, who does the security escort. They almost come together. … And on weekends it's the same, simply if nobody is here, then it's immediately the ambulance and they do the first measures and then decide whether they have to go to hospital or not. |
| Quote 5: S4, head of prison health service | If someone is really in very, very, very bad shape, then he is taken in by the medical ambulance team. But if we have the feeling that he can still make it to [to the hospital on his own] then it's the simple, normal transport. (…) I think that we can already estimate whether someone can go with the normal transport or with the ambulance. (…) Nothing ever happened until now, nothing ever happened to me yet. |
| Quote 6: S15, prison director | Of course we have a very clear agreement, a very clear structure. For the vast majority of prisoners who are not yet entitled to leave, this is clearly an emergency with a police escort and police supervision in the cantonal hospital, emergency treatment and then immediately transfer to the guarded ward in (hospital in main urban center). That is quite obvious. If this is not possible for any reason, the police must ensure that guarding and supervision is fully guaranteed. |
| Quote 7: A23, prison director | Depending on the situation: sometimes the ambulance. There is the right to go out, medical permission, take the bus, she goes to the hospital alone, anything is possible. That's not a problem. |
| Quote 8: S22, lecturer and secretary of concordate | That's the tiresome story in every canton, how do we transport them? You would really have to settle that, you would have to make an administrative order with the cantonal doctor and with the police. Then one would have to decide if the prisoner can be transferred using a normal vehicle and a doctor has to decide that. And if there is no doctor on site, the prisoner must be transported by ambulance, and (…) a civil servant, a police officer in an ambulance and the patrol must follow the car. There has to be (…) an institutional protocol with the emergency services, if you establish this cleanly, it doesn't cause big problems (…), it should also be regulated that inmates can also go to the dentist or have a routine check-up with a specialist. |
| Quote 9: S1, prison director | We once had one that had renal insufficiency, so now he had to go twice a week to dialysis. And then it's exactly the same. The police pick him up, there a dialysis center in [city z]. Then we take him there with the prisoner car, there he is taken over by a police officer, and he guarded him then, during these two or three hours it took each time. And then we picked him up again. That goes smoothly. So without problems, although it is an effort. |

| | |
|---|---|
| Quote 10: S23, prison director | We have had cases where we asked the question if we could do this. (…) It's possible to bring him there two or three times per week, and then I was told that this didn't make sense. |
| Quote 11: S15, prison director | No, that is impossible. We have just asked for one recently – but we are not able during many hours, three times per week, it's impossible to have the staff for this, it's impossible. |
| Quote 12: P 40; 63 years | Finally I could then go down to [city y] to do a performance ECG. And then after that, they did that here and they said, well, we don't notice anything. But then the heart specialist was called in anyway, and she immediately sent me to the emergency ward. (P 40; 63 years) |
| Quote 13: P 40; 63 years | Yes, I was there for three days in the cell, always severe pain, finally I was transferred t the hospital. Well, I had pancreatitis. |
| Quote 14: P 62; 62 years | I haven't been able to breathe through my nose. After a year (…) I could go to a specialist and he said, immediately operate, and the (prison) doctor has determined that it's early enough in September (…). I couldn't breathe anymore, everything was closed. An inmate who had found me brought me upstairs. And afterwards they gave me oxygen upstairs, afterwards he [someone from the prison healthcare team] said: "Would you like to go to the hospital? Or what do we want to do now? And I said "Please, please, to the hospital." I thought I was going to die. |
| Quote 15: P23; 60 years | I think it's more like the hospital calling, from what I understand. They follow up, and then they say "we'd like you at such and such a date ", that's it. And then they prepare the transport, you see. |
| Quote 16: P23; 60 years | In principle, we shouldn't know when we go to the hospital. In fact, sometimes we receive our appointment from the hospital directly in the cell. They say "you will come in May" (…) Then they change the date. Because there are always risks of escape, you understand, you have time to prepare an escape. There was a time when we were told nothing, we knew nothing. At a quarter to six o'clock you are woken up and told that you have to go to the hospital on an empty stomach. But often, at a quarter to six I've already had my coffee (…). As it turned out, the doctors said that something had to be done. So now we're notified the day before. |
| Quote 17: P34; prison psychiatrist | After that (…) there are also for many reasons cancellations of extractions. There are also care services that normally have to accommodate (...) the detained person who for reasons that are sometimes medical service reasons cannot be there on time, because they have something else to do. |
| Quote 18: P 40; 63 years | I don't like going out for an appointment at all. I avoid where it is possible. Although I actually should go to a specialist, yes. |
| Quote 19: P29; 58 years | On the way back I had to go on the rail transport (…) you are locked into the waiting cell in [hospital] and then wait there for about two hours. Then the transport car leaves for the office building in [city X]. Then they wait there for three, four hours depending on the time. Then you will be brought to the loading station in [city X]. There you wait at least (…) another one and a half, two hours. Then the whole transport happens by train, inside the prisoner transport wagon, there you are locked up in a small compartment. You can't even stretch your feet properly (…) because everything is so tight. You can't even stand up properly, nothing. Then this takes at least two hours by train, because the train has to dodge all other trains.. (…) It took six and a half hours on the way back (…) Makes you wonder about going to hospital at all. |

**Table 3: Transport conditions**

| Quote and participant details | Participant's quote |
|---|---|
| Quote 1: P28; 63 years | I'm picked up at 6:30 downstairs, it's around 10:00, 10:15 that we get to where I have to go. |
| Quote 2: P28; 63 years | You see, in about a month, I should go down to (hospital in city Y) for a cardiac examination and so on. But I dread that. Because I'm going to be in the van, the cell van. (…) We have about 65 cm wide by about 90 cm deep by 1.20 meters high. (…) Last time, two months or three months ago, I had to go (…), - it's really the ghost train. |
| Quote 3: P28; 63 years | There can be a van for those who are known to be violent because they have already been in fights, because they have had problems and all- well. And then if they're young, okay. But for us, that's what we're talking about here, for those who are over 50 years old, who are a little bit - not obese but at least a little fat to drive them around all morning and back and forth in this - I don't see what it's for. There's no justification. It was just someone in an office who said, "Yeah, that's how we're going to do it. " |
| Quote 4: P 35, 67 years | Well, and then I wrote to Strasbourg, saying if I would transport a cattle like that, any animal, then the animal welfare society would come and say, hey, not like that. - But since we are neither animals nor human beings, these regulations do not apply. |
| Quote 4: P30; 67 years | (Using a special vehicle) would be feasible, right, but if we apply in here for a special transport vehicle, then they say: "Yes, that's not possible". So first somebody has to see that things are really bad. Or that you have some handicaps, for example, that you can't be tied up or anything else. Then it works from the start. But otherwise? No. |
| Quote 5: S4, head of prison health services | There is what the transport station called the cages. And also our security service has three places. They (the prisoners) have to get into one of those cages, into a cage. Once one of them was hospitalized during the doctor's visit and I urged not to put him into the cage, but to take him in the front and they did it. |
| Quote 6: P 62; 62 years | They gave me oxygen upstairs. (…) Afterwards the ambulance vehicle came, and they were supposed to drive up (to the prison building), but then it was said "ah no, she can still walk down to the gate. The ambulance speeded like the devil and the hospital doctor said that I should have come there two weeks before already." The same prisoner had had knee surgery and asked to be allowed more time on leave days to walk down to the village bus stop in order to catch the bus but was told "even if you had a walker you would have to respect the rules, there are no special favors." |

**Table 4: Use of handcuffs**

| Quote and participant details | Participant's quote |
|---|---|
| Quote 1: P 67; 74 years | It's horrible. And always with the cuffs on, and all that. Like we were some/ we were going to for example I have/ I'm not going to take off running especially since I had a leg like that! You see, I found it ridiculous. |
| Quote 2: P67; 74 years | …some of them (authors' note: younger prisoners) here are very happy (…) not have to work for one day and all that. But it would make me mad. That's something that I hate, I prefer working an entire day than go to the hospital. So that would be my - let's say my fear, I don't think about it otherwise. |

**Table 5: Exposure to the public and humiliation**

| Quote and participant details | Participant's quote |
|---|---|
| Quote 1: P28; 63 years | There were at least a hundred people because in this hospital, the corridors are the waiting room. Everywhere there are people waiting. There I was, without glasses, without lenses, without anything, I saw a lot of people from this region where people may know me a little. I have no idea who I saw, but I know that because we are human, all those people who saw me said "Ah, he must be a horrible criminal, he's tied up, two policemen…" |
| Quote 2: S23; prison director | Cuffs on feet and hands, [and their noise] clink, clink, clink (...) through a corridor and everyone watching you, it was not very respectful of the human dignity of the people who went to the hospital. So that has changed now. I don't know about the other cantons. |
| Quote 3: P59; 62 years | Up there you are put in a wheelchair and then afterwards you are chauffeured through all the people. So all the people can look at you, with handcuffs and ankle cuffs. Yes, that doesn't matter at all, or because you're a prisoner and you have nothing to say anyway. People should just see what kind of person you are. |
| Quote 4: P 67; 74 years | You always go through (…) the entire basement, but it's very big, very long. So they put us in wheelchairs. And then I sometimes saw people coming, I said: "But I hope she can steer". Yeah with the cuffs on and all you feel powerless. You feel diminished anyway. |
| Quote 5: P1; 56 years | You can tell the doctors and the staff of hospital X all this: when we go, we are with guards, and the doctors (…) they talk to the guards, they don't talk to us. It's like being a child, and them talking to the mother. Because we're in prison. |

# Chapter 4: Directing citizens to create advance directives

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**Directing citizens to create advance directives**

**Summary**
This article describes the Swiss law on advance directives that was passed at the beginning of 2013 and led to more certainty about the legally binding character of such directives. However, for various reasons the drafting of advance directives is not yet widespread in Switzerland, and many resources might be put to better use if this became a common practice. A recent proposal by members of a political party to make the discussion, although not the actual drafting, of advance directives mandatory was rejected by the Swiss Federal Parliament, and the proposal was written off after having been pending for 2 years. We consider that the rejection of this proposal was not justified and that discussion of advance directives should become mandatory, so that individuals can fully assume their role as responsible citizens taking proactive decisions. The decision not to draft advance directives should be a deliberate one, marking a shift from the current "opt-in" approach to an "opt-out" scenario.

***Keywords:*** *advance directives, Switzerland, decision making, mandatory discussion, opt-out approach*

## Introduction

The topic of advance directives is becoming more and more prominent in public discussion about the end of life.
In Switzerland, a revision of the Swiss Civil Code has made it mandatory for medical staff to act according to patients' advance directives. This law was passed at the beginning of 2013. Unfortunately, even though many people know about the existence of advance directives, only a small minority actually draft them – Breitschmid and Wittwer (2011) estimated 5% of the population – and leave instructions about where to find the documents (Breitschmid & Wittwer, 2011).

Although in theory overtreatment or "medically futile treatment" should not occur if well-informed patients state clearly which treatments they do and do not wish to receive, there are various determinants of overtreatment. Not all of them can be addressed by increased use of advance directives and, of course, when drafting directives, the patient can still choose to have as much treatment as possible, which can be challenging in the context of scarce resources (Bobbert, 2016). However, the fact that medical care for patients in hospitals is most intensive during their last year of life might indicate unrealistic wishes and maybe overblown expectations of treatment. Conti et al. (2012) stated that "It is not clear how much should be invested in the last years of life whereas the costs are known to increase in parallel. Since intensive care units (ICU) are costly with highly specialized personnel, it seems of paramount importance that they would be used efficiently" and emphasised the importance of "the need of examining not solely the hospital survival but the quality of life of the patients when they return to their real life" to achieve "a better allocation of resources", judge "the appropriateness of care" (in this case for ICU caregivers, but this can be extended to many other fields of medicine) and initiate "a social and political reflection" (Conti et al., 2012).

Switzerland is a member state of the Council of Europe and has signed the "Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine" (1997), usually called the "Oviedo Convention". This Convention states in article 9 that the "previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account", underlining the importance of advance directives (Council of Europe, 1997). The binding character of advance directives is reflected in Swiss legislation, but has not yet led to a notable increase in their use. According to a survey from 2017, 76% of participants in the German-speaking part of Switzerland, 48% in the Italian-speaking part and 38% in the French-speaking part had heard about advanced directives. However, only 27% of persons in the German-speaking, 10% in the French-speaking and 5% in the Italian-speaking part of Switzerland had completed advance directives (Pro Senectute Schweiz, 2017).

Advance directives have been discussed regularly in Swiss medical journals, mostly by physicians. Authors describe various obstacles to addressing them. Lenherr et al. (2012) cite as the two foremost reasons "lack of time and/or privacy" and "personal reasons, such as feeling confronted with one's own mortality". Organisational problems such as lack of time or privacy might be easily remedied, but more deep-seated problems such as denial of death may represent the main reasons for the general avoidance, as is the case for the topic of organ donation (Shaw, 2015). This is possibly not only on the patients' part but also from that of the physicians, for whom "resistance or denial in their patients" may be one reason to avoid the topic (Shaw, 2015). Lenherr et al. stated that "biomedical rhetoric of death as a 'medical failure' now competes with the emerging public rhetoric of 'death as a part of life'" but that "communication about a patient's end of life is not yet a routine part of care", making it too easy to keep this on a general level and avoid it with one's own patients. They also point out that the communication skills of physicians were criticised by family members of dying patients and wondered if participating physicians overstated their willingness to address this topic because of social desirability (Lenherr et al., 2012). Other possible obstacles may be lack of awareness of advance directives, the false assumption that advance directives are mainly used to refuse treatment and consequently shorten life, perceived stress and fear of formalities and technical language, unwillingness of healthcare professionals in general to address the subject, or perceived irrelevance of advance directives (Perkins, 2007; Fagerlin et al., 2004; Sahm et al., 2005).

Another hypothesis is that the massive extension of out-patient care in the US led to a significant decrease of advance directives there (Bobbert, 2016).

A well-informed patient cannot make choices without considering questions regarding the end of life, which is not a possibility but a certainty. Lenherr et al. (2012) discussed the "ethical obligation on the side of the healthcare professionals to support openness, respect for autonomy and dignity by addressing issues of dying and death with the patient in order to assist in advance care planning." Too often, however, the notion of "advance care planning" even in palliative hospital wards is not much more than a simple routine question about reanimation wishes and

a note “do not attempt resuscitation” (Lenherr et al., 2012). Otte et al. (2014) underlined the necessity of an extensive, specific and concrete record of the patient’s preferences (Otte et al., 2014).

Unlike the case of organ donation, where young people are actively encouraged to think about the issue (in spite of the associated idea of mortality and death) and ideally fill out a donor card, public discussion of the need for clear directives is low-key. For organ donation, certain countries have changed from an opt-in to an opt-out model, making the decision in favour of organ donation the default, unless a clear statement of opting out can be produced. For advance directives, this might be difficult or even impossible from a logistical point of view, and the benefit is not as straightforward and easy to see. However, a possible option could be to make drafting advance directives mandatory unless a specific opt-out document stating that for specific reasons the individual did not want to do so is signed. This document would then be stored in the same place as advance directives (discussed below). In the absence of advance directives, the decision-making process as defined by the law involves the treating healthcare professional and a therapeutic representative designated by the patient. If no therapeutic representative has been named, the healthcare professional must obtain the consent of the patient’s legal representative before any intervention. In the absence of a legal representative, relatives can give consent on the patient’s behalf. If no relatives are known, or if they do not want to take medical decisions, the competent authority appoints an independent counsel.

In 2014, members of a political party proposed to the Swiss National Council a law to making discussion of advance directives mandatory for everybody aged 50 years or older (Postulate 14.3258 submitted by Alec von Graffenried and taken over by Christine Häsler, see https://www.parlament.ch/de/ratsbetrieb/suche-curia-vista/geschaeft?AffairId=20143258).
The reasoning behind this initiative was that although in theory advance directives are approved of by a large part of the population, only a minority have drafted one and communicated its contents to family members or healthcare proxies. The Federal Council voted to reject this proposal on the grounds that more experience with optional advance directives was needed and that this topic had been discussed in Parliament, although it also stated that ways in which optional advance directives could become more widespread should be examined. The proposal was finally written off in 2016 because the topic had been pending for more than 2 years.
We wonder if the arguments presented by the Federal Council are sufficient reason for the rejection and would like to develop practical measures to increase public discussion of, and adherence to, advance directives.

**Ethical arguments**

In bioethics, from a principlist point of view, there are several arguments in favour of a more straightforward approach to advance directives. We will first consider the principles of biomedical ethics as formulated by Beauchamp and Childress in accordance with their principlist approach (Beauchamp & Childress, 2001).

**Autonomy**

Patients should make the decisions that are documented in advance directives after considering all potential consequences for their health and wellbeing, and these decisions must be respected by the other parties involved in the process. Family wishes must not supersede the patient's own wishes; this point must be respected by caregivers and medical staff. A person who, after careful deliberation, does not want to draft advance directives should not be obliged to do so, although the fact of it being a sensitive or personal matter does not in itself constitute enough reason to avoid the discussion (see Shaw, 2015). Advance directives should be seen as a means to maintain autonomy by making personal preferences clear. It might be argued that making discussion of directives mandatory is itself a violation of autonomy, but the aim is to increase patients' autonomy when they are incapacitated, which enhances autonomy overall; in addition, we suggest allowing an opt-out for those who do not wish to create a directive.

**Justice**

Scarce and finite healthcare resources must be allocated across the whole population. If they are spent on unnecessary interventions, they cannot be spent on treatments that may be beneficial. In the context of dementia patients in nursing homes, Nicholas et al. (2014) showed that having advance directives was associated with significantly less aggressive care at the end of life and consequently also with less healthcare spending (Nicolas et al., 2014), maybe because of fewer interventions such as tracheostomy, intubation, feeding tube placement, haemodialysis or enteral/parenteral nutrition.

Resource allocation relates to not only financial but also human resources. Conti et al. (2012) suggested that ICU (and probably other) caregivers might suffer from decreasing motivation and even from burnout when they see the medical situation and that wishes of patients at the end of life are not respected and that the care they provide for these persons is not appropriate. Physicians need to forgo treatments that are unreasonable or will not achieve the results expected by the patient, not only in line with this principle, but also because futile interventions are against their professional ethics. In addition, Breitschmid and Wittwer (2011) mentioned that significant resources might be needed in order to determine the probable wishes of an individual who has not made an advance directive and to determine the legally binding representation of a person who has neither drafted an advance directive nor appointed a legal representative. Although introducing systematic advance directives could be costly in the beginning, this could be seen as an initial, one-off cost intended to lead to a more just system.

**Beneficence**

Avoiding discussion about the end of life might increase the number of days lived, but this is not equivalent to quality of life. Predictions of caregivers are incorrect in many cases, and benefit of treatments can be increased by relying on advance directives (Conti et al., 2012).
The beneficence principle usually revolves around what would be good for the patient. Views of what defines "good for the patient" might differ depending on moral or religious convictions,

and problems arise when there is not much information about the patient's convictions. The possibility described by Roscam Abbing in 2012 (relatives of vulnerable persons are influenced by healthcare professionals to agree to the course of action that is considered "best" by the healthcare professional) presents a risk that must not be neglected, even if there usually is no malign intent on the part of the healthcare professional. Advance directives can help to avoid this problem as the individual has the possibility not only to choose specific treatment options for certain situations, but also to convey more general information on preferences, world view and moral or religious values that need to be respected in a situation that was not specifically described in the advance directives. If we assume that a formerly competent patient generally knows best what is good for him or her, this principle is in line with the principle of respect for autonomy (Roscam Abbing, 2012).

Advance directives can also help in situations where families would otherwise project their own values onto the patient, rather than providing information about his or her values, which might be different. Ideally, treatment options are discussed by the patient and his/her family, and in addition to drafting advance directives, the patient designates a healthcare proxy who is aware of this role and willing to accept it. The choice of a healthcare proxy should not rely on medical or clinical knowledge alone, but must also take into account family dynamics so that the proxy receives as much support as possible when defending the patient's choices. Written advance directives would support the healthcare proxy when discussing treatment options with healthcare professionals. Such a balanced and sufficiently early approach to advance directives would avoid incomplete directives that are hastily drafted as a requirement before moving to a nursing home, as described by Wiesing et al. (2010) in the German context and Otte et al. (2014) for Switzerland. This practice is still widespread although the 2017 guidelines of the Swiss Academy of Medical Sciences explicitly prohibit it (Schweizerische Akademie der Medizinischen Wissenschaften, 2017).

**Non-maleficence**

As formulated by Beauchamp and Childress (2001), nonmaleficence means that "one ought not to inflict evil or harm." Overtreatment or "futile treatment" can cause actual harm to the patient. As Conti and colleagues (2012) stated, the care given should be appropriate, and benefit of care and burden of care need to be carefully balanced. Wiesing and colleagues (2012) stated that physicians may sometimes overtreat because they focus on the technically feasible instead of the medically appropriate treatment (which may consist of doing nothing). Application of treatments mentioned as unwanted in advance directives may represent physical assault, which can result in criminal charges (Otte et al., 2014). Possible liability has been described by Castillo et al. (2011) and Burkle et al. (2012); Pope (2017) emphasised that many clinicians seem to think, mistakenly, that there are no legal consequences of "doing too much" and to "err on the side of saving or prolonging life" in spite of the patient's documentedwishes. The question of whether this might be a reason for physicians to circumvent the topic of advance directives is not within the scope of this article, but merits more thought. More information for physicians on the legal framework might be necessary to show that correctly written advance directives help to clarify the limits of their responsibility.

## Other ethical approaches

Apart from the principlist approach, sometimes criticized as being ambiguous or incomplete (see Serna & Seoane, 2016), other bioethical arguments merit examination, for example the deliberative and value-based approach.

A human rights-based approach, as described by Andorno (2016), could be applied to the topic of advance directives because of their high value, as expressed in an international convention, although these directives are not legally binding in all member states of the Council of Europe.

Switzerland incorporated the binding character of advance directives into its civil law, so a more proactive approach towards drafting them would show that individuals are seen less as patients or "consumers of health care" (Malpas 2011) and more as informed and empowered citizens that are not only able but supposed to make informed choices. This outlook would correspond to the subsidiary principle that is found in Switzerland on many levels – that decision- making powers should always be at the lowest possible level, and that Swiss citizens are supposed to make many decisions themselves, for example through popular votes and referendums, instead of delegating them to experts.

Zambrano (2016) recommended concentrating on action instead of principles, and establishing a correspondence between the two. For example, on the basis of a wider view of the relations between individuals, drafting advance directives would be useful as the persons involved would know the individual's wishes and could act accordingly, even if they did not agree with all of them. Instead of the individual declaring preferences in isolation, these preferences could be discussed and explained. If goals are genuinely divergent, the will of the individual would prevail, but in many cases where conflict is feared, it can be minimized or eliminated through discussion, explanation or mediation. In this way, our proposal would enhance rather than violate autonomy through increased discussion and exchange.

## Practical steps towards a possible solution

Accepting and facing one's own mortality is not easy, but needs to be addressed not only in order to gain optimal control over one's living conditions, goals and aims in a broad sense, but also to dispel unrealistic ideas concerning healthcare and treatment wishes. If family members or close friends are designated as healthcare proxies, advance directives can help to reduce the burden of decision making, as the wishes of the patient are documented. According to Hickman et al. (2015) and Lord et al. (2015), healthcare proxies of seriously ill patients who had drafted advance directives reported less emotional and decisional burden than those who were less aware of the patient's healthcare preferences. If a person agrees to face these possibly uncomfortable topics and think about future questions related to health and illness, there are a number of models for advance directives, as many health institutions and nongovernmental associations offer their own versions. Having to choose between these and the additional possibility of drafting a free text directive may be overwhelming and lead to discouragement when trying to find the "best" model. Once the advance directives are completed in a correct

and legally binding way, it is important for them to be easily accessible. This means that (1) the existence of advance directives must be known in case of hospitalisation and (2) the advance directives must be easy to find, in either a paper or an electronic version.

However, the drafting of advance directives should not be an isolated act, but integrated into a broader framework of advance care planning. As Rietjens et al. (2017) and Bobbert (2016) explained, this involves patients, families and healthcare professionals working together in an interdisciplinary manner, and may even require changes to the healthcare system and society in general to encourage discussions around illness and the end of life. Advance directives should be revised periodically as an individual's circumstances may change, for example, after diagnosis of a disease or its progression.

In line with the proposed law, we suggest that certain timepoints in life could be suitable for discussing advance directives with knowledgeable persons (advance directives experts) employed by some public and neutral body. This could be seen as a modern rite of passage, in order to prepare for older age. We could imagine triggers such as reaching the age for early retirement, or turning 50 and thus entering the second half of life, as the number of centenarians continues to steadily increase: according to the UN (2011), the number of centenarians in 2050 is estimated at 3.2 million, 68% of whom will be living in the more developed regions (United Nations, 2001).

An alternative age would be 40 years, the advent of middle age. Although this age (or 50) might seem too young, there is no harm in recording one's wishes with a directive that can be revised whenever one wishes. It would also prevent presumed "ageism" and the erroneous perception that advance directives usually concern end-of-life situations after a long, chronic illness, as discussed by Malpas (2011). During this conversation, advice could be given on different models of advance directives, their respective advantages and disadvantages, and possible problems when completing them. It would also be stressed that there is no obligation to complete advance directives, only to be aware of their importance. If the person is open to completing advance directives, a follow-up meeting could be offered to go over the completed version and make sure that the contents are in line with legal requirements and are informed, understood and voluntary (see Bobbert, 2016). The discussion could also cover nomination of a proxy for decision-making in the event of loss of capacity.

For this conversation to be nonthreatening and useful, we think that advance directives experts need to be trained in interpersonal communications and negotiation skills, in addition to having a knowledge of psychology. It is also important that the body that employs these experts does not depend directly on an institution connected to health or social benefits, as this could be perceived as a conflict of interest.

Ideally, if complete advance directives are part of a broader model of advance care planning (see Bobbert, 2016), they should include not only treatment wishes and preferences, but also cover related topics, most of all organ donation. If organ donation were included in these discussions as a matter of course, making directives mandatory would also make it mandatory

to at least consider recording one's wishes regarding donation – which would probably improve donation rates. Making discussion about directives mandatory would also benefit organ donation in another way in the Swiss context: if (as we suggest below) health insurance cards routinely recorded whether a person has a directive, and most such directives contain a record of donation intentions, a *de facto* organ registry would be created in a country where one does not currently exist, and confidentiality of the information would be guaranteed. Although people can create organ donor cards in Switzerland, many of those who do so do not remember to carry them – this is less likely with a health insurance card. (Electronic directives would be more appropriate in relation to donation as they can be accessed more quickly.) When discussing organ donation in the context of a discussion around advance directives, the advance directives experts must be careful not to express their own preferences or values, or irrational forms of influence, as described by MacKay and Robinson (2016). Neither should the expert propose treatment options or limitations that have an impact on a possible organ donation. One possibility might be to have a standardized conversation guide.

As stated above, general principles and values can sometimes help to indicate what the person would have preferred in a specific situation that has not been explicitly covered. The course of many illnesses and treatments cannot be predicted, so deducing the patient's wishes from this information can be crucial. The drafting of useful and appropriate advance directives is in itself a complex matter, as many patient organisations and other nongovernmental organisations offer forms that vary in content. Furthermore, it is possible to draft advance directives in a free text format, without any legal requirements other than that their content must not contravene any law that is in place and that the directives must be dated and signed by the person who drafted them.

The completed and signed advance directives could then be stored centrally (for example in a registry on a secured website) to facilitate accessibility in case of need. Again, this site should be independent from healthcare providers or health insurance companies to avoid any conflict of interest.

However, health insurance companies could be notified of the existence of advance directives so that they can make a corresponding entry on the health insurance card and make sure that the data can be read with the software used by nursing homes, hospitals, physicians' practices and other health institutions. Another, less formal, possibility is to add a sticker on the health insurance card indicating the existence of advance directives and giving access information. Even today, article 371 II of the Swiss Civil Code states that a person who has drafted advance directives can enter this fact, as well as the place where the advance directives are stored, on their health insurance card.

However, this is only a proposal that is not likely to prevent cases where written advance directives are in the person's home with nobody else knowing about them, as according to article 372 I of the Swiss Civil Code the treating physician must only ascertain the existence of advance directives according to the health insurance card. The change from an optional to a

mandatory entry on the health card or a similar document would thus seem reasonable in order to guarantee execution of the patient's wishes.

The electronic patient file that was approved in April 2017 and will be introduced from mid-2018 would be an ideal place, but here as well the opening of an electronic patient file is not mandatory. Persons with an electronic patient file who already have drafted advance directives will probably tend to store their advance directives there for reasons of traceability, but the existence of an electronic patient file *per se* does not address the question of how to reach people who have neither drafted them nor thought about drafting them.

## Conclusion

In a modern, secular society, the finite character of life should not be a taboo subject, and topics that once were considered marginal, such as planning one's own funeral or holding death cafés to talk openly about matters around personal mortality, seem to be becoming more popular. Unfortunately, many resources are spent in a suboptimal way because this topic is still avoided and because patients are not always clear about their preferences for the end of life. This, in turn, is partly because of insufficient information about treatment options and their chances for success.

Clear and open communication between physicians and patients could partly remedy this. Proactive explanations from doctors and other health professionals of why initiating advance care planning, and as a part of this drafting advance directives, is a constructive and responsible action might encourage patients to think about this matter and follow it up. Some nudging from public authorities might be another step towards having more people taking conscious decisions on how to approach possible and realistic options at the end of life. This should be facilitated by ensuring that the drafted decisions will be easily traceable when necessary.

We are of the opinion that the arguments presented by the Federal Council were not sufficient reason for the rejection, but rather served to avoid the discussion of mortality and illness-related costs in society. In a time of scarce resources, accentuated by an ever-higher life expectancy, this strategy is questionable and does not serve the interests of the general population. Instead, steps should be taken to encourage proactive discussion of advance directives so that their drafting becomes common practice.

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# Chapter 5: How People Traveling Abroad to Die Came to be Called "Death Tourists", and Why They Shouldn't

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**How People Traveling Abroad to Die Came to be Called "Death Tourists", and Why They Shouldn't**

Switzerland has a unique position among countries permitting some form of assisted dying. However, not all Swiss citizens and institutions are welcoming this fact and have coined the term "suicide tourism" for the phenomenon of foreign residents coming to Switzerland in order to request assisted dying. This reflection shows how the term was created and why it is misleading.

Due to its special legislation concerning assisted suicide, Switzerland has a unique position among the countries that permit various forms of assisted dying. The fact that assisted death does not have to be directly supervised by a physician has led to the existence of several end-of-life associations whose non-medical staff can be present at the accompanied death. The prerequisite of this is still a prescription made by a physician after careful examination of the individual person's situation.

Unlike the Netherlands or Belgium, the Swiss law does not require a long-term therapeutic relationship with a local physician. For this reason, many persons who were either terminally ill or suffering from an incurable disease, which reduced their quality of life so much that they preferred to die came to Switzerland to end their life. The more known this option becomes, the more people will inquire and also follow up on their decision. This trend is shown in the increasing numbers over the years, although the absolute numbers are small in relation to all deaths occurring in Switzerland. This corresponds to the rising numbers of demands for assisted dying among Swiss residents (Federal Statistical Office, 2016).

The big majority of the Swiss population agrees to the current situation and does not want it changed. Initiatives to increase regulations around assisted suicide have been turned down in popular votes, the last time in May 2011, in the canton of Zurich (home of the well-known organization Dignitas (Tagesanzeiger, 2011). Even the Swiss Academy for Medical Sciences (SAMW) is changing its general position towards assisted suicide in the newly-drafted guidelines (SAMW, 2018); however, the professional organization of physicians FMH opposes these more liberal guidelines (Medinside, 2018).

Swiss media have coined the term "death tourism" (German: Sterbetourismus), which was the Swiss "word of the year" in 2007 and the respective "death tourists". According to the German authority on spelling and etymology, the Duden, a "death tourist" is someone who travels in order to request an assisted death at the final destination. This expression - which has been taken up by others and even appears in scientific articles (for example Gauthier, Mausbach, Reisch, & Bartsch, 2015) - bears resemblance to the widely known phenomenon of "medical tourism" but is a misnomer. In this short reflection, I want to explain how it came into being, what is wrong with it, and why it needs to be changed.

For a long time, people have traveled to far-away destinations in order to seek treatment. Spas from the Roman era and the alpine clinics in Switzerland bear witness to this. The mass

phenomenon of medical tourism had appeared in the early 1990s when it became popular to have dental surgeries in Hungary, due to the lower prices for comparable services. Cheaper travel costs and better information and access to such services led to a democratization of medical tourism; and it is indeed often advertised as such on the internet or in magazines, with the possibility of renting an apartment and booking excursions during the time that you wait for a control visit or need to have several interventions. Finally, let us not forget that a "tourist" – someone taking a tour – usually goes back to the place where he has come from after having completed the tour.

The term "death tourism" had appeared for the first time around the year 2002, for example in a parliamentary motion presented by the then member of the national council Dorle Vallender (Vallender 2002) and in a critical editorial of the member magazine of the Swiss right-to-die association Exit (Blum, 2004). It was readily picked up by mainstream print media and made its way to other publications like books and scientific articles (e.g. Eicker, 2006). I think that this term has been coined by someone who has ambivalent feelings about assisted dying and wanted to express his or her disapproval of this phenomenon. The connotations of this term are contradictory: the association of tourism, with its notions of vacation, excitement and relaxing activities, is joined with death, which usually provokes rather lugubrious feelings. We are not sure which of the two parts we should emphasize: the "death" part, which will make us feel empathy for the suffering; or the "tourism" part which will make us remember our own travels which are usually spent in an atmosphere of pleasure and recreation.

In my work with persons coming from abroad in order to have access to assisted dying, I have seldom encountered "tourists". Apart from the fact that they have to travel to Switzerland, sometimes from other continents, and need accommodation which in most cases is a hotel, the few days in Switzerland are hardly filled with activities a tourist would think of. Usually, two visits to a physician are required, so transportation can be an issue. In some cases, final paperwork needs to be completed with the association. When all this is done, there might be some time left for sightseeing. However, most of the persons coming to Switzerland to end their lives are old, in a frail state, sometimes suffering from multiple illnesses, and in general tired of life under conditions, they deem "unbearable". If touristic activities even appear on such a list, they usually are the last point on the to-do list.

The main motivation for these individuals to come to Switzerland is to make use of a possibility that is not offered in their country of residence. If legislation changed there, there would be no need of traveling long distances, sometimes concealing the real reason so as not to make anybody an "accomplice" who could be persecuted for "assisting suicide".

To me, qualifying these individuals as "tourists" is a cynical attempt to decrease credibility for their reasons, and at the same time criticize the associations they turn to for assistance. When we read about "death tourists" over and over, the catchy word remains and settles somewhere in our subconscious. It is easy to forget that Swiss people have the same possibility but with much fewer complications and hardships. For them, it is enough to find a physician who is open to the idea or to be a member of the biggest Swiss association for assisted suicide (which, by

the way, is offering this possibility only to residents of Switzerland, a fact that is not always laid out in the media).

The creeping adoption of this term even in serious publications reflects an unwillingness to accept the fact that people come to Switzerland for various reasons and uneasiness with the phenomenon in itself among certain stakeholders. Even if the majority of the population is in favor of the current legislation, not all key players are. This has been shown in the heated debate around the national research program 67 on the end of life (NRP 67, n.d.), where associations for assisted dying felt unrepresented and silenced by an openly religious president of the steering group who was at the same time professor for moral theology. Many people consider Switzerland a beacon of democracy and neutrality. We should stop to criticize persons who come here because our laws are more advanced, and rather inform about the serious Swiss approach to debunk myths around assisted suicide. This, in turn, could help to change the local laws. The fact that most Swiss people do not use this possibility, although they are in favor of it (just as in the Netherlands and other countries that allow assisted dying), shows that the majority of the population enjoys a sufficient quality of life and hopefully dies under conditions that reflect their wishes and preferences either at home or in a facility of any kind.

Finally, what could be an alternative to the expression? I have thought long and hard about this and want to propose several terms. While “death travelers” (Sterbereisende) already sounds more neutral and less catchy, and puts them on a similar plane with persons who enter a hospice to die, terms like “death emigrants” (Sterbeemigranten) or “death exilees” (Sterbeexilanten) reflects the grim reality of having to leave one’s home country without ever coming back.

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# General Discussion

The group of ageing prisoners is increasing worldwide also in Switzerland. This presents new challenges to the correctional system. The four main objectives of this thesis stated in the introduction were defined in order to assess challenges and opportunities for older prisoners in Switzerland to exercise their right to health. They included

1. Development of an overview about substance use and mental health problems among older prisoners.

2. Examination of ways to build an identity under conditions that may in many ways be different from conditions in free society.

3. Exploration of access to somatic and mental health care services that are not offered in prison but that need transportation to other locations and institutions.

4. Analysis of the question if access to advance directives and assisted dying qualify as parts of healthcare and if access to them affects the reality of older prisoners in Switzerland.

Based on these goals, we can attempt to assess challenges and opportunities for older prisoners in Switzerland to exercise their right to health. We have grouped these challenges and opportunities according to the four components of the right to health as described by the World Health Organization.

**General remarks on the right to health in prison**

There is no doubt that the overall situation in Switzerland ranks among the higher-quality solutions in Europe. The Swiss prison population rate is 81 per 100'000 of national population (World Prison Brief, 2019), as compared to 418.3 (Russia), 252.2 (Georgia) or 235 (Azerbaijan) for the lowest-ranking European countries, or to 102.5 as the average of the countries of the Council of Europe (Council of Europe, 2019). This indicates that there are worse situations, and a higher number of problems to solve, elsewhere but does not mean that everything is impeccable.

Due to the federal organization of Switzerland and its impact on the prison organisation as described in the introduction, there are challenges that are specific to Switzerland and other countries that have a highly decentralized system. Decentralization of health services was one of the overarching themes of international initiatives starting in the 1980s (Mills et al. 1990; World Bank Decentralization Thematic Team, n.d.), with the related claims and expectations that those services, even if decentralized, were to be of comparable standard. Likewise, Klaue (2012) states that cantonal health services should respect the principle of equivalence of care in theory but this is not yet true for all cantons (Klaue 2012).

The Swiss correctional system is also characterized by a duality of sanctions, those being penal sentences and measures. Penal sentences are served in a prison, while therapeutic measures should be treated in specialized institutions. Duality of sanctions is also present in other countries, for example in Germany, Austria or the Netherlands, but in these countries ~~difference~~ the choice of the sanction and the institution where the offender is placed solely depend on the offender's legal status: An offender who is criminally responsible is sent to prison; an offender

who is not criminally responsible is placed in a specialized institution that is better adapted to this condition (Bundesgesetz vom 23. Jänner 1974 über die mit gerichtlicher Strafe bedrohten Handlungen (Strafgesetzbuch), Artikel 21; Strafgesetzbuch in der Fassung der Bekanntmachung vom 13. November 1998 (BGBl. I S. 3322), Artikel 63 and 64; Wet van 25 juni 1997 tot vaststelling van een Beginselenwet verpleging ter beschikking gestelden en overige verpleegden strafrechtstoepassing en daarmede verband houdende wijzigingen van het Wetboek van Strafrecht en de Beginselenwet gevangeniswezen.

## Availability: challenges and opportunities

The state must provide a sufficient quantity of functioning public health and health-care facilities, goods and services as well as programmes. This includes in any case underlying determinants of health such as hospitals, trained and competitively paid medical personnel, medication, water and sanitation.

In Switzerland, the general standard of living, and also the general maintenance standard of correctional institutions, is elevated, and the basic needs like food, water and sanitation are met in all health facilities although Wangmo and colleagues (2018) describe the need to improve the quality of prison food and, in the case of older prisoners, adjust it to this group's age-specific or disease-based needs such as diabetics, increased need of vitamin D or toothlessness. Their research shows that the overwhelming majority of older prisoners are negative about meal quality and experience them as less healthy than the food they used to eat before incarceration (Wangmo et al., 2018).

For the prison population, public and private external hospitals are available but not always easily accessible and not in sufficient numbers, as explained further on in the section on accessibility. The number of available institutions that usually follow after hospital for patients who cannot return home is insufficient as well. In free society these institutions are usually nursing homes or other long-term care facilities. For detained individuals who are not sick enough to stay in hospital but not healthy enough to return to the usual prison environment, stakeholder interviews revealed that it is often difficult to find suitable facilities as nursing homes can refuse to accept a resident with a criminal sentence.

Chapter 1 gave a broad overview of older offenders with mental health disorders. The number of older offenders with and without mental health disorders is increasing in Switzerland. There are several possible reasons for this increase. There may be a higher number of offenders, courts may order longer sentences, there may be a shift in sanctions from sentences to measures, or release procedures may have become more difficult. Prisons are currently not prepared for the increase of specialized care that old and infirm prisoners require. Also, there is a growing number of elderly persons who are interned but placed in prisons in spite of the legal requirement of separation from prisoners sentenced to custodial sentences (Brägger, 2014). For this reason, there is a need to create facilities that can house this specific subgroup of prisoners on a long-term basis, as is the case in other countries like Belgium or the Netherlands (de Boer & Gerrits, 2007; Wittkowski et al., 2017).

## Accessibility: challenges and opportunities

Everyone must be able to access prison health facilities, goods and services. The four sub components of accessibility are non-discrimination and physical, economic and information accessibility.

Regarding non-discrimination, Moschetti and colleagues (2015) mention that the proportion of Swiss detainees was much higher among the older adults (51% vs. 20 %). Penal statistics indicate that more measures according to articles 59 and 64 of the SCC seem to be pronounced for Swiss nationals. This impression is reflected in the fact that the big majority (44 of 55) of prisoner participants were Swiss nationals, while among all prisoners in Swiss correctional institutions, only 26% are of Swiss nationality (Bundesamt für Statistik, 2018). The selection of potential participants was facilitated by prison health services. This may have led to selection bias and may not reflect the actual percentages of Swiss and non-Swiss prisoners.

Physical accessibility can be difficult if prison health services are located on separate floors or separate buildings. While all facilities and buildings must be equipped with elevators, barriers for individual prisoners to use these elevators can be high. If being frail is seen as a sign of weakness (Heidari et al., 2017), fear of showing weakness may prevent prisoners from using elevators, respectively to ask guards with specific keys for elevators to facilitate use of elevators, if the use of elevators is allowed at all. We have seen in chapter 3 that the physical access to external health services and institutions is not without problems and depends on numerous factors, such as a health professional approving the discomfort of the prisoner, or the availability of transportation. This need of approval by a third party is also an obstacle for solutions to permanently transfer prisoners with sentences or measures to institutions that are more suited to house older and frail individuals, such as nursing homes or hospices.

Economic accessibility means that healthcare must be affordable to everyone, irrespectively of his economic situation. In free society, health insurance for persons having an income includes an out of pocket participation of 10 or 20 %) to be paid by the insured person as well as a deductible that can be chosen among various amounts. For prisoners, the situation depends on their legal status. Swiss citizens or residents are required to have health insurance, and if the patient does not have a sufficient income, social services may take over payment. For illegal aliens, the situation differs in that emergency assistance is paid but the coverage of costs of further health services depends of the canton. The three concordates have differing conditions. The concordate of Eastern Switzerland states that the respective penal institution clarifies who will pay medical services, and covers emergency assistance (Ostschweizer Strafvollzugskonkordat, 2018, p. 4). The concordate of Latin Switzerland decided in 2018 that it is usually either the canton of judgment who covers expenses for health services or the canton of attribution for persons under asylum law (Concordat latin, 2018). The concordate of Northwestern and Interior Switzerland states that health services within the correctional institution are covered by the pension and that for foreign nationals without residence or health insurance, the penal institution covers expenses if no other payer can be found (Strafvollzugskonkordat Nordwest- und Innerschweiz, 2019). The central ethic commission of the Swiss Academy of Medical Sciences states in a position paper that administrative

clarifications may never hinder or delay decisions on the necessity of a medical intervention, and that all prisoners must have access to health services, irrespective of their legal status (SAMW, 2019). These financial restrictions lead to very limited access to health services for resource allocation reasons and are in clear contradiction to international obligations such as the Mandela Rules or the European Prison Rules, as Switzerland is a member of the United Nations and the Council of Europe and has ratified both documents.

The information accessibility in prison happens in a different way than for the general population. Whereas persons outside of prisons have access to a wide spectrum of health information sources such as pharmacies, libraries, books, contacting governmental and non-governmental organizations or the internet, such information sources in prison are usually limited to the health services and the staff working there. Depending on the time the staff can allocate to a patient, possibilities for exchange may be limited to emergencies or acute care and may not include general information for example on end-of-life decisions. Prisoners who want to contact an association providing suicide assistance can have problems finding out the contact details, and the mail may then be read, with the possibly confidential information transmitted to prison administration. A private person in the community may simply call or write to the association and receive information without external interference, unless he or she resides in a care facility that may not agree with this decision for religious or philosophical reasons. It is questionable if care facilities like hospitals or nursing homes may restrict freedom of information and access of right-to-die associations to their grounds. The Federal Court has ruled in the case of Salvation Army vs Neuchâtel (BGE 2C_66/2015) that the Salvation Army had to allow a resident's request for assisted suicide, as this institution was financed with public money and had the status of "public utility". It was thus not entitled to place religious or other convictions above a resident's "right to choose the circumstances and the moment of his death" (Federal Court (2016), Rz. 73). The question if a similar case could be made for prisoners who are residing in institutions financed with public money exceeds the scope of this thesis.

Limited informational accessibility may also underly larger discussions on creating healthy identities. Chapter 2 depicts that the range of possibilities for this vital part of personality formation is restricted in prison compared to free society. We define "free society" as the part of the population residing outside of psychiatric care facilities and other "total" institutions which may be comparable to a prison in what concerns limitations of access and movement. Residents of nursing homes are usually not confined to these institutions unless there is serious loss of mental capacity or of physical mobility. Even in the latter case, it is possible for them to receive visitors without much limitation. Also, the range of activities available is much broader and depends on the free choice of the person. All these factors contribute to an identity of an older person according to widespread cultural definitions.

### Acceptability: challenges and opportunities

Health facilities, goods and services must respect principles of medical ethics and confidentiality and also respect individuals, minorities, communities and people and their

culture and choices. They also have to be committed to improving the health status of the concerned patients.

The principles of medical ethics are usually already transmitted in medical school and reiterated during professional training. However, the principle of confidentiality may be breached or jeopardized if dual loyalty problems arise. We have seen that according to the canton, responsibility of prison health lies with different departments. International recommendations clearly recommend professional independence of prison health services from prison administration. The best way to guarantee this is to place the entire prison health services under the department of health, as is the case for example in the cantons of Vaud or Neuchâtel. Placing doctors under the department of health but leaving other health professionals such as nurses under the department of justice, create misunderstandings and doubts and show ambivalence. Health teams should not be divided into "leading" and "executing" elements but must be considered as a whole entity as they all have the duty to put the patient's well-being as their topmost priority. In Basel City, this setup was changed to placing all health professionals under the department of health as per January 1st, 2019 (Gesundheitsdepartement des Kantons Basel Stadt, 2019). This example shows that change is possible on a cantonal level although it may take a certain time due to the multiple actors implicated in the necessary decisions.

## Quality: challenges and opportunities

Health facilities, goods and services such as preventive, curative and palliative care must be culturally acceptable, scientifically and medically appropriate, and of good quality.

The quality of health facilities, goods and services such as the range of medication, number of staff, range of opening times or the instruments available are directly depending upon available resources. Currently, allocation of resources for prison health services happens at the cantonal level (Bundesrat, 2014). Prison health professionals encounter problems that are also characteristic for public health services in the community: The public consults them for apparently minimal reasons, not all drugs are reimbursed, pressure to use generic instead of original products is increased, or there are not enough young professionals replacing those who change careers or are retiring. Training for new medical professionals is an important part of quality assurance. Depending on the training medical institution's setup and location, professional training for health professionals can incorporate correctional institutions. For example, medical and nursing students in Geneva can spend internships or residencies in the service responsible for prison health in order to encounter and later enter this area of public health (Département de médecine communautaire des HUG, n.d.).

In free society, advance directives are drafted by only a fifth of the adult population due to different reasons including misinformation and unrealistic expectations (Brotschi, 2018). . The situation for prisoners is similar as only a third of prisoners who participated in a study on the end of life in prison mentioned advanced directives (Gramigna (ed.), 2016, p. 8). It can be challenging to imagine a situation where one is not anymore able to decide for oneself. Just as an older person in detention and in the community may not really be able to imagine being in a

state of unconsciousness, a prisoner entering a hunger strike may not be able to imagine the consequences of this decision.

## Advance directives and assisted dying as part of medicine

One objective of this thesis is to determine if advance directives – which are generally discussed in chapter 4) and assisted dying (which is depicted in chapter 5) can be considered being part of health. This is obvious for advance directives. The WMA's Montevideo declaration contains guidelines for physicians how to approach this topic. We can conclude from this that dealing with advance directives are part of medicine and thus also are included in the right to health.

Tensions can arise if a patient is not able to express his or her wishes anymore and relatives do not know the patient's the preferences and choices. Respecting a patient's will could also lead to less health expenses due to intensive and unnecessary treatment that does not corresponded to what the patient would have wanted (Maurer et al., 2017, p. 44). For these reasons, it would be reasonable to ask persons deciding to move to a nursing home if they already have advance directives. If not, they should be asked to draft them so the situation is clear. Patients who enter a hospital may or may not be in a conscious state of mind where they can still make decisions. Individuals entering prison are usually legally responsible and thus able to draft advance directives. This is not yet common practice in prisons but could be introduced as a routine practice, for example starting at a certain age (Maurer et al., 2017, p. 44).

The answer is less obvious for medical aid in dying. In Switzerland, the SAMW has issued guidelines stating that medically definable symptoms of disease or functional impairments must be present to justify why assisted suicide should be considered a medical matter at all (SAMW, 2018, p. 24). Barnikol (2018) underlines that patients cannot claim a right to suicide assistance but that it is under certain circumstances permissible for doctors to assist a patient'suicide. The parliament of the Swiss Medical Association (Foederatio Medicorum Helveticorum, FMH) refused to incorporate these guidelines into their professional code due to unclear terminology (FMH, 2018), and the statutes assert that doctors may abstain from life-prolonging measures for terminal patients (FMH, 2019).

On an international level, similar differences of opinion have led to national medical associations leaving the WMA because of the latter's perceived inflexibility to discuss modifications of the wording of their declaration on euthanasia and assisted suicide. Although other declarations of the WMA have been constantly modified and rendered more detailed, for example, the declaration of Helsinki, it is improbable that this will be the case for a declaration with a very short and concise content.

Even if assisted dying will be considered as a part of medicine for the general public, discussing this in the Swiss prison context presents additional challenges. When the first Swiss person sentenced to internment asked to contact an organization facilitating assisted suicide in 2018,

there was no immediate position of the department of justice. In the meantime, the Conference of Cantonal Directors of Justice and Police (KKJPD) has ordered a policy document to create foundations for this situation. This document will be discussed at the KKJPD's autumn session in November 2019, and decisions about further actions as well as the publication of this document will also be made at that occasion (personal communication Alain Hofer/KKJPD, September 5th, 2019)

This subject has not been taboo in other countries. In Belgium, euthanasia is a legal medical procedure (Thienpont et al., 2015). Frank van den Bleeken's request for euthanasia was approved by the justice ministry although psychiatrists, human rights specialists and ethicists opposed this decision (The Guardian, 2014). The Dutch psychiatrist Wim Distelmans criticized the insufficient psychiatric care for interned prisoners and stated that euthanasia should not solve society's failure to improve living conditions leading to unberable suffering (Vervaeke, 2015). Van den Bleeken was subsequently transferred to a special ward of a newly instituted Belgian university psychiatric centrum, the longterm forensic institution at Bierbeek (Sint-Kamillus, n.d.) designed for 30 persons sentenced to lifelong internment and staffed among others with criminologists, psychologists, nurses and occupational therapists (HLN, 2017).

In the Netherlands, the Royal Dutch Medical Association KNMG has issued detailed guidelines for the practice of euthanasia and physician-assisted suicide (KNMG, 2012). Although physicians do not include euthanasia and assisted suicide in their standard care, they can perform these procedures under certain conditions (KNMG, 2011). Although Loosman (2016) states suicide rates among persons imprisoned to a life sentence or internment are high, and the wish to die is uttered regularly, no case comparable to Frank van den Bleeken has emerged yet, and the problem has not yet been discussed sufficiently on the legal and societal levels (Loosman, 2016).

In Canada official guidelines for medical aid in dying have been passed for the prison context after medical assistance in dying was legalized in 2016 through the Bill C-14 of June 17, 2016. The Correctional Investigator Ivan Zinger makes recommendations for the clarification of certain topics in the current legislation, for example increased cooperation with community health providers (Zinger, 2018).

We see from this that MAID can be considered a medical procedure although patients cannot oblige a physician to perform this procedure. It would follow that the right to health includes the right for prisoners in Switzerland to request assisted suicide. Just like for members of the community, such a request needs to be thoroughly examined.

## Strengths and limitations of research methods

The data presented in this thesis were collected as part of the research project "Agequake-2". Quantitative research is not part of this thesis, as data collection is still ongoing at this time due to the scope of the project.

Prisons were sampled using the official list of correctional institutions in Switzerland. Inclusion criteria were: institutions located in 20 previously defined cantons, institutions with more than 20 places, institutions housing prisoners aged 50 years or older, and long-term institutions (at least 6 months). Exclusion criteria were remand prisons, deportation centres, institutions holding less than 20 places, and institutions not housing prisoners aged 50 years and older. All prisons corresponding to the inclusion criteria were contacted either until they formally declined to participate or until the research team had attempted contact a predefined number of times with no avail.

Prisons in the French and German speaking regions were included, the Italian speaking region of Switzerland was excluded for language reasons. The participating institutions had a capacity of 2234 places and represent 63 % of the eligible population. However, the findings cannot be transferred to the national level because of the previously mentioned cantonal differences that limit any generalization of findings at a regional level.

For the qualitative part of the study, Swiss stakeholders were chosen among members of associations of forensic psychiatrists and psychologists. Dutch stakeholders were initially chosen among members of the Dutch Institute of Forensic Psychiatrists and Psychologists (NIFP) and later also following a snowball sampling approach. Canadian stakeholders were sampled following a convenience approach. For the prisoner participants, the correctional institutions were contacted and the research project was presented to prisoners by the prison health services. The degree of commitment varied among institutions due to factors such as resources and institutional regulations.

For data extraction from medical records, it is important to state that this procedure is quite common to access health information on prisoners, especially older prisoners (Loeb & AbuDagga 2006). Practical difficulties arose due to the fact that mental health records were stored in different places, sometimes physically away from prisons, and that the scope of access to them depended on the respective institution. While some institutions agreed to collection of basic data from all prisoners, others insisted on a previously defined selection of prisoners. This has methodological consequences on sampling.

It is difficult to draw conclusions on the national level as several big correctional institutions either declined participation or limited participation to access to select small prisoner samples. However, some conclusions can be drawn on the necessity of further research as stated in the following chapter.

## Implications for further research

In a very broad sense, the responsibilities of state and cantons in a federally organized state must be examined to establish where regional autonomy outweighs the principle of individual justice. In the penal context, this refers to the question if the autonomy of the canton in penal execution outweighs the creation of equal conditions for prison healthcare over the whole Swiss territory. The question if there is a conflict with anti-discrimination rules stated in the European Convention on Human Rights exceeds the scope of this thesis, but a thorough ethical discussion must support a purely legal discussion of this question.

Several fundamental aspects of mandatory treatment merit academic attention. In the community, this relationship results from the patient's choice and can be modified or ended from both sides. The fact that this is not possible in the context of mandatory therapy leads to the question to which extent is therapy progress influenced by the quality of the therapeutic relationship. Mandatory therapy can also have implications for dual loyalty and equivalence of care. Our research has shown that there are different approaches on forensic therapy in the German and the French speaking regions of Switzerland. Research in these linguistic regions may shed light on the therapist's self-image in a forensic situation and could be complemented by data from other multilingual states like Belgium or Canada.

More research is also needed on what can be done to better respect older prisoners' right to health. This question covers specific problems like transfers to specialists or transportation in general, but also broader topics like adequate housing for older persons sentenced to therapeutic or safety measures. Current administrative procedures should be thoroughly examined by a transdisciplinary research group that does not only consider ethical, legal and medical aspects but is complemented by representatives of administration as well as by current or former older prisoners to consider the acceptability of proposed modifications.

Further research projects should include other types of prisons, such as remand prisons, and cover the entire Swiss territory. This would cover the complete reality and make results valid for the national context.

## Implications for practice

The research project that provided the basis for this thesis aimed to explore the reality of mental healthcare for older prisoners in Switzerland. This explorative approach leads to the detaile academic discussion of the findings but also has practical implications. Such implications include the creation of more of places in specialized institutions for therapeutic measures. This necessitates changes in budget allocation for prison healthcare which need to be discussed on the political and societal level. At the same time, current resources available for older prisoners might be distributed differently and lead to better results. This must be examined from a financial, organizational and security perspective.

Clear regulations for medical transport must be defined and established over all three penal concordates so that cantonal differences can be reduced. The creation of central prison hospital with sufficient places and services, including a palliative ward, could reduce the need for medical transports and improve somatic care. This institution could be planned and executed on a national level, even if for reasons such as accessibility for families, the local or regional scale is usually preferred.

A transdisciplinary working group needs to be established to define conditions for physician-assisted suicide for prisoners. Swiss authorities should strive to exchange information with other countries where MAIDs is legal to see how this topic can be approached and managed in the correctional setting.

Advance directives should be routinely asked about upon entry to prison, just as it is already done in many other institutions such as hospitals or nursing homes. Inability to make decisions can arise from other conditions than old age or chronic diseases.

# Conclusion

We have shown that although Switzerland has already fulfilled many conditions for older prisoners to enjoy the right to health, several areas for improvement can be identified, especially regarding accessibility and availability of healthcare. Appropriate treatment and state–of-the-art therapy in suitable institutions must be offered to prisoners with therapeutic measures all over the country and replace the current regional differences.

General society and specific actors must be aware of the implications of the principle of equivalence. Switzerland is a part of the Council of Europe and the United Nations, and needs to apply the documents that it has ratified, such as the Universal Declaration of Human Rights, the European Prison Rules or the Mandela Rules. This means accepting that the obligations that come with ratification are not subject to political orientation but are a basic fundament of democratic and enlightened governance. The perspective towards law, breaking it and how to treat persons who break the law has changed over time and shows the development of a society from a retributive towards a restorative outlook on justice and towards accepting the inherent dignity of all human beings.

In a broad way, the question must be discussed how to approach assisted dying in the context of persons in correctional institutions. The role of the state between the protection of the individual and safeguarding the individual's autonomy needs to be defined. The transparent and consequent application of ethical standards such as dignity, justice, or autonomy should protect from overbearing paternalism and help to find the most appropriate solution.

In practical terms, reducing cantonal differences in the execution of sentences – including the provision of prison health services – and harmonizing practices need to be advanced. For the independence of prison health, which used to be very different between cantons, a certain progress can be noted. More cantons also in German-speaking Switzerland have transferred the prison health staff to the cantonal health department. However, most cantonal prison health services are still under the responsibility of the justice department so that the problem of dual loyalty is still a major challenge for prison health professionals (personal communication Peter Menzi/SKJV, September 2nd, 2019).

Payment for health services must be discussed and harmonized. Even though health insurance is compulsory for persons residing in Switzerland, covering the required individual contribution can be out of proportion for this vulnerable population. Persons who do not officially reside in Switzerland often cannot access appropriate and necessary healthcare as they may only be entitled to emergency assistance. International obligations imply that prison health services are accessible for Swiss and foreign prisoners alike, regardless of their legal status.

Switzerland must engage in closer exchange with other countries or regional bodies that may face similar problems. The distribution of powers between national, cantonal and communal levels is not unique to Switzerland, so experience from other multilingual and decentralized countries like Canada or Belgium may help find solutions to topics such as spatial inequalities or effective communication between stakeholders on different administrative levels.

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# Appendix

**Agequake in Prisons 2: Stakeholder Interview Guide**

Dear Participant: You are taking part in a study that concerns mental health, well-being and ethical care of older prisoners with mental illness or those sentenced to security measures. 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 of mental health and risk assessment. 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.

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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 been working in the prison context?
    - What motivated you to work in the prisons/with prisoners?
    - Could you please explain what type of work you carry out?
2. Could you explain the way in which mental health care is organized in your institution?

**Older prisoners with mental health problems.**

3. Could you explain the process of how a decision is made that an older prisoner needs mental health care?
4. What are the characteristics of these treatments (one-on-one treatment or group therapy)?
5. What is the general frequency of these treatments (per week or month), and how long do they last?
6. Have you experienced cases where an older prisoner had to wait too long for appointments? Please explain the reasons.
7. How is access to a psychiatrist guaranteed in case of unexpected episodes?
8. So far, what has been your experience/understanding concerning provision of mental health care to older prisoners?
9. What is your general experience working with the prison mental health system?

**Older prisoners with Security Measures.**

10. What specific aspects of mental health care are considered for older prisoners who are serving security measures?
11. What are the major challenges that you face with older prisoners serving security measures? Probe on the following three types of mental health care provided:
    Provision of therapeutic care to prisoners with mental health problems or prisoners with security measures
    Provision of court-mandated therapies to older prisoners
    Assessment of future risks of older prisoners
12. How are risk assessments made for prisoners serving security measures?

13. Is the risk assessment different for older prisoners? Please explain.
14. What factors are important for you when considering their risk to the general population?
15. How often are you asked to carry out such risk assessments for prisoners (over a period of 12 months)?
16. What are your institution's guidelines concerning carrying out these assessments?

**Problems and solutions to mental health care:**

17. What are the 3 biggest challenges that you face caring for the following groups of prisoners:
    - Aging prisoners
    - Older prisoners with mental health problems
    - Older prisoners with security measures

18. What solutions would you suggest to address the challenges that you mentioned concerning aging prisoners? (restate the problems that the participant discussed)
19. What solutions do you see for these problems with which the mental health care providers are confronted when providing care to older prisoners? (restate the problems named by the participant)
20. In your opinion, how can the care provided to older prisoners with mental health problems and those with security measures be improved? (restate the problems named by the participant)

**The following questions assess the topic "Ageing in Prison", particularly to see the circumstances of older prisoners.**

21. 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?
22. 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?
23. What minimal criteria are considered for provision of end-of-life care for a terminally ill older prisoner?
24. What minimal criteria are considered for early release of a terminally ill older prisoner?
25. What services should prisons provide to improve the quality of life of older prisoners?
26. Do you think that older prisoners would use these services and/or would profit from them? Please explain.
27. Is there anything else that you would like to add on the topic of aging prisoners?

Thank you!

## Agequake in Prisons 2: Prisoner Interview Guide

Dear Participant: You are taking part in a study that concerns mental health, well-being and ethical care of older prisoners with mental illness or those sentenced to security measures. During this interview, I will ask you questions about your general health, your mental health care, and your impressions on getting old in prison. As stated in the information and consent form, you can be sure that all responses will be treated anonymously and confidentially.

If you are fine with the purpose of the study and the reasons we are here (talking) today, I would first like to start asking you about your day.

1. Can you describe a typical day in [name of the institution]?

**Social network**

2. Are you close to somebody in the institution ?
    - Staff, other prisoners ?
3. Do you keep in touch with people outside the institution?
4. What do you think of the health services here in [name of the institution]?

**Diagnostics, Prison/Mental Healthcare Interface**

5. Which type of mental disorders do you have ?
    - Since when do you have this disorder ?
    - Since when do you receive treatment for this disorder ?
6. Which type of mental disorders do you have ?
    - Since when do you have this disorder ?
    - Since when do you receive treatment for this disorder ?
7. When have you been in touch with mental health services for the first time?
    - How?
    - With whom?
    - Why?

**Treatments**

8. Which type of treatment do you receive for your mental health problem?
    - In the institution
    - Before incarceration
    - Are there differences?
    - Frequency, every week/month etc.?
    - Which specialists do you see?
    - How long does a session last?
9. What are the first 3 words that come to mind when you think about your mental health problems? (Elicitation technique 1)
10. Do you think anything has changed in your mental health since you've been here?
    - Do you feel any improvement or deterioration regarding your mental health problems?
    - Which treatments have helped/help you the most?
    - Are you satisfied with these treatments?
    - What treatment/activity would you be most likely to stop?
    - Do you think you are treated differently because of your age?
11. Do you talk to other inmates about your contacts with mental health services?

12. Has anything changed since you contacted the mental health service/since you joined the institution?
13. If you could change anything about the treatment you receive, what would it be?
14. Which kind of additional medical care would you need?
15. Where would you place the health professional? (Elicitation Technique 2)

**Locus of control**

16. What are you doing yourself about the mental health problems you have?
17. What influences the progress of your therapy?
18. Who influences the progress of your therapy?

**Ageing**

19. What seems to be the most challenging thing in your life right now?
    - During your stay at the institution, what has changed for you? Are you facing new challenges now?
    - Do you think that ageing has an impact on your daily life in the institution?
20. Is the prison environment suitable for people of your age and older?
    - What would you improve? What would you need?
21. Which projects do you have for your life ?
22. What advice would you give to a younger prisoner who asks you how to deal with a mental illness? (Elicitation technique 3)
23. Is there anything else you would like to add regarding this topic?

Thank you!

# Curriculum Vitae


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| **Name** | Beate Sophie Haesen, née Herr |
| **Address** | 16 rue de la Montagne, F-68480 Vieux Ferrette<br>Tel. +33 671 32 34 03<br>sophie.haesen@unibas.ch |
| **Date of birth** | 4.9.1963 |


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| **Languages** | German (mother tongue), English, French, Dutch (fluent), Italian, Spanish,Portuguese (basics) |
| **Nationality** | Swiss (Hägglingen AG), German, French |

**Education**

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|---|---|
| 2017 to present | University of Basel/ Institute of Biomedical Ethics: PhD student (Prof. Elger)<br>PhD topic: Agequake in prisons – second part: Mental health care and forensic evaluation of aging prisoners and persons serving security measures in Switzerland (SNF-funded project 166043) |
| 2012-2014 | University of Basel/Swiss TPH (Switzerland): M.Sc.in Epidemiology (5.5)<br>Master thesis: Synergies Between Human, Animal and Plant Health Systems in Uganda |
| 2009-2012 | University of Basel (Switzerland): Medical studies, Bachelor of Medicine<br>Project course "Lernen am Projekt" on End-of-Life questions<br>Archiving and visual inventory of wax models by Wilhelm His for Department of Anatomy (Prof. Göbbel)<br>Several 4-week internships at Hospiz im Park, Arlesheim (Dr. Gudat) |
| 1993 | Chamber of Commerce Karlsruhe: Translator Certificate English/German |
| 1991 | Mercantile Institute Zurich (Switzerland): Higher Economic Diploma |
| 1983-1989 | University of Hamburg (Germany), M.A. in Romance Studies and Education<br>Master thesis: Das Bild der Türkei im Werk Pierre Lotis (German) |
| 1970-1983 | Primary school and grammar school (Germany), university-entrance diploma |

**Work experience**

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|---|---|
| 2015-2016 | University of Basel: Scientific assistant at the Institute of Medical Ethics |
| 2013 -2014 | Association Lifecircle, Biel-Benken (Switzerland): Coordinator |
| 2012-2014 | Exhibition coordination "MenschMikrobe" at Kollegienhaus Basel<br>Research assistance at Swiss Centre for International Health |

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| 2009-2012 | Inventory of slide collection, Department of Pathology (Prof. Bruder) |
| | ALK analysis in renal cell carcinoma specimens, Department of Pathology (Prof. Bruder) |
| | Surgery monitoring for infection prevention project, Hospital Hygiene Department (Prof. Widmer) |
| | Medgate Telemedicine, Basel (Switzerland): medical inbound agent |
| 2001-2016 | Translations of books and publications for several NGOs in Switzerland and the US |
| 1999-2001 | Founder and editor-in-chief of the bimonthly publication „Grandir Sans Ecole“ |
| 1996-2000 | Various activities related to homeschooling (editing, writing, PR) |
| 1996-1998 | Accountant for the French homeschooling association „Les Enfants d'Abord“ |
| 1994-2009 | Educator (homeschooling) and homemaker, Switzerland and France |
| 1991-1994 | KPMG Fides Peat, Zurich: Auditor |
| 1989-1991 | American Express, Zurich: collection official / head of group legal service |

**Conferences and Workshops**

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|---|---|
| 2019 | *Prisons in Portugal and in Europe – Regimes of Detention and Monitoring of Regimes* International conference, May 2019 Lisbon: active participant |
| | *Gesundheitsförderung in Haft*, Bonn: active participant |
| 2018 | *International Association of Forensic Mental Health Services* June 2018 Conference, Antwerp: presenter (2 posters) |
| | *European Society on Philosophy of Medicine and Health Care* conference August 2018, Lisbon: presenter (presentation) |
| | *Annual Conference of the European Society of Criminology*, Sarajevo (August/September 2018): presenter (poster) |
| | *Diss:kurs* of the University of Basel: presenter |
| 2017 | *Internationales Symposium Forensische Psychologie und Psychiatrie Zurich*: active participant |
| | *Prisons in Portugal and in Europe – History, Culture and Photography: Comparative Approaches*, Porto: active participant |
| | *Bioethics Curricula in Medical Education*, Chisinau: presenter |
| | *Gesundheitsförderung in Haft*, Vienna: presenter |
| | *Enhancement – Optimierungswahn oder Steigerung der Lebensqualität?* Gummersbach: active participant |
| | *Caring family members in palliative care and ALS*, Basel: active participant |
| | *Gibt es die Wahrheit noch? Alternative Fakten und narrative Ethik*, Bern: active participant |
| 2016 | *Euthanasia 2016*, Amsterdam: active participant |
| | *Forum Suizidprävention*, Rüschlikon: active participant |
| 2014 | *Paratrop (Gemeinsame Tagung DGP,DTG und SGTP)* Zurich: presenter |
| | *5th Biennial Conference of the International Association for Ecology & Health*, Montreal: presenter |

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| | *63rd Annual Meeting of the American Society of Tropical Medicine and Hygiene*, New Orleans: presenter |
| | *One Health Plus*: Exploring Common Challenges, Aberdeen: presenter |
| 2013 | *Environment and Health*, Basel: presenter |
| 2012 | *Advanced Trauma and Life Support*, Basel: student participant |
| 2010 | *Advanced Trauma and Life Support*, Basel: student participant |
| | Symposium *Knowing One's Medical Fate in Advance*, Basel: active participant |
| 2009 | Swiss Medical Student Convention, Basel: active participant |

**Teaching and supervision:**

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|---|---|
| 2019 | Course instructor for *Contemporary debates on insights into prison*, University of Basel. Supervisor for a Philosophy Master student writing a seminar paper on this topic. |
| 2018 | Co-supervisor for medical Master student, supervisor for psychology interns at the Institute for Biomedical Ethics |
| 2017-18 | Tutor for medical students, module *Körper, Subjekt, Umwelt* |
| 2017 | Course instructor for *Nursing Ethics*, University of Basel |

**Courses:**

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| 2018 | Course *Health in detention* at Swiss TPH, organized by the ICRC |
| 2017 | *Writing Productivity Tools and Techniques*, Advanced Studies Center, University of Basel |
| | *The Art of Fundraising: An Introduction to Philanthropic Fundraising*, Advanced Studies Center, University of Basel |
| | *Communicate successfully – collaborate effectively*. Advanced Studies Center, University of Basel |
| 2014 | *Leben und sterben lassen – Patientenautonomie am Lebensende*, Medizinische Gesellschaft Basel |
| 2013 | *Introduction to the Principles of Critical Appraisal of Health Economic Interventions*, National Library of Medicine |
| | *Protecting Human Research Participants*, NIH Office of Extramural Research |
| | *Basic Security in the Field* (BSITF II) and *Advanced Security in the Field*, UNDSS |
| 2010 | *Die persönliche Patientenverfügung im beruflichen Alltag*, GGG Basel |

**Memberships:**
European Society for Criminology
International Association of Forensic Mental Health Services
European Society for Philosophy of Medicine and Health Care

**Community Service:**
Reviewer for Journal of Medical Ethics
Reviewer for Journal of Forensic and Legal Medicine

**Publication list**

**Peer-reviewed journal articles**

**Haesen S**, Merkt H, Elger BS, Wangmo T**:** Chains, trains and automobiles. Medical transport for prisoners in Switzerland. Submitted to European Journal of Criminology

**Haesen S**, Merkt H, Imber A, Wangmo T, Elger B: Substance abuse and other mental health disorders among older prisoners. International Journal for Law and Psychiatry 62 (2019) 20-31, DOI 10.1016/j.ijlp.2018.10.004

**Haesen S**: How People Traveling Abroad to Die Came to be Called "Death Tourists", and Why They Shouldn't. Journal of Social Work in End-of-Life & Palliative Care, e-pub 20 November 2018, DOI 10.1080/15524256.2018.1528934

**Haesen S**, Shaw D: Directing Citizens to Create Advance Directives. Swiss Medical Weekly, e-pub 16 May 2018, DOI 10.4414/smw.2018.14628

**Haesen S**, Wangmo T, Elger BS: Identity as an older prisoner: Findings from a qualitative study in Switzerland. European Journal of Aging, e-pub 20 October 2017, DOI 10.1007/s10433-017-0443-2

**Book chapters**

Wienand I, **Haesen S**, Rakic M, Elger B: How Should One Die? Nietzsche's Contribution to the Issue on Suicide in Medical Ethic. In: Mihailov E, Wangmo T, Federiuc V, Elger BS (ed.) (2017): *Autonomy and Wellbeing in Bioethics: European Perspectives*. De Gruyter, Berlin, Germany

Boa E, **Haesen S,** Danielsen S: Better together: identifying the benefits of a closer integration between plant health, agriculture and one health. In: Zinsstag, J, Schelling, E, Whittaker, M, Tanner, M (ed.) (2015): *"One health": The added value of integrated health approaches*. CABI, Egham, United Kingdom

**Monographs**

**Haesen S** (2013): Synergies Between Human, Animal and Plant Health Systems in Uganda. Master Thesis. University of Basel, Switzerland

**Haesen S** (1989): Das Bild der Türkei im Werk Pierre Lotis (German). Master Thesis. University of Hamburg, Germany

**Conference proceedings**

**Haesen S,** Imber A, Merkt H, Wangmo T, Elger B: Quality of forensic-psychiatric expertises for therapeutic measures in Switzerland and Austria**.** Presented at ESC Eurocrim "Crimes Against Humans and Crimes Against Humanity" (Sarajevo, Bosnia and Herzegowina) 29.8.-1.9.2018

**Haesen S,** Merkt H, Imber A, Wangmo T, Elger BS: Forensic therapeutic measures for older individuals in Austria and Switzerland. Presented at 32nd European Conference on Philosophy of Medicine and Healthcare, "The Human Condition in between Medicine, Arts and the Humanities" (Lisbon, Portugal) 22.-25.8.2018

**Haesen S,** Merkt H, Imber A, Elger BS, Wangmo T: Substance abuse and other mental health disorders among older prisoners. Presented at IAFMHS Annual Conference (Antwerp, Belgium) 12.-14-6-2018

**Haesen S**, Wangmo T, Imber A, Merkt H, Elger B: Forensic therapeutic measures in Austria and Switzerland. Presented at IAFMHS Annual Conference (Antwerp, Belgium) 12.-14-6-2018

**Haesen S,** Merkt H, Wangmo T, Elger BS: Drogenmissbrauch bei älteren Gefangenen. Presented at 9. Europäische Konferenz zur Gesundheitsförderung in Haft (Vienna, Austria) 20.-22.9.2017

**Haesen S**: Mental health in prison, with a focus on older prisoners in Switzerland. Presented at Bioethics Curricula in Medical Education (Chisinau, Moldova), 17.-19.5.2017
**Haesen S**, Boa E, Schelling E: A Novel Approach in Joining Services for Tripartite Health Service Delivery in Order to Increase Community Effectiveness for Service Delivery. Presented at the 63rd Annual Meeting of The American Society of Tropical Medicine and Hygiene (New Orleans, USA) 2.-6.11.2014
**Haesen S**, Boa E, Danielsen S, Waiswa C, Schelling E: Synergies between human, animal and plant health systems in Uganda. Presented at Ecohealth2014 (Montreal, Canada) 11.-16.8.2014

**Haesen S**, Boa E, Danielsen S, Waiswa C, Schelling E: Can Synergies Between Human, Animal and Plant Health Systems Increase Community Effectiveness for Service Delivery? Presented at Paratrop 2014 (Zurich) 16.-19.7.2014
**Haesen S**: Synergies between human, animal and plant health systems. Presented during introductory lecture on Ecohealth at Institute for Evolutionary Biology and Environmental Sciences, University of Zurich (course UWW 152, PD Dr. Marcus Hall) 26.5.2014
**Haesen S**: Synergies between human, animal and plant health systems in Uganda. Presented at One Health Plus: Exploring Common Challenges (Aberdeen, UK) 2.-3-12-2013
Schelling E, **Haesen S**, Asaba J, Waiswa C, Danielsen S, Boa E, Kanouté Y: Synergies in Service Delivery and Learning Between Plant, Human and Animal Health: an Approach Perceived with High Potential in Rural Zones in Uganda. Presented at Ecosanté Africa 2013 (Grand-Bassam, Côte d'Ivoire) 1.-5.10.2013
**Haesen S**, Fürst T, Utzinger J: Noma: Epidemiology and Global Burden of a Neglected Disease. Presented at Environment and Health 2013 (Basel, Switzerland) 20.-23.8.2013
**Haesen S**, Boa E, Danielsen S, Asaba J, Waiswa C, Schelling E: Synergies between Human, Animal and Plant Health. Presented at Environment and Health 2013 (Basel, Switzerland) 20.-23.8.2013

**Other publications**
**Haesen S** (2013): Zurück aus Uganda (German). NZZ Campus 19.10.2013. Retrieved from http://campus.nzz.ch/special/zurueck-aus-uganda
**Haesen S** (2012): Novel Therapy for Sickle Cell Disease: Tests Confirm High Potential. Checkorphan 29.2.2012. Retrieved from http://www.checkorphan.org/grid/news/treatment/novel-therapy-for-sickle-cell-disease-tests-confirm-high-potential
**Haesen S** (1999): Un député non-scolarisant. Grandir Sans Ecole 8 (4/1999), p 12-13
**Haesen S** (1999): Impressions de la première rencontre trinationale à Colmar. Grandir Sans Ecole 8 (4/1999), p 15
**Haesen S** (1999): Foundation for Online Learning. Grandir Sans Ecole 8 (4/1999), p 18-19
**Haesen S** (1999): Péres et déscolarisation. Grandir Sans Ecole 6 (2/1999), p 5-9
**Haesen S** (1999): Michael Farris en Europe. Grandir Sans Ecole 6 (2/1999) p 12-15
**Haesen S** (1999): Entretien avec un déscolarisant américain. Grandir Sans Ecole 6 (2/1999), p 17
**Haesen S** (1999): Déscolarisation et religion. Grandir Sans Ecole 5 (1/1999), p 5-7
**Haesen S** (1998): Déscolarisants connus. Grandir Sans Ecole 4 (4/1998), p 18
**Haesen S** (1998): Homeschooling in France. The Magazine of the Alternative Education Resource Organization (Roslyn Heights, NY 11577) Spring 1998
**Haesen S** (1998): Fifi va à l'école. Grandir Sans Ecole 3 (3/1998), p 11
**Haesen S** (1998): Co-Sleeping. Basel Childbirth Trust Sept. 1998, p 3
**Haesen S** (1998): Learning Anytime, Anywhere! Basel Childbirth Trust May 1998, p 9
**Haesen S** (1998): The "Freie Volksschule". Basel Childbirth Trust May 1998, p 9
**Haesen S** (1998): Berceaux et Carrières. Carnet Sans Notes 7 (Feb. 1998), p 9-10

**Haesen S** (1998): Un ministre éduqué à la maison. Grandir Sans Ecole 2 (2/1998), p 7-8
**Haesen S** (1998): Enseignement mode d'emploi? Grandir Sans Ecole 2 (2/1998), p 10-11
**Haesen S** (1998): L'excellence – question d'équipement ? Grandir Sans Ecole 2 (2/1998), p 13-14
**Haesen S** (1998): Etude autrichienne en faveur des enfants déscolarisés. Grandir Sans Ecole 1 (1/1998), p 5
**Haesen S** (1998): Homeschooling in France. Growing Without Schooling 120 (Jan./Feb. 1998), p 4
**Haesen S** (1993): Sharing the Work, Dividing the Responsibility. Editorial Inter.act (Feb. 1993), p 3