

# **Equality Within Medical Care**

## ***Discrimination of Elderly With Covid-19 in Residential Homes***

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This chapter investigates whether discrimination in the provision of medical care to older people with Covid-19 occurred during the spring of 2020 by the Swedish public authorities. The responsibility for medical care in Sweden exists at different regional levels. The counties are responsible for organising care in a manner that guarantees that all county residents have access to good health care. The municipalities are responsible for the care of the elderly, as well as for support and services for those who have been discharged from hospitals. In addition, the municipalities have an overall medical and social responsibility. The municipality's medical responsibility applies with respect to nurses and as discussed below, the key persons in medical care are the nurses. Doctors, on the other hand, remain the responsibility of the counties.

Deciding what constitutes good medical care is difficult in the absence of publicly-available decisions by courts or other decision-making bodies in individual cases on whether the patient “does/does not have a right” to good medical care. The issue of whether a legal right to medical care exists has an impact on the problem as to the possible discrimination of elderly, as investigated further in this chapter.

Prioritisation with respect to medical care is of the greatest significance for ageing patients and plays an important role in this context. How does prioritisation within medical care work? This is analysed further below, entailing an examination of ethical principles on human dignity, need/solidarity and economic efficacy. Human dignity is superior as a norm to these other factors, and the need/solidarity principle is superior to economic efficacy. These principles constitute the Swedish medical care prioritisation regime, which has been in place since 1997 as established through statutory regulations and governs all medical care. The National Board of Health and Welfare issued a 2020 agency guidelines supplement to the statutory 1997 prioritisation scheme, “National Principles on Prioritisation Within Intensive Care Under Extraordinary Circumstances.” The question can be raised as to whether these 2020 agency guidelines are consistent with the statutory 1997 medical care prioritisation scheme.

Individual medical assessments of elderly persons in residential homes were rarely made during the first pandemic wave during the spring of 2020, with the result that these older persons never became patients from a legal point of view. This is a genuine inequality, as older persons were then not offered regular medical care, even if they needed it. On the other hand, if palliative care is most appropriate, this is to be given in a way so as to comply with patient wishes and be as sufficient as possible. As we shall see, palliative care was not always given in this manner in residential homes during the spring of 2020.

Instead, access to medical care of the elderly in the wake of the pandemic can be seen as characterised by a lack of equality. What are the reasons for this? Were elderly persons set aside? The first question to answer is whether elderly patients have a right to receive individual assessments as to care needs. The second question is whether the decision-making about palliative care was made in accordance with laws and regulations, and whether the care provider had fulfilled its obligation to document such decision-making. Does “usefulness” in the sense of remaining life expectancy have a higher priority than solidarity with those who have the greatest need of medical care?

To complicate things further, it seems many elderly patients do not always receive good health care in their final days. Medical care has to comply with the law, with the prioritisation rules and be equal. However, it seems medical care during the first phase of the Covid-19 pandemic was often not in concordance with the law, and was thus not ethical, as discussed below.

## **1 The Swedish Population Group of the Elderly**

The large number of people born in the 1940s will all turn 80 in the 2020s. This means they will be entering an age where the need for medical care increases greatly. This in turn places special requirements on housing, and the demand for housing that can accommodate the needs of the elderly will likely increase. Life expectancy has increased significantly, and consequently also the proportion of older people. Every fifth resident in Sweden is now 65 years old or older (2020). However, the proportion of older people varies greatly between municipalities. There are municipalities where over 30% of the population is over the age of 65. These municipalities are often small, and have had a net emigration of people of working age for many years. From 2020, the number of citizens over the age of 80 will also increase. According to the population projection made by Statistics Sweden in April 2019, the number of inhabitants over the age of 80 will increase by more than 50% between 2019 and 2030. This equals an increase of more than 270,000 people, 130,000 of whom will be over 85.

A reform was introduced in Sweden in 1992, where the responsibility for medical care for elderly and disabled people in designated housing was taken over by the municipalities from the county councils. Approximately 40,000 care homes and 55,000 medical staff who were previously employed by the county councils, were taken over by the municipalities. Special housing for the elderly was created, where the individual's right to their own housing was emphasized. The municipalities were given an overall medical and social responsibility. Regarding medical staff, the municipalities were responsible for nurses, with nurses becoming the key persons responsible for medical care. Doctors, on the other hand, remained the responsibility of the counties.

This has resulted in nurses having to be available around the clock, and that the elderly's need for care must be met by nurses with doctors as intermittent advisors. In connection with the reform, roughly half of the municipalities took over the responsibility for at-home medical care for inhabitants in ordinary housing. Thereafter, this responsibility has gradually been transferred to more and more municipalities.

## **2 Legislation in the Medical Care Field**

Medical care is regulated in the Health Care Act (2017: 30) (HSL), with additional legislation in a number of areas, which together with the National Board of Health and Welfare agency regulations, govern these activities. The State is responsible for overall health and medical care policy and, via the National Board of Health and Welfare, for authority standardisation of all health and medical care in the country. Since 2013, the supervising authority, the Health

and Social Care Inspectorate (IVO), is responsible for complaints and care injury cases.

The Swedish counties are responsible for organising care in such a way that all residents in the county have access to good care. As mentioned, the municipalities are responsible for the care of the elderly, as well as for support and services for those who have been discharged from the hospital. The municipalities are also responsible for housing, employment and support of those with mental disabilities. Municipal health care is the focus in this chapter.

Municipal health care is regulated not just in HSL, but also in several other laws, such as the Patient Safety Act (2010: 659) (PSL), and the Patient Act (2014: 821) (PL). The HSL, however, is most central in this context. This law applies to all care providers and municipalities as responsible authorities. The municipality that is responsible for offering health and medical care is referred to here as the “responsible authority”. Even if a municipality has agreed to use a third-party care provider, the municipality still has a responsibility to ensure that this care is of good quality. This can be done, for example, by introducing clauses stating the relevant requirements in contracts with third parties. However, the responsible authority does not have power over the care provider’s daily activities, nor can it relieve the care provider of the responsibility that comes with that role.

In many aspects, the legal regulations in medical care as well their interpretive instances differ from the legal regulations in other social areas. The legislation on social services is interpreted by municipal boards and administrative courts, where the legal terms are carefully and rather technically applied. Such decisions and court judgments are available to the public online and in print. This type of legal application contributes to providing the law with clarity. The application becomes normative. The legal application and formation of precedents, with decisions from the highest instance, makes up a central source of law along with legal text and preparatory works. However, this system of legal interpretation is not invoked in the field of medical care. Whereas there is a legal requirement for good quality in social services, specified by an abundance of legal decisions and practices, the same is not true for medical care. The question then becomes, how can one determine what constitutes good medical care in the absence of decisions by courts and other decision-making bodies in individual cases on whether a patient has a right to good medical care.

Certain “complements” to the medical care statutory regulations exist, but these are not legally-binding. Examples include government standardisations in the shape of guidelines, general advice, and comprehensive reviews published by the Swedish Board of Health and Welfare. Verdicts from IVO constitute another type of “complement”. A number of those decisions are analysed here for the purpose of investigating how standardisation develops. Many complaints are about illnesses and injuries such as falls, pressure ulcers, malnutrition, fractures and poor oral hygiene. The question is whether it is possible to determine where the limit is for “good care”. The text of the law does not provide any guidance, but other tools may be used, such as IVO’s interpretations and decisions.

### 3 Patient Rights to Medical Care

Central principles as to medical care are stipulated in Chapter 3, paragraph 1, section 2 of the HSL. The standard goal for medical care is good health and health care on *equal* terms for the entire population. Care must be given with respect for the *equal* value of all human beings and for the dignity of the individual human being. Those who have the greatest need for health and medical care must be given priority.

The National Board of Health and Welfare has issued a non-binding publication, “National Indicators for Good Care.” In this, the authority refers to the handbook “Good Care - On Management Systems for Quality and Patient Safety in Health Care”, and identifies six areas that are crucial for the supply of good care: *knowledge-based* and *expedient* medical care, *safe* medical care, *patient-oriented* medical care, *effective* medical care, *equal* medical care, and the supply of medical care within a reasonable time frame.

Whether someone has the right to become a patient is not explicitly addressed in the legislation. This, together with the fact that patients are not able to appeal individual decisions concerning care, i.e., there is no formal avenue for an appeal, means that there is no legal right to become a patient (see more about the possibilities to become a patient below in section 8). An individual cannot claim access to medical care services, and it is only in special situations where it can be determined whether any error has been committed. The right to become a patient can be perceived as a “quasi-right”, meaning that the individual is given the opportunity to compete for scarce resources, even though there are no legally-binding requirements. However, the obligations of care providers and care staff have become increasingly clear in recent decades. That which cannot be claimed by patients as rights is regulated instead as an obligation for the care provider. This has meant that the patient has been “made visible” as an individual and not simply as a care recipient. This “patient visibility” in the Health Care Act has led to a more general discussion about patient rights. However, patient rights are not to be confused with legal rights (see more about patient rights as patients below in section 8).

### 4 The Statutory 1997 Medical Care Prioritisation Scheme

The wording in both the HSL and the Patient Act states that care must be provided on equal terms and that those with the greatest need must first receive care in accordance with the priority as to medical care adopted by the Parliament in 1997. Care is dependent on the availability of care resources. The smaller the supply, the more difficult it is to receive care. The scarcity of care resources, or more generally-speaking, the lack of economic resources, could be an explanation as to why patients do not have a legal right to receive medical care, and consequently cannot appeal such decisions to court.

The prioritisation scheme as to medical care includes the ethical principles of human dignity as well as need/solidarity and the principle of economic efficiency. All individuals have a human value because they are human and not because of what they own or what they do. All people have the same right to receive care regardless of age, ethnicity, talent, social status, income or any other factors. The prioritisation scheme primarily states factors which those

responsible for health care should not take into account when making decisions regarding the allocation of resources or care and treatments. Age in itself should not matter from this prioritisation point of view. It is the overall assessment of the patient's needs and how the patient can benefit from the care that is to determine the measures of care. The need/solidarity principle prescribes that care resources must be invested in those patients who have the greatest need. Who these patients are is assessed on the basis of the severity and duration of the medical condition, and what potential health improvement a certain care intervention can entail. According to this principle, special attention must be paid to the needs of vulnerable groups and persons who have difficulties making their voices heard or lacking agency.

Prioritisation within medical care is of the greatest importance for ageing patients. In what order should different patients be prioritised? As mentioned above, the prioritisation scheme contains ethical principles on human dignity, on need and solidarity and on economic efficiency. The principle of human dignity is superior to the others and the need/solidarity principle is superior to economic efficiency. These principles have governed prioritisation of medical care in Sweden since 1997.

The analysis here is based on the assumption of equal rights. All people have the same human rights and deserve to have these rights respected. All people deserve to be treated with dignity regardless of age, sex, religion, ethnic origins, sexual orientation, gender identity, disability, social function, political opinions and economic situation. In other words, this is an anti-discrimination principle, as it states what is not allowed. Patients must not be discriminated against because of their chronological age. The need for health care, and the risk of complications can vary with age and gender, but it is the need for health care that should determine the treatment, rather than gender or chronological age. Thus, age as such is not important from a prioritisation point of view, instead it is the overall appreciation of the patient's needs and possible benefits from the intended care that should decide which action to take.

The need/solidarity principle states that care resources should be given to patients with the greatest need. The degree of need is determined by the seriousness and duration of the health condition and by the recovery potential of the intended care. The principle states the importance of paying extra attention to the needs of more vulnerable groups in society and groups that have difficulties making their voices heard. To be able to decide who will receive care, something more than simply the principle of human dignity is needed. The medical care prioritisation legislative inquiry stated that "the resources should be distributed where the needs are greater".<sup>1</sup> However, statistics have shown that this has not always been the case.<sup>2</sup> Instead, the people most in need of care have in some cases not received any. Despite the prioritisation investigation, utility has been the dominating basis for decision-making.

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<sup>1</sup> Swedish Government Official Report, SOU 1995:5, *Vårdens svåra val* [The Difficult Choices of Care] 117.

<sup>2</sup> Survey in 2020 by the Swedish daily newspaper, Svenska Dagbladet, showed that elderly persons sick in Covid-19 did not have intensive care when the situation was at its worst. At the same time, insufficient medical competence aggravated the corona crisis at the residential homes, see Henrik Mellgren and Fredrik Ennart, 'Okända kurvan visar hur äldre prioriteras bort' [Are We Giving Our Older People in Sweden Second Class Care?] SvD, 2020-05-30.

The cost efficiency principle means that health care has a duty to utilise its resources as effectively as possible. Thus, health care has to strive for a reasonable balance between the cost of resources and positive outcomes on health and quality of life. A consequence of the fact that the need/solidarity principle is superior to the cost efficiency principle, is that severe illness and a substantial deterioration of quality of life is to be prioritised over minor complaints, even if the former cost more to treat.

## **5 The National Board of Health and Welfare's 2020 Agency Prioritisation Guidelines**

On 27 March 2020, the National Board of Health and Welfare published "National Principles of Prioritisation Within Intensive Care Under Extraordinary Circumstances", the purpose of which was to supplement through agency guidelines the statutory 1997 prioritisation scheme. The 2020 principles are meant to be used by care providers when the Covid-19 pandemic entailed that the need for intensive care exceeded available resources. The first step is to expand the resources of intensive care as far as possible, but when all possible resources have been put to use, the document is to serve as a guideline for how to distribute the available care resources. These prioritisation rules were applied at elder residential homes (see below) in 2020.<sup>3</sup>

The purpose of the 2020 document was to support medical care when patients with Covid-19 needed increasingly more of the care resources. Within the framework of the Covid-19 pandemic, the concept of biological age was introduced. Chronological age has never been allowed to count as an important prioritising factor due to the principle of all human lives being of equal worth. Shouldn't this also be the case when it comes to biological age? The benefit of a measure is dependent, on one hand, on the patient's need, and on the other hand, on the use of resources in relation to patient benefit.

The patient's benefit from a measure is assessed normally on the basis of life expectancy and quality of life. As it is impossible to assess a patient's future quality of life, the focus lies on longevity. However, if it is impossible to assess another person's quality of life, is it not also impossible to estimate his or her life expectancy? Both assessments are more or less speculative, with predominant value assessments and few factual circumstances. The fact that a speculatively-determined life span should be allowed to determine whether resource use is reasonable or not (the cost-effectiveness principle), seems to be a precarious basis for deciding matters concerning life and death.

A patient with a severe illness or injury with a life expectancy of more than twelve months is to be given the highest priority to intensive care. If further prioritisation is needed within that group, patients with the highest expected remaining life span are to be prioritised. Biological age thus is taken into account. A patient of the highest priority will continue to receive medical

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<sup>3</sup> IVO, as the supervisory agency, initiated an audit of the intensive care units at all emergency hospitals in Region Stockholm, where the cases were applied the following diary numbers: 14720/2020 Karolinska sjukhuset, 17555/2020 Danderyds sjukhus, 17725/2020 Norrtälje sjukhus, 17717/2020 Södertälje sjukhus, 17516/2020 Södersjukhuset och 17535/2020 Capió S:t Görans sjukhus.

intervention until the patient's health has improved. When this happens, the patient's need for care is to be re-evaluated and if there are patients of a higher priority waiting to receive care, the medical intervention will be discontinued. The next group to be prioritised consists of patients with one or several serious medical conditions with noticeable functional limitations, and an expected survival of 6-12 months. The third group to be prioritised consists of patients with a very low chance of survival. In those cases, intensive care is to be used only when a new assessment is relevant and in accordance with the will of those who are next of kin. Patients not eligible for intensive care will be offered other forms of care.

These prioritisation levels contain noticeable clarifications in contrast with the statutory 1997 prioritisation regulation. The clarifications contain differences in type as well as grade. At first, expected remaining lifespan appears to be of a grade character, but in the concept of expected remaining lifespan, there is also a difference in type between the guidelines of the National Board of Health and Welfare and the statutory 1997 prioritisation regulation. Biological age is a measurement that takes chronological age into account, which is puzzling seeing as chronological age has never before been taken into account while making prioritisations about who should receive care.<sup>4</sup> As a matter of fact, taking chronological age into account while prioritizing goes against the human dignity principle. As biological age is a part of the guidelines of the National Board of Health and Welfare, this new type has been added to the prioritisation evaluation, and this type contradicts the statutory 1997 regulation.

## **6 The Role of the Health and Social Care Inspectorate (IVO)**

The twenty-one IVO investigations of the regions mentioned above is analysed below. The IVO judgments are based on the extent to which the actions adhered to laws and other regulations and whether the elderly received good medical care as well as good palliative care. Have elderly patients had the possibility to receive an individual assessment to determine how great their need for care is? Good care should correspond to the level of care that is deemed to be needed based on an individual assessment. The patient should have the opportunity to give informed consent, or the fundamental principle of free will in health care legislation would be violated. Due to the facts that Covid-19 is a new disease with a wide clinical spectrum, that it has a relatively high mortality rate and is classified as a public danger in the Communicable Diseases Act (2004:168), it is of great importance that patients receive individual medical assessments and that positive test results are followed up. A physician's assessment is important as it determines what type of medical care the patient should receive also when it comes to elderly patients in residential homes. Below are some examples of how and to what extent elderly people in residential homes have received medical care in a number of different Swedish regions.

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<sup>4</sup> The Board's 2020 document states that the "patient need" has to be an important parameter when prioritizing. The Board in a footnote states what it means with patient need: "Normally the patient's need of the medical measure is considered from the parameters of life span and life quality. In this situation it is impossible to assess the future life quality of the patient. Thus the prioritisation principles will only have focus on lifespan."



An individual assessment of a patient's health status is fundamental to all medical care and treatment, something that is made very clear in The Patient Act. In an investigation of journals in *Region Skåne*<sup>5</sup>, it emerged that in several cases, patients had not been assessed individually. Doctors had also decided group testing for Covid-19 without following up the test results and without making individual decisions about continued care and treatment. From an interview with the head of a primary health care centre, it could be concluded that patients with less severe symptoms had been tested, but no medical assessments were made in patients with suspected Covid-19. The elderly persons at residential homes with suspected or ascertained Covid-19 were not treated according to their needs. From IVO's investigation of medical journals they found that patients in several cases did not receive any individual assessments of care and treatment when they became sick. Some of the patients who had not received individual assessments only had mild symptoms, but there were also examples of patients whose general condition was greatly impaired and patients who had died without any documentation of a clinical examination or what treatment had been prescribed.

While interviewing medically-responsible nurses in Skåne, information emerged showing that individual assessments were not always made. In one interview, it was described that it was difficult to get a doctor to make assessments of which care-level patients should receive, something that resulted in a nurse sending the patient to the hospital as she lacked the support from a medical assessment and a decision about care and treatment. Information also surfaced about a private health care center that had decided to offer only palliative treatment to the patients. One nurse at a residential care home stated that patients would not receive assessments if there had been previous decisions made which stated that the patients should not be brought to a hospital.

In the *Västra Götaland region*,<sup>6</sup> older persons living in elderly homes also did not receive care and treatment according to their individual needs. During the pandemic, several elderly patients had once again not received individual assessments of their needs for care and treatment, especially at the beginning of the pandemic. This was confirmed by representatives of the Västra Götaland region. There were reportedly some patients in whom the disease developed very quickly, and who passed away before an individual assessment was made. Patients with no severe symptoms did not receive medical assessments. There were also reports of patients in need of medical care who were denied it. From the investigation it was apparent that some nurses felt that they were given a far too great responsibility when it came to making medical assessments.

It can be concluded from the investigation of the Västra Götaland region that the lack of individual assessments could have resulted in the patient not receiving prescribed treatment, or that the treatment administered did not necessarily fit the needs of the patient, or that an infection that developed quickly became fatal before any treatment could be prescribed. The responsibility of nurses has become much heavier as a consequence of the lack of physician-led individual assessments.

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<sup>5</sup> Dnr 3.5.1-21332/2020-47.

<sup>6</sup> Dnr 3.5.1-21793/2020-141.

In the *Region Jämtland*,<sup>7</sup> IVO also found that older people living in residential homes did not receive care and treatment according to the needs of the elderly persons suffering from suspected or ascertained Covid-19. Each patient's needs for care and treatment had not been examined individually by physicians. There was a general guideline stating that patients living in elderly homes should not be offered care at a hospital when suffering from suspected or ascertained Covid-19. There was also a routine that all patients with Covid-19 in elderly homes should stay and be treated in the residential homes. Representatives of the Region Jämtland have said that the region published a statement in March 2020 that people living in residential homes should almost always be treated in these residences if they got Covid-19, and should not be taken to a hospital. Later the statement was revised to that an individual assessment of required care-level should be carried out. It was said that the patients almost always received the best help at the residential homes. However, the investigation of patient journals showed that physicians in several cases had not assessed the patient's needs for care and treatment despite suspicion of Covid-19.

In *Region Jönköpings län*,<sup>8</sup> IVO found that at the beginning of the pandemic older persons living in residential homes had not received any care or treatment based on the individual's own needs of suspected or determined Covid-19. There were general guidelines stating that patients living in care homes should not be sent to hospitals for intensive care or CPR, something that was also evident in interviews with medically-responsible nurses and doctors. A medically-responsible nurse raised at an early stage the issue of care-level and the answer she received was that no patients should be sent to hospital, but this was later changed. In interviews with nurses it emerged that they had a very great responsibility in the individual assessments.

IVO's journal investigation of *Region Västernorrland*<sup>9</sup> revealed that several patients in different elderly homes had not received individual assessments by physicians. In the medical records, it emerged that the patients had received positive test results for Covid-19 and that, if the patients' health deteriorated, they should not receive intensive care or CPR. It was unclear what lay behind these decisions.

Decisions in *Region Västerbotten*<sup>10</sup> about care and treatment for several patients had only been preceded by a notification about estimation of fragility.<sup>11</sup> IVO considered that an estimation of fragility should be followed by an individual assessment of the patient's care and treatment. Patients who had previously been assessed and considered to be in a palliative phase did not receive a new assessment when falling ill with Covid-19. If one to three persons at a ward had positive Covid tests, the ward was considered to be contaminated,

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<sup>7</sup> Dnr 3.5.1-21317/2020-29.

<sup>8</sup> Dnr 3.5.1-21477/2020-25.

<sup>9</sup> Dnr 3.5.1-21310/2020-24.

<sup>10</sup> Dnr 3.5.1-21311/2020-19.

<sup>11</sup> Fragility assessments have been particularly important as a contribution in identifying chronologically-aged patients as not being fragile, in Tommy Cederholm, Anne W. Ekdahl et al., *Dagens Medicin* [Medicine of Today] 2020-05-13. See also Laura Fratiglioni et al., 'Behind Chronological Age – Risk Profiles, Fragility and Multi Diseases, Forte Fokus at the Aging Research Center, KI.

which meant that no more tests were made on patients with symptoms. The same guideline was used in *Region Östergötland*.<sup>12</sup>

In conclusion, it is quite clear from IVO's investigations that many elderly patients did not receive good health care during their last days of life. This was the case despite the fact that the medical care of a sick person must be carried out in a way that is both according to the rule of law, according to the prioritisation rules, and the principle of human equality. In several cases, the care was neither materially or legally sufficient, and hence not ethically good as discussed further below.

## **7 The Legal Right to be a Patient**

This review of IVO's twenty-one judgments concerning the twenty-one regions demonstrates that elderly people many times had difficulties even getting patient status, let alone care. It is difficult to determine when an older person goes from just being someone who receives social care to becoming a patient. The most natural way to gain patient status is to receive an individual assessment by a physician. Persons sick with Covid-19 who actively sought medical assistance seem almost without any exceptions to have been subject to an individual assessment and have hence become patients. But IVO's investigation of residential homes shows that older persons sick with Covid-19 and residing at these homes, did not receive individual assessments and hence have not been dealt with as patients. The lack of individual assessment has resulted in the older patients not getting the care and treatment they ought to have according to the Medical Care Act which resulted in unnecessary suffering and death.

General treatment limitations for the elderly and guidelines stating that hospital care should not be given to elderly people in residential homes are a flagrant departure from care provider legislation. Treatment limitations implying that only palliative care should be offered to the elderly indicates that life-supporting health care is not in accordance with the patients' needs. The use of the word "limitation" indicates this.

In the beginning of the pandemic, some regions presented guidelines stating that if only a few patients in a ward at a residential home tested positive for Covid-19, the ward was to be considered to be contaminated, and no more tests were to be taken, even if patients had symptoms, meaning that these persons did not achieve patient status. At the beginning of the pandemic, but before the infection had started to spread to residential homes, several regions had begun to plan and decide about which patients could be expected to survive intensive care. Some older patients have had greatly impaired general conditions or have deceased without it being apparent from the journal documentation that an individual assessment had been made or that the patients had been prescribed treatment. It was also clear that decisions about possible future care and treatment of several patients had only been preceded by an estimation of fragility. As mentioned before, IVO considers that an estimation of fragility ought to be based on an individual assessment.

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<sup>12</sup> Dnr 3.5.1-21479/2020-27.

In conclusion, individual medical assessments of older people in elderly homes were seldom made during the first pandemic wave of 2020 which resulted in the elderly people never becoming patients from a medical legal point of view.

## **8 Legal Rights as Patients**

Elderly people in residential homes who were infected with Covid-19 were not always left without medical care, but instead of receiving intensive care, the patient would at times only receive palliative care. A decision about palliative care leads to the older person achieving patient status. Health care centers have sometimes announced treatment limitations which state that only palliative care should be considered, thus significantly limiting the kind of care available to the elderly.

The sequence of events could vary. If an individual assessment was made, resulting in a decision about palliative care, such an evaluation is to be made by a medical doctor plus another person with a medical license, such as a nurse. This legal requirement was often not fulfilled. That doctors did not participate in these decisions occurred on numerous occasions in residential homes. Doctors rarely made physical assessments of patients, despite nurses requesting such assessments. The care that the elderly received, if they received any, was palliative; not life supporting treatment, just caring. No hospital treatment and hence no intensive care was offered.

All medical care should be performed with the individual's consent according to the law, as mentioned above. An elderly patient has to give their informed consent to the care and it is the care personnel's duty to make sure that consent is given. But journals showed that in many cases, documentation of the older person's consent was lacking. In the cases where the older person received palliative care, no consent was documented. There was no documentation of related parties being informed either and the individual's participation was lacking. Decisions were made without first consulting the older person. According to IVO, the medical records should have stated why Covid-19 care should be carried out in the residential homes. It appears such individual assessments had not been performed.

As mentioned above, some elderly persons at residential homes did not receive any treatment based on an individual assessment. Even if the elderly person has attained patient status, this is of no help if the quality of the care is poor, or if no care at all is provided. Physicians in several cases did not make individual assessments of the needed care level. In other cases the physician ordinated testing without following up the test results or making a new decision about continued care and treatment. To conclude, older persons living in residential homes did not have access to good medical care based on each individual's own need when sick with Covid-19.

Palliative care becomes relevant upon a determination that it would be futile to continue with life-sustaining treatment. However, palliative care is not to be a replacement for life-sustaining treatment where there is a lack of intensive care equipment or hospital beds. This does not mean that palliative care in general is unsatisfactory health care; on the contrary, if palliative care is thought to be the most adequate form of care based on an individual assessment, then it is perfectly suitable, and the quality of the palliative care should be of utmost importance.

However, the palliative was sadly not of the best quality for the elderly in residential homes during the spring 2020. There is a significant inequality when elderly persons are not offered regular medical care or satisfactory care when they are in need of such.

Unfortunately, the care provided for the elderly has been signified by qualitative deficiencies. What has been the reason for this decisional-basis? Were the elderly purposefully not prioritised? Below is a review of the recommendations from the National Board of Health and Welfare concerning prioritisations during extraordinary relationships prevailing during the first wave of the corona pandemic in March to June 2020. With the help of these recommendations, I shall attempt to answer these questions.

## **9 The Evaluation of IVO's Audit**

The Inspectorate of Care and Support, IVO, examined the twenty-one regions in Sweden responsible for medical care and treatment, with the aim of determining whether the elderly living in residential care received care and treatment based on their individual needs in cases of suspected or established Covid-19. IVO, being ultimately responsible for medical care according to section III of the Medical Care Act (2017: 30), HSL, examined the regions' work during the Covid-19 pandemic at an overall level. IVO found that there were serious shortcomings in the regions with regards to medical care and treatment of persons in residential care, and concluded that none of the regions had taken full responsibility for ensuring individually-tailored care and treatment.

IVO initiated this audit after information had emerged that elderly people in residential care who contracted Covid-19 did not receive good care and treatment. Interviews were conducted with the medical care directors or equivalent in all regions, as well as the medically-responsible nurses in all Swedish municipalities. The first question that IVO asked was whether the individual patient's right to receive individual assessment of his or her need for care had been met. The second question focused on whether the decision-making about palliative care was made in accordance with laws and given regulations, and whether the care provider had fulfilled its obligation documenting such decision-making.

These two questions are very closely related to one another. Good palliative care must correspond to the level of care that the individual needs, and must be prescribed after individual assessment. The patient must be given the opportunity to give informed consent, as otherwise, the basic principle of voluntariness in health care legislation would be violated. As mentioned before, IVO has emphasized that, in light of the fact that Covid-19 is a new disease with very varying clinical manifestations, high mortality rates in older age groups and is classified as dangerous to public health and society according to the Communicable Diseases Act (2004:168), it is of particular importance that the patient receives an individual medical assessment, and that positive test results are followed up. The assessment made by doctors is also of importance as a means of support for other health care staff and as a basis for the continued treatment of the elderly in residential care.

The predominant number of regions had fallen short in terms of formal compliance with how palliative care should be provided and how end of life

communication should be conducted. The review of the twenty-one decisions concerning the twenty-one regions shows that elderly persons often had difficulty obtaining patient status. It also proved difficult to determine when the individual went from being a care recipient to becoming a patient. It is natural to assume that an individual assessment by a doctor is needed in order to obtain patient status. People with Covid-19 who have actively sought medical care have most likely, almost without exception, been individually assessed and thus gained patient status. However, IVO's examination shows that elderly in residential care who fell ill with Covid-19 were often not given an individual assessment, and had thus not gained patient status. This is contrary to both the principle of legal certainty about predictability and controllability and the principle of justice regarding everybody's right to equal care. These two principles, in turn, originate in the principle of the equal value of all humans.

At the beginning of the pandemic, the regions issued guidelines stating that when one to three patients in residential care tested positive for Covid-19, the ward should be considered contaminated and no further testing should be performed on patients with symptoms, something that resulted in these patients not actually receiving patient status. At the beginning of the pandemic, before the elderly started to become ill with Covid-19, several regions made general decisions about which patients should be subject to intensive care in hospitals. Some patients in residential care obviously suffered from an impaired general condition or even died, without it being apparent in the medical charts that an individual assessment had been made by a doctor, or if any treatments were prescribed. It also emerged that decisions about care and treatment had only been preceded by a note about the estimation of fragility.

## **10 Reasons Underlying the Inequality in Covid-19 Care**

Adhering to the rule of law is considered to be one of the most important cornerstones in the relation between society and the individual. Within medical care, the legislation mandates care providers and the care personnel making decisions in formally correct ways, resulting in reasonable possibilities of predictability and controllability for the patient. The law contains even to what extent these decisions are materially correct in the sense that they are in accordance with central ethical principles concerning distribution of benefits and usefulness. The requirements of care on equal conditions are based on the constitutional equality principle as espoused in chapter 1, section 2 of the constitutional act, the Instrument of Government, regarding social rights meaning that all individuals will be treated equally. This does not mean that every person must receive exactly the same care and treatment. Instead, those with the same needs for the same care should receive the same treatment. The care provider has a duty to satisfy everyone's needs in a manner based on science and proven experience.

The 2020 document of the National Board of Health and Welfare has been characterized as an implementation specification of the statutory 1997 prioritisation regulation. The content of the Board's agency prioritisation regulation should act as a specification of the prioritisation rule where the bottom line is that those with the greatest need for care shall receive care first. If the specifications are considered to be of grade character, the Board's rules can be

seen as implementation agency regulations which do not nor should not add new content to the current laws, nor restrict them.

However, if the 2020 agency specifications are of a different type, they are adding new content to the statutory regulation. In the statutory 1997 prioritisation regulation, chronological age was never allowed to be a factor in deciding who receives care due to the principle of human dignity. Chronological age is never mentioned explicitly in the Board's document but on the other hand biological age in the context of "expected remaining life span" is used. Here is a type difference between the Board's agency document and the statutory 1997 regulation. There is a great component of chronological age in the concept of biological age even though chronological age is not a criteria of interest in the statutory prioritisation regulation.<sup>13</sup> In the Board's document, biological age is a factor of importance regarding decisions about who will receive care. In this way, a new component, which is in conflict with the statutory regulation, has been introduced in the medical care prioritisation scheme. Hence, the Board's document cannot be considered a pure implementation regulation, and technically is not to change the content of the statutory 1997 prioritisation regulation. But in fact, the content of the statutory law can be seen as changed, however, not through another law, but through a non-binding agency regulation.

To introduce the concept of biological age within the framework of the Covid pandemic is dubious. As stated, chronological age has never been permitted to have importance when prioritising due to the principle of human dignity. Should this not be the case for biological age as well? Normally the patient's need for care is assessed by the parameters of life span and life quality. The Board has very clearly stated in its document that it is impossible to assess the future life quality of the patient, which is why the prioritisation principles, according to the Board, should only focus on life span. But if quality of life is not possible to assess, why is this not the same for the expected remaining life span of a patient? Both assessments are more or less speculative with their basis lying predominantly in subjective valuations and they are seldom anchored in reality. Letting a speculatively-decided life span decide the reasonableness of how to use the resources according to the cost efficiency principle, seems to be a precarious foundation for deciding questions of life and death.

But what do both prioritisation regulations look like more concretely? Providing care first to the person with the greatest need according to the statutory 1997 prioritisation regulation means that:

the resources will be used on fields (activities or individuals), where the needs are greatest;

the need of the weakest will be considered;

the resources of the medical care will be given to those with the greatest need, to those with the most severe illnesses and the lowest life quality; and that

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<sup>13</sup> See also Mikael Sandlund, "Comments to the Board's National Principles Concerning Prioritisation in Intensive Care" in *The Swedish Society of Physicians*, 2020-03-27.

one should never refrain from giving medical care for financial reasons or reduce the quality of care for dying patients, persons with severe or prolonged illness, elderly, demented, developmentally disabled and other badly disabled people.

Some examples of care categories in residential homes are palliative care, advanced home medical care, dementia care, care for chronic psychotic illness and other chronic diseases such as diabetes, chronic obstructive pulmonary disease, asthma, chronic heart failure, vascular diseases such as arterial leg ulcers, malignant diseases, rheumatoid arthritis and neurological diseases as stroke with more. These diseases belong to group 1 in the statutory 1997 prioritisation regulation.

On the other hand, we have the Board's 2020 document which states that patients with an expected life span of more than 12 months should be given the highest priority for intensive care (group 1). After group 1, the next group to be prioritised for intensive care is those who have one or several severe systemic diseases with noticeable functional limitation and/or an expected remaining life span of 6-12 months (group 2), and the last group to be prioritised is patients with a very low chance of survival from the beginning (group 3). The Board's document constitutes an ethical platform that seems to be the opposite of the 1997 ethical platform created by the Parliament's statutory regulations. Both groups 2 and 3 in the Board's document belong to group 1 in statutory 1997 prioritisation regulation.

This almost total reversal of the prioritisation groups appears neither legally nor ethically defensible.<sup>14</sup> Usefulness in the meaning of expected increased life span has been considered as having a higher priority than solidarity with those who have the greatest need. In the Board's opinion, the humanistic approach no longer matters in the same way as previously. Instead, it has been replaced by a significantly utilitarian approach where those with the greatest chances of survival will be given care.

This utilitarian approach is quite different to the approach of the still valid medical care prioritisation regulation from 1997. Implementing such a drastic change to the prioritisation rules without first handling them according to the usual legislative procedure is not in any way correct. This goes against the legal certainty principles of predictability and controllability and thus against the rule of law principle. It is quite clear that a pandemic like Covid-19 will demand changes of the medical care prioritisation system where there is, for example, a great lack of respirators, intensive care beds and personnel, but the changes cannot be allowed to be rushed. Such changes need to be handled according to the correct procedures according to the rule of law, according to the legislation of Parliament, and according to our concept of democracy.

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<sup>14</sup> Such a definition violates the principle of all human beings' equal value and also violates the principle of need, see Ingemar Engström, Göran Hermerén, Nils-Eric Sahlin and Barbro Westerholm, "Principles of Prioritisations of Intensive Care are Questioned" in *Läkartidningen* [The Physician's Newspaper] 2020-03-31.