Coping Ageing Population and Long Term Care in European Countries: Ethical Considerations on Justice in Health Care With Regard to Digitalisation, Health Care Policies and Resource Management

Cómo hacer frente a la población envejecida y asistencia de larga duración en los países europeos: Consideraciones éticas con respecto a la política sanitaria y la digitalización

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Abstract: Studies forecast the growth of the older population of the European Union (EU) as well as an associated increase in the need for healthcare. All EU member states share comparable challenges. Resources and coping strategies differ widely within the European Union. Strategies of the Netherlands (high spending power, decentralized long-term care) and Estonia (low spending power, digitalization, separated framework for healthcare and social care) will be exemplified for ethical considerations on justice in healthcare as well as pointing out ideas for shaping the future of elderly people's care. This article emphasizes that, particularly in the field of long-term care, need-oriented and patient-oriented integration of health and social systems at a governmental level is a necessary prerequisite for an equitable distribution of resources.

Keywords: ageing population, healthcare, long-term care, justice

Resumen: Se está pronosticando una proporción creciente de la población de la tercera edad para la Unión Europea (UE), y también un incremento asociado con la necesidad de atención (sanitaria). Los Estados miembros de la UE están enfrentando desafíos comparables. Sin embargo, los recursos y las estrategias difieren ampliamente en la Unión Europea. Las estrategias de los Países Bajos (alto poder adquisitivo, descentralización de la asistencia de larga duración) y Estonia (escaso poder adquisitivo, digitalización, un esquema separado para la atención sanitaria y social) se ilustrarán de la manera ejemplar para consideraciones éticas sobre la justicia en la atención (sanitaria) y para señalar ideas para el futuro. El artículo destaca que, en particular en el ámbito de la asistencia de larga duración, la integración de la salud y el sistema social a nivel gubernamental orientada a las necesidades y al paciente es un requisito necesario para una distribución equitativa de los recursos.

Palabras clave: envejecimiento de la población, atención (sanitaria), justicia

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1. Introduction

While the share of the population aged 65 years and older was 19.4% (including 5.4% aged older than 80 years) in the European Union (EU) in 2015, the forecasts predict a rise to 28.8% in 2070 which includes a share of 12.5% aged older than 80 years (European Commission, 2018, 23). This takes into account an average life expectancy at birth in the EU of 83.7 years for women and of 78.3 years for men (European Commission, 2018, 369) and a healthy life expectancy of 63.3 years for women and of 62.6 years for men in the EU (European Commission, 2019, 202). As shown in the 2018 Ageing Report, it is assumed that life expectancy for both sexes will increase by around another five years by 2050 (European Commission, 2018, 369).

A larger proportion of older people in the general populous is likely to lead to an increasing proportion of people with multimorbidity and an increase in diseases with a

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high prevalence in old age, such as dementia, osteoarthritis, cataract, and others. This will result in challenges for public health design, which in turn will have consequences for healthcare, including but not limited to an increasing need for (in)formal care capacities and rising costs due to an increase in complex medical treatments. It is estimated that expenditure on long-term care in the EU will increase by at least 1% from a current average of 1.6% of the gross domestic product (GDP) by 2050 (European Commission, 2018, 145). A similar increase of GDP is forecast for public spending on healthcare. Depending on the forecast scenario, a possible increase in the cost of public healthcare expenditure between 0.1% of GDP (healthy ageing scenario) and 2.5% of GDP (non-demographic determinants scenario) is assumed by 2070. (European Commission, 2018, 122; 125; 145). In addition to the predicted increase in the demand for care services, the lack of availability of informal care is also likely to exacerbate the situation. The reasons for a decline in informal care resources are not only the age structure itself due to an increasing old-age dependency ratio from about 30% in 2016 to about 50% in 2070 (European Commission, 2018, 24), but also societal changes like an increase in the number of women in the labour market, higher retirement age and more single households (Spasova et al., 2018, 4).

To sum up, it can be said that in the EU, cross-border forecasts assume an increasing ageing population and a growing need for long-term care. It is therefore conceivable that there will be an increase in the cost of long-term care and that the number of people in employment who will be paying into the statutory health insurance scheme will be lower in percentage terms due to the rising old-age dependency ratio. This results in all EU countries having to deal with the challenge of fair resource management. Every EU state is faced with their obligation to create the conditions for an equal and highest attainable standard of health taking into account their resources (Universal Declaration of Human Rights Art. 25, European Social Charter Art. 11, International Convenant on Economic, Social and Cultural Rights Art. 12, UN Committee on Economic, Social and Cultural Rights General Comment No. 14[1]). Through principle 16 of the European Pillar of Social Rights in 20 principles the states have committed themselves to curative and preventive medical care. In addition, they have committed themselves to long-term care through principle 18 which was formulated under the following wording: *„Everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services"*[2].

Of course, it is difficult to compare EU countries or aspects of their healthcare because they differ in their preconditions such as political design, legislation, resources and cultural values of a society. Also, in addition to divergent historical political developments, the healthcare systems in the EU countries are designed differently. Based on data provided by the Organization for Economic Co-operation and Development (OECD), EU health systems differ absolutely and relatively regarding the financial resources that are provided for healthcare. The expenses per capita range between €895 (Latvia, 2018) and €4,890 (Sweden, 2018, equivalent to SEK 52,249) and the share of health expenditure relative to the GDP ranges between 5.4% (Luxembourg, 2018) and 11.2% (Germany and France, 2018)[3].

Moreover, the financing of long-term care varies extremely between EU countries. In most cases, the care service consists of health-related care (e.g. nursing care) and social care services (e.g. support for activities in daily life) and is therefore often financed by both, the health system and the social security systems. On average, 1.6% of the GDP was spent on

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care services in 2016 (European Commission, 2019, 348; Spasova et al., 2018, 35). Depending on the availability, performance and cost efficiency of the insurance systems for long-term care and presumed access and availability of care providers or residential care capacity the out-of-pocket payments vary (Bucher-Koenen et al., 2015; Spasova et al., 2018, 20).

Besides explicit socio-political regulation, there are current and upcoming developments in the field of digitalization of the healthcare system which also have the potential to address the current challenges. For example, extensive information on (multimorbid elderly) patients can be shared more easily between healthcare settings (e.g. primary vs. secondary care) and thus lead to greater patient safety. Developments in Ambient Assisted Living[4] could help to support self-determined living with age-related limitations. According to the World Health Organization (WHO), information and communications technology (ICT) and eHealth are an important part of the healthcare systems' shift towards an older-person-centred approach (WHO, 2015, 103) inter alia to make health services and information accessible from any location or to facilitate self-management and prevent loneliness by linking to community services (WHO, 2015, 109).

Despite the different political and social circumstances and the resulting different healthcare and social care systems, there are similar challenges in the regulation of healthcare. For the ethical considerations on the justice of healthcare for the elderly and the handling of the increasing need for long-term care, the following will therefore present the coping strategies of two EU countries in an exemplary manner. The first example, the Netherlands, which have a long-standing history of health and social care, have recently introduced comprehensive reforms to decentralize long-term care to a municipality centred approach. The financial resources of the Netherlands are above the EU average, especially in the care sector. The Netherlands take a middle position compared to other EU countries regarding digitalization in healthcare (Thiel et al., 2018, 225). Estonia, which has comparatively low resources among the EU countries, is nevertheless considered a pioneer of digitalization in the healthcare system, will serve as the second example.

2. Coping with Ageing Population and Long-Term Care in European Countries

One key European trend for the future shape of long-term care, namely the readjustment of long-term care through decreasing residential care and promoting home care and community care, is to be highlighted using the example of the Long-term Care Act *Wet Langdurige Zorg (Wlz)* of the Netherlands that came into force in 2015 (Spasova et al., 2018, 8-9;37). Before focusing on this reform, an overview of the characteristics of the healthcare system in the Netherlands will be outlined.

2.1 Netherlands: Coping with the increasing need for long-term care through decentralization and self-reliance

Of the 17.2 million inhabitants living in the Netherlands a share of 99.9%[5] are insured. Average life expectancy is 81.8 years (OECD, 2019a). For people with low socioeconomic status, life expectancy is 4.6 years lower for women and 5.8 years lower for men compared to people with high socioeconomic status. Prior to 2006, the Netherlands had a dual insurance

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system. Residents were either covered by statutory or by private insurance. Since the major health reform in 2006, there has been a uniform compulsory insurance system with 99.9% coverage (Kroneman et al., 2016, 16). Nowadays 84.1% of the population additionally make use of a complementary voluntary health insurance (VHI) (WHO, 2016, 101). In general, out-of-pocket payments for healthcare expenditure in the Netherlands (11.1%) are below the EU average (15.8%) (OECD, 2019a). Per capita health expenditure in 2017 was €3,791 whereas the EU average was €2,884 (OECD, 2019a). While a 10.1% spending in the healthcare system relative to the GDP was only slightly above the EU average of 9.8%, spending on long-term care (including social long-term care and health-related long-term care) amounted to 3.5% of the GDP, which is a large difference in comparison to the EU average of 1.6% in 2016 (European Commission, 2019, 429). In addition to the health insurance contribution, since 2008 co-payments have had to be made when utilizing health services. These co-payments are capped at €365 per year until 2021. Excluded from this are general practitioner consultation, maternity care, home nursing care and integrated care. A "healthcare allowance", which is a subsidy to lower the deductible, exists for people with the lowest incomes (Kroneman et al., 2016, 25; 66; 75; 87; 189).

In 2015, the reorganization and centralization of long-term care in the Netherlands took place with an unique determination. Before 2015, care in the Netherlands was covered by the Exceptional Medical Expenses Act *(AWBZ)*, an integrated national scheme which, at its introduction in 1986, was the first universal mandatory social health insurance scheme that provided long-term care services (Schut and Berg, 2012). Now responsibilities for care are split and regulated by three Acts: Health Insurance Act *(Zorgverzekeringswet, ZvW)*, Social Support Act *(Wet Maatschappelijke Ondersteuning, Wmo)* and Long-term Care Act *(Wet Langdurige Zorg*, *Wlz)* (Kroneman et al., 2016, 22).

Persons who require 24-hour care receive benefits under the Long-term Care Act *(Wlz)*, which is financed through income dependent contributions and an income and assets dependent deductible paid by each recipient. The Centre for Needs Assessment (CIZ) carries out a needs assessment and assigns a care intensity level to the patient. The *Wlz* offers the possibility to make use of professional care services in a residential long-term care facility or at home. The Social Insurance Bank manages a budget allocated for care at home (Kroneman et al., 2016, 58; 74; 89; 96).

Home nursing, as a part of the Health Insurance Act *(ZvW)* is mainly financed (more than 2/3) through compulsory health insurance (composed of community-rated premium and income-dependent premium) and partly by general taxation and private supplementary expenditure. Beneficiaries receive support through contributions in kind or personal budgets. If the care service is subject to the regulations of the Health Insurance Act *(ZvW)*, the need for care is assessed by district nurses (Kroneman et al., 2016, 58; 66-67).

A core issue of the 2015 reform transfers the responsibility for the furnishing of all other types of long-term care to the local authorities. The additional budget provided from tax revenues for this purpose is not earmarked. According to the Social Support Act *(Wmo)* municipalities are responsible for care services such as support for activities of daily living. Municipalities need to determine whether these services are necessary and also assess whether the index person's social network can be used to meet their needs. Within the framework

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of the *Wmo*, municipalities are otherwise obliged to allocate the budget and purchase care services (e.g. domestic care). Municipalities can demand a personal contribution from the recipient but it is not possible that the recipient is charged more than the maximum of *Wmo*-care in case they are receiving both *Wlz*- and *Wmo*-care. Some communities have additionally formed multidisciplinary social district teams to coordinate support in the recipient's social network (Kroneman et al., 2016, 47; 91; 155). However, the first results show that access to services from the Social Support Act *(Wmo)* has been more limited since 2015 and informal care is confronted with rising expectations (Kelders and de Vaan, 2018).

In summary, the legal regulations in the Netherlands in 2015 result in a distinction according to the extent of long-term care. Care in the residential long-term care facility is only provided for persons who require 24-hour assistance. The need for home nursing care is assessed by district nurses. Since 2015, the municipalities have been responsible for the extensive task of all other forms of long-term assistance. They therefore receive a non-earmarked budget and are accountable for determining the need for care, making use of the support available from the social network of the person in need or, failing that, to purchase care services.

While the Netherlands regulate long-term care responsibilities according to the extent of care, the allocation of long-term care services in Estonia depends on whether they are provided by the health or social sector. To illustrate this, the Estonian healthcare system is described below.

2.2 Estonia: Limited social care services but outstanding digitalization in healthcare

Since Estonia regained independence in 1991, healthcare reforms have so far been able to achieve many milestones in renewing the healthcare system (e.g. Health Insurance Act in 1991, Medical Products Act in 1995 to ensure access to pharmaceuticals) with remarkable modifications in 2008, namely the adaption of the National Health Plan and the establishment of a nationwide E-Health system (OECD, 2019b).

The integration of the E-Health system into Estonia's IT infrastructure (established 2001), named "X-Road", began in 2008 and by now includes a wide range of functionalities such as electronic health records, digital images, e-referral, e-consultation and e-prescription (Metsallik et al., 2018). Patients have unrestricted access to their health data via the platform www.digilugu.ee and can determine which data they want to make available to certain healthcare professionals (Habicht et al., 2018, 46). The Estonian health system is based on financial solidarity and is placed under the Ministry of Social Affairs' (MoSA) purview. Since 2014 it is managed by the Minister of Health and Labour and the Minister of Social Protection. The Estonian Health Insurance Fund (EHIF, *Eesti Haigekassa*) is a legally independent public organization that, due to Estonian Health Insurance Fund Act 2000, acts as the only player responsible for purchasing and paying for healthcare services (Habicht et al., 2018, 38). The EHIF Supervisory Board, consisting of 15 representatives from state, employers and insured individuals' organizations, decides on healthcare allocation, yearly health insurance budget and approves long- and short-term strategies (Habicht et al., 2018, 26; 39; 50).

Of the 1.3 million Estonians, 94.5% have social health insurance[5]. The share of out-of-pocket payments in Estonian's healthcare is 23.6%[6] and consists mainly of co-payments for pharmaceuticals and dental care (OECD, 2019a). Private health insurances play an insignificant

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role. EU investment in Estonia focuses on primary care, prevention, community-based care, children's health service and E-Health (OECD, 2019b). The Estonian spending on healthcare is €1,559 per capita (EU average €2,884 in 2017). This corresponds to 6.4% of GDP share (EU average 9.8%). In 2016 public spending on long-term care, including health related long-term care and social long-term care, amounted to 0.5% of the GDP (EU average 1.6% of GDP) (European Commission, 2019, 346). In the last years Estonia has recorded the highest increase in life expectancy among EU countries, reaching an average life expectancy of 78.9 years (female: 81.9 years; male: 72.8 years) (European Commission, 2018). In Estonia women with low socioeconomic status live on average 5.4 years less than women with high socioeconomic status, for men it is even 8.5 years less (OECD, 2019b). Compared to other EU countries, Estonia has a relatively small increase in health-related life years despite the large increase in life years. After the age of 65 on average ten more years are spent without disability in the EU versus only 5.6 years in Estonia (Habicht et al., 2018, 6). Currently 21.1% of the population in Estonia are older than 65 years, of which 5.9% are 80 years or older (European Commission, 2018). In Estonia, in contrast to most other EU countries, no increase but a decrease in the number of inhabitants is forecasted (European Commission, 2019, 74). Nevertheless, the growing number of elderly inhabitants will increase the need for long-term care and, according to estimates, public spending on long-term care could at least double by 2060 (Paat-Ahi and Masso, 2018, 12).

As in most EU countries long-term care responsibilities in Estonia concern both- the health and social policy sectors (Spasova et al., 2018, 6). To address long-term care there are services provided by the healthcare system (e.g. institutional and home nursing care, geriatric assessment, medical rehabilitation) on the one hand and services provided through the social care system organized by the state (e.g. special care services) and by local municipalities (e.g. domestic service, personal assistance, social transport service) on the other hand (World Bank, 2017, 22;28-29). Especially in the healthcare sector different governance mechanisms have been adopted to meet the challenge of supporting the ageing society in an older-person-centred way. Facing the growing old-age dependency ratio, Estonia decided to gradually transfer a share of 13% on behalf of non-working pensioners to the main fund of the healthcare system from 2018 onwards. The state pensioner contribution is comparable to the earnings-based employer's contribution to the main fund of the healthcare system and thus helps to stabilize the financing opportunities of the healthcare system even if the old-age dependency ratio rises (OECD, 2019b). Also, EU structural funds will be used for informal caregivers relieve, to develop social services in municipalities and to reorganize long-time care. Financial barriers to access pharmaceuticals were dismantled by capping the out-of-pocket payment for prescribed medications and abatement for those receiving disability or old age pensions has been established (Habicht et al., 2018). While older-person-centred services exist in the health sector and the costs of long-term healthcare services are clearly defined by the EHIF (European Commission, 2019, 347; World Bank, 2017, 76), social care services vary substantially between the different municipalities. The rate of out-of-pocket payments to social care homes is high (European Commission, 2019, 348) and has risen disproportionately in recent years compared to state and municipal spending (World Bank, 2017, 55). The Estonian Constitution lays down an obligation to provide informal care (Constitution of the Republic of Estonia Art. 27). Yet the quality and quantity of informal care services is non-transparent, partly because municipalities may grant a caregivers' allowance at their own discretion (World Bank, 2017, 58). The future EHIF strategy primarily focuses on setting incentives for high quality

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care and better coordination between care settings, especially between the healthcare and social care system (Paat-Ahi et al., 2018, 13), which appears to be extremely necessary in the light of subsequent ethical considerations.

3. Ethical considerations focusing on the increasing need for elderly healthcare and assistance

The following reflections particularly concern aspects of distributive justice and equitability.

The aspiration behind community-based care approaches is to preferably provide tailored services to elderly needs. Assuming that a more detailed analysis of the needs and available resources of the needy person as well as a better coordination of services from different areas is possible at the local level, these approaches could be better suited than a cross-country needs assessment which has the claim to fit everyone. Both the example of the Netherlands and the example of Estonia show that such regulation can lead to inequities between municipalities in the care of the needy. The lack of earmarking of the funds made available to the municipalities has the potential to exacerbate injustice in the Netherlands and the great freedom in the design of co-payments or caregiver allowances in Estonia could lead to an exacerbation of injustice in the healthcare in different municipalities. This has the consequence of the distribution of resources no longer taking place according to a principle of justice, but being much tighter linked to one's current place of residence and the associated resources provided by the local municipality. In addition to this, the different financing logics of the Estonian health and social care system allow people with comparable restricting conditions resulting from different illnesses to be covered either of the services of the healthcare system and thus to be insured financially, or to receive hardly any financing within the social care system in cases where the disease record is less obvious. Investigations show that every fourth inpatient who has received nursing care should have received other assistance such as welfare care or home (nursing) care, suggesting that injustice leads to a misallocation of resources (World Bank, 2017, 78). The allocation policy in the Netherlands has resulted in residential long-term care only being available to persons who require 24-hour care. This regulation might not receive universal consensus, but it will allow resources to be allocated according to explicit, needs-based criteria.

While the previous part relates primarily to long-term care, another aspect of distributive justice in the health sector will be presented in the following, using the example of the elderly population in Estonia, as this may also be relevant for other countries in regard to future digitalization of healthcare systems. The Estonian E-Health system offers enormous possibilities for efficient, patient-centred healthcare and is widely accepted by the population. Although public transport barriers have been reduced by the use of eConsultation or eReciept, there may be other barriers, such as a non-existent internet access. This limits the equal access of older people to health services and leads to inequality by systematically excluding those who do not have access to a digital health system or are not empowered to use it. Not only from a critical perspective towards the E-Health system of Estonia (Paimre, 2019), but also on the basis of objective indicators, a potential for discrimination of the older population in the course of digitalization in the healthcare system becomes obvious as shown in figure 1.

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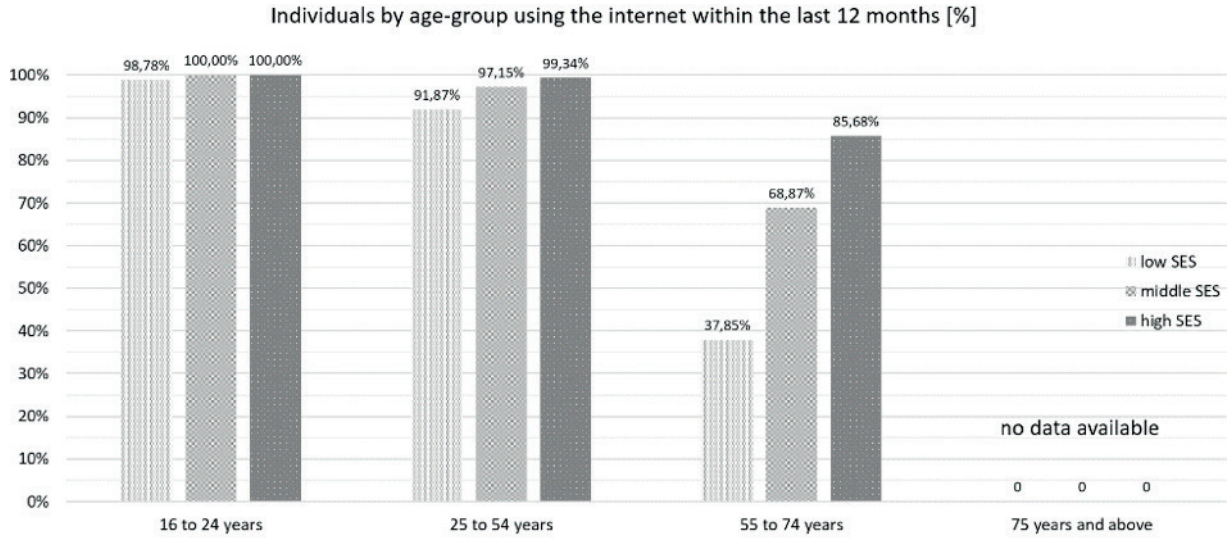

Figure 1: Estonian's by age-group and socioeconomic status (SES) using the internet within the last 12 months [%] based on 2018 data. Available from: https://stats.oecd.org/index.aspx?queryid=72702 [Accessed on: 16. December 2019]

It is possible that this effect will be compressed over the next few years, but the figure is still suitable to show an example of how cumulative health inequalities can exist through an interplay of societal developments at different levels. In particular, older people with low socioeconomic status in Estonia are a vulnerable group for accumulated risk factors leading to potentially increased exclusion from the social and health systems. Among the EU countries, Estonia is behind Lithuania the country with the greatest difference in self-assessed health by socioeconomic status (in low income groups approx. 35% report good health, in high income groups approx. 64% report good health)[7]. Self-assessment of health in Estonia also varies widely between age groups (52.5% of the 15+ year old report good health, only 17.6% of the subgroup of people aged 65 years and older report good health)[8]. It should be emphasized that there are inequalities in healthcare in all European countries, although the extent of these differences varies. For this reason, all other EU countries should try to avoid a discrimination of vulnerable groups like elderly with low socioeconomic status in both the course of the digitalization of the health system (in terms of providing internet access and enabling the use of technological services) and in the course of policymaking for healthcare.

Conclusion

Two countries with different financial resources in the area of healthcare as well as different legislation and different focus topics in the area of healthcare were presented in advance. The Netherlands served as a first example having high healthcare spending, especially for long-term care, the best accessibility to healthcare in the EU and a clear agenda through legislation for caring needs. The second example was Estonia, which has low health and long-term care spending, a significant focus on digital patient-centred health services and two currently independent financial systems for health and social care. It should be pointed out that inequality is not simply a question of financial resources, as any system is challenged with limited resources. The example of the delegation of care services to municipalities re-

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veals that similar distributive justice issues emerge despite very different policy systems. The implementation and reduction of inequality between municipalities and within the allocation of care services appears to be a challenging issue. Regular reviews of the incentive systems (e.g. like Alders and Schut, 2019) could help identify misleading decisions that arise from a financial rather than a needs perspective. Although the principle of justice in healthcare cannot be weighed in the context of the scale of financial resources, there is in fact a higher risk of exacerbating inequalities when a state struggles with financial constraints (e.g. tendency to the exploitation of misguided financial incentive systems, more out-of-pocket spending). A changed old-age dependency ratio will probably increase the financial pressure on the health and social system in the coming years. Control mechanisms to promote distributive justice and equal rights must therefore be established foresightedly. Another interim result is that the Estonian health system has already achieved effective integration of and cooperation between different actors in the health system through digitalization in recent years. However, there is little integration between the health and social systems, as would be particularly important in the area of long-term care. But digitalization only serves to shape political objectives and therefore cannot be the first step towards a better integration of healthcare and social care services. The example of long-term care in Estonia illustrates that the allocation issue cannot be solved by the respective prioritisation logic of a healthcare system itself, but needs to be considered and solved for society as a whole to promote justice in healthcare. In 2013, the Helsinki Declaration of the World Health Organization "Health in all policies" (WHO, 2014) called for precisely these policy sectors to be given a health structure that spans all policy sectors in order to increase equal health opportunities. Integrated policy approaches could also help to address known inequalities in individual policy sectors, such as poor health status due to low socio-economic status in the healthcare system or lack of ability to use (digital) services, and to adopt policy shaping mechanisms across sectors to reduce inequality.

For a conclusive evaluation it is indispensable to incorporate health and social issues in a political system as a whole and to extend the ethical considerations to further standards. Questions arising therefrom might be:

(1) Does the potential of an inclusive community based social development and ageing in place outweigh the threat of unequal resource distribution in different communities? How could the latter be reduced so that benefits predominate?

(2) How can (inter)national knowledge about injustices and their potential to accumulate for vulnerable groups (like elderly with low socio-economic status and also financial barriers or knowledge barriers for internet access) contribute to avoiding implicit rationing in the future design of healthcare? How does the injustice potential relate in consideration with ethical values such as transparency and patient-orientation in the healthcare system, quality and safety of care and others?

(3) How can it be recognized and avoided that political obligations or incentive systems contribute to overstretching and restricting the rights of informal carers for example by jeopardizing their mental health (Bauer and Sousa-Poza, 2015)?

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Endnotes:

1. Universal Declaration of Human Rights Art. 25 available from: https://www.un.org/en/universal-declaration-human-rights/, European Social Charter Art. 11 available from: https://rm.coe.int/168006b642, International Convenant on Economic, Social and Cultural Rights Art. 12 available from: https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx, CESCR General Comment No. 14 available from:https://www.refworld.org/pdfid/4538838d0.pdf [Accessed on: 16. December 2019].

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