COVID-19 and health disparities: threat and opportunity for rethinking the system towards more equity and justice.[1]

MARIA VAN DEN MUIJSENBERGH

Summary

The COVID-19 pandemic reveals limitations in healthcare and society to protect us from the disease and its consequences. The biomedical, epidemiological approach falls short now it is apparent that the consequences of the pandemic are far-reaching, beyond the domain of healthcare. Choices based on this view, tend to turn out not well for socially vulnerable groups and increase existing inequalities in wealth, health and wellbeing. It is obvious that choices have to be made. However, we plead that these should not be based on economical and clinical evidence alone, but also on moral principles. In this chapter, we first describe what social circumstances make populations especially vulnerable to suffer from COVID-19 infection and preventive measures. Then we argue to base choices on solidarity, dosed subsidiarity and reflection. When we do this, the COVID-19 pandemic will act as a welcome wake-up call to change our societal perspective towards more solidarity, thus protecting our most vulnerable in society.

Introduction

The COVID-19 pandemic is not only a medical crisis but also a social one. Already underprivileged groups suffer disproportionally from the disease and from the consequences of the preventive measures that are taken. The approach in most countries shows the limits of the current paradigm of biomedical focussed healthcare, led by principles of utilitarian outcome measures of biomedical evidence and cost-efficacy.

Worldwide this pandemic has led to a mountain of scientific research; however, advices based on science are often contradictory or subject to heavy debate. Measures differ greatly between countries, although based on the same available knowledge. For instance, only very recently in the Netherlands face masks are being advised, in sharp contrast to most other countries. Apparently, the current '*evidence based medicin*e' paradigm does not provide as much conclusive evidence as one would think. Still, the policy approach of the pandemic is very much focussed on biomedical, epidemiological facts despite the indications that the consequences of the pandemic and the connected policies reach beyond the healthcare domain. Policy choices do not affect all people in society equally: different sources such as UN (United Nations 2020) point out that the current pandemic measures increase societal inequalities and widen the gap between poor and rich.

We have to accept that due to scarcity of means, difficult choices have to be made. However, these choices should not be based only on economic and clinical evidence, but also on moral values. The dominant contemporary ethical principles of autonomy, non-maleficence, beneficence and justice (Beachamp 2019) are insufficient to guarantee the protection of the most vulnerable groups in our society from suffering disproportionally from the pandemic. Therefore we plead to add attention to reflection and solidarity, as suggested by Ter Meulen. (Ter Meulen 2017) He defines solidarity as the responsibility to protect those persons whose existence are being threatened by circumstances beyond their own control, in particular natural fate or unfair social structures. If politicians would grant them and us time to reflect on the lessons learned of this pandemic, and shift their policies more towards solidarity and justice, the COVID-19 pandemic can provide a wake-up call to change our perspective on society.

1 This chapter is a based on the Dutch publication: Van den Muijsenbergh M, Wollersheim H, Hol C, Lange M, Vorselaars A, Vos MC. Grenzeloze ziekte vraagt om reflectie en solidariteit. Corona legt kwetsbaarheden bloot en stelt nieuwe grenzen (*limitless disease asks for reflection and solidarity. Corona reveals vulnerabilities and new limits)* In: Wobbes T & van den Muijsenbergh M. De menselijke maat. Grenzen aan de gezondheidszorg? *(The human measure. Limits to healthcare?),* Valkhof pers 2020: 49 – 69

In this contribution, we will describe the impact of the pandemic on socially underprivileged groups and the limitations of the current approach. We will plead for a paradigm shift in healthcare and politics towards a person-centred approach and choices based on a morality of equity, and reflective solidarity.

The impact of COVID-19 pandemic on underprivileged groups

The current COVID-19 pandemic affects the whole population. The extent of the impact differs between countries, depending on the accessibility and quality of healthcare facilities and public health, density and distribution of wealth in the population, and the social welfare regime. But as always, everywhere, marginalized populations, including people with low income, low-paid jobs, refugees and other migrants, homeless and prisoners are likely to suffer most (Madhav 2018) and can be called suffering from structural vulnerability. (Solis 2020) Social inequality, poverty, and their environmental correlates can increase individual susceptibility to infection significantly and so lead to elevated risks of morbidity and mortality during a pandemic. (Tricco 2013) As such, a pandemic tends to add to the burden of "structural violence[1]" (Farmer 2006) these groups experience. Low (health) literacy, lack of access to understandable information on risks and confinement measures and lack of opportunities to comply with the confinement measures contribute to these higher risks.

We see this reflected in the disproportionally high numbers of ethnic minorities and people of low income among COVID-19 infected and deaths'. (Williamson et al 2020, Darici et al 2020, Chiriboga et al 2020, Wise 2020, Kirby 2020), also in the Netherlands. (Kunst et al 2020)

Besides the immediate negative influence of COVID-19 on the health of the population, there is substantial "collateral damage": unintended effects, due to the impact on living conditions (loss of job, income) and domestic violence of the confinement measures. Thus, deepening existing societal inequalities that in turn, increase existing health disparities. (Okonwo et al 2020)

These health inequalities are persistent all over the world and entail that the lower the educational level of income, the younger a person dies with fewer years spent in good health and more chronic diseases. (Marmot et al 2012) Thus, overweight, high blood pressure, diabetes, cardiovascular diseases, and pulmonary diseases are more prevalent among people with lower educational level and less income, increasing the risk of severe Covid-19 infection. Keeping your distance is much more difficult when living in a crowded neighbourhood, and working from home is often not possible in low-income jobs.

So people from underprivileged groups not only are at greater risk of becoming (seriously) ill from Covid-19, they also suffer most from the mental, economic and social consequences of the pandemic. (Martin et al 2020) During the first month of the lockdown in the UK, people in the lowest income groups nine times more often were not able to pay their bills, and their financial position has only worsened since. (Wright et al 2020) The lockdown measures also impacted access to food. For instance, estimates pointed to a four-fold increase in the number of food insecure people in the UK since the beginning of the crisis. (Loopstra 2020) GDP fell by more than 10 % in the second quarter of 2020 in many European countries, and the initial impact of the COVID19 crisis on labour markets has been ten times larger than that observed in the first months following the 2008 Global Financial Crisis. (OECD 2020)

Health literacy skills are of even more importance during this pandemic than before. These skills, to find, understand and apply health-related information, as well as digital skills, are often lacking among people with low income and education. And even for highly educated persons the amount of information, rapidly changing and not seldom contradictory, it is difficult to follow and assess. On top of the previously mentioned difficulties to follow up the preventive measures, this lack of understanding hampers further a correct implementation of confinement measures, testing devices and quarantine regulations. Official government information and instructions often are too complicated to understand for many people. In Europe, one in five 15 – 65 year-olds have poor reading skills (Elinet 2015), also in prosperous countries like the Netherlands. As a result, many people retrieve their information from friends and families, relying on social media. (van Loenen et al 2020) This pandemic has also been called an 'infodemic' referring to the large amount of fast-spreading misinformation and 'fake-news' through social media. (Chong et al 2020, Zaragostas 2020) People with limited (health-)literacy skills may be even more prone to believe this information. As these groups are underrepresented in large questionnaire studies among citizens, due to lack of trust in official institutions and to limited digital skills, their opinions and experiences often are unknown, and scientific advices are not always adapted to their needs and possibilities.

Social vulnerability limits options and the capability to flourish or survive when normal life gets disrupted. (Vawter et al 2011) Natural disasters increase social inequalities. COVID-19, as for instance the hurricane Katrina (2005) and the epidemic of cholera on Haiti (2010) before, demonstrate that socially deprived populations have limited options to protect themselves and to make use of existing protection systems. (Cooper & Block 2006) The movie '*Beasts of the southern wild*' (Benh Zeithlin 2012) visualizes this social inequality following the events of a family living in deprived circumstances when suffering from a flood comparable to Katerina. Besides limited material possibilities to cope with disaster, limited resilience of deprived populations plays a role as well, which is the result of chronic stress. We see this also reflected in the higher levels of mental distress the COVID-19-pandemic cau-

1 *Structural violence* describes social structures – economic, political, legal, religious, and cultural – that stop individuals, groups, and societies from reaching their full potential. It refers to the "avoidable impairment of fundamental human needs or…the impairment of human life, which lowers the actual degree to which someone is able to meet their needs below that which would otherwise be possible"

ses them. (Brooks et al 2020) On top of this, chronic stress has a negative influence on the immune system, increasing the risk of catching an infection. (McEwen 2007)

During the first wave of the pandemic, medical and social services all over Europe rapidly changed from face-to-face contacts to remote by default contacts by video, telephone or email. Although in many instances useful and feasible, these forms of contact can hamper rapport and information gathering. (Mac Kinstry 2010). Thus, they probably pose extra barriers in access and quality of care for populations with limited proficiency in the local language or limited means to put their complaints in words. Family doctors also notice that the loss of non-verbal communication leads to sub-optimal care in some of their more vulnerable patients. (Verhoeven et al 2020, Wolfson &Cheung 2020)

So we have to conclude that COVID-19 highlights inequalities, with the most deprived in society both at the highest risk of catching and dying from the disease and at highest risk of adverse health outcomes secondary to lockdown. (Bibby et al 2020) Many of whom already have difficulties in accessing good quality healthcare. The populations concerned include, amongst others those experiencing homelessness, vulnerable migrants, those on low income and those with mental health problems. This is exposing the structural disadvantage of these groups and increases the already existing social-economic and ethnic health disparities. (Bibby et al 2020)

Limits to our healthcare systems

This pandemic confronts us with the limitations our healthcare systems pose to deal effectively with unknown and unforeseen infectious diseases. Not every disease can be prevented or cured, our knowledge is limited, and even rich countries suffer from scarcity in technical provisions (forced respiration devices, COVID-19 tests, preventive masks etc.) and in skilled human resources for intensive care units and public health surveillance. We see large differences between countries in the strength and effectiveness of preventive policies and cure. (OECD 2020) However, not so much the number of available intensive care beds, but the strength of the primary healthcare defines the number of patients who end up in a hospital. (Krist et al 2020, De Maeseneer 2020) The Italian province of Veneto has provided a strong example of this. The number of COVID-19 related hospital admissions and deaths' during the first wave was thrice as low there, compared to their neighbour province Lombardy. The explanation is that from the start of the pandemic, in Veneto a strong collaboration existed between primary care doctors and public health epidemiologists, who focused on rapid recognition of infections, home-isolation and active contact tracing. In contrast, Lombardy focused on (intensive) hospital care. (Binkin et al 2020)

In all countries, the high demand for COVID-19 related hospital care leads to reduced availability of medical care for other diseases, thus adversely affecting patients with other health care needs. (OECD 2020)

We are also confronted with societal limits: not all preventive measures can be implemented and maintained because of the economic and mental damage they would cause, and because of human nature as an essentially social being, needing physical proximity. Besides, substantial groups in all countries oppose to the limitations to their personal freedom these measure pose. These limits force politicians and citizens alike to make choices. The question is, what morals will guide our choices?

Moral choices.

Justice is an important leading principle in medical ethics. However, it remains to be seen if this broad concept is suitable or sufficient to guide decisions in the context of the pandemic. What elements of justice should be emphasized? Efficiency or effectivity, equality or equity, or vulnerability and marginalisation as these factors determine the effects of the pandemic? How to relate the right to be at maximum protected against the infection to the right to have human contact and proximity? And what outcomes are more important: health-related ones or economic ones – that are mutually influenced. In daily life, justice always conflicts with other values. (Page 2012) Apparently, the notion of justice is insufficient to protect the interests of the socially most vulnerable populations. These groups deserve specific support because of the strong relation between difficult to influence determinants of social inequalities and bad health outcomes.

The perspective of justice protects the rights and interests of individuals as autonomous beings, focused on their self-interest. Solidarity concerns "the commitments and recognition of the well-being of the other, without personal interest". (Ter Meulen 2017 p.171) It expresses the view of man as being essentially in relation to others. (Ter Meulen p.170). To quote Ter Meulen further (p.171): "Habermas sees justice and solidarity as 'two sides of a coin': justice concerns the rights and liberties of autonomous, self-interested individuals, whereas solidarity concerns the mutual recognition of and well-being of individuals who are connected in the lifeworld". According to Ter Meulen, both concepts are necessary for the moral interpretation of regulations and policies in society and particularly in health care. Solidarity needs to be the basis to build upon just regulations that acknowledge individual needs and differences between people. A fortiori this applies to the context of the current pandemic, where solidarity with socially and physically vulnerable groups should be the base. In his words: "Solidarity in times of Corona means more than emphasising the common interest or (well understood) self-interest: it also concerns showing connectivity with and respect for the other. It means that we take care that every individual counts, and nobody is left behind." (Ter Meulen 2020)

When we think about the role of the government in mitigating the effects of COVID-19, not only justice and solidarity are essential to consider, but also the principle of subsidiarity. This principle means that the best support a society can offer, is the support that results in self – help. Individuals should feel encouraged to

develop as much as possible their own talents and potential and only as a last resort rely on support by the state. (Ter Meulen p.174) However, subsidiarity should not mean the total reliance on self-help and informal support. When professional support is lacking, due to financial or other restraints, caring for ill, old or otherwise vulnerable family members too often poses a heavy burden on the shoulders of women, children or members of the community who already are overburdened by other demands. We saw this during the *lockdown* when schools were closed, and parents were expected to provide home teaching. Subsidiarity should not mean the total withdrawal of professional support for informal caregivers, but instead, adequate support to enable these caregivers to help their dependent family members. If we integrate the principles of justice, solidarity and subsidiarity in the example of the children during the lockdown, parents with limited skills or possibilities should receive more financial and practical professional support than other parents.

People living in nursing homes, or mental health institutions, and their family should get more control over the implementation of preventive measures to protect against COVID-19 in their institution. They, with their experiential knowledge of the specific situation, could better than the government judge how to weigh in their case the collective risk of infection against the personal need for physical contact. Anyhow, all stakeholders, care recipients, caregivers and other citizens alike, should be more involved in the decision making process concerning healthcare and regulations – especially when such far-reaching decisions are being made as now related to the pandemic. Only in this way healthcare and regulations can be tailored to the specific needs and capacities of the people involved, also the most vulnerable. (Ter Meulen 2017 p.169 -174) Socially vulnerable populations, like migrants, people living in poverty, or people with limited literacy, are often called "hard to reach", as they are less likely to circulate in the networks of researchers and politicians or to react on on-line invitations to participate in an inquiry. However, it turns out to be very well possible to also involve these people in research and policy-making, as well as in decision-making concerning their own health. (van den Muijsenbergh et al 2016) They can often be reached through trusted organisations or influential persons from their community, and together with them, solutions can be tailored to their needs. (Van den Muijsenbergh et al 2016) For instance, for effective implementation of confinement measures, it appeared essential to maintain the natural cohesion of families, members of the same religious groups or clubs, especially for people who depend on the help of others. (Usher-Pines et al 2007) Decisions should be made in a continuous reflection on the effect of them on all involved, professionals as well as clients, care recipients or caregivers.

Chaos does not match well with reflection. Sadly, also after the first wave of the pandemic, we still experience in many countries how ad hoc policies fail, resulting in short-term, fast-changing regulations, sometimes causing confusion and often lack of motivation in the population. We would wish for some reflection in politics on lessons learned. Thus, this difficult time could cause positive change: the organisation of healthcare and society based on solidarity, resulting in structural justice, equity and protection of vulnerable groups.

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Prof. Dr. Maria van den Muijsenbergh

(1956) is general practitioner for over 35 years and researcher at Radboud University Medical Centre Nijmegen, the Netherlands, and at Pharos, the Dutch centre of expertise on health disparities. Her chair on "health disparities and person centered integrated primary care" focusses on the possible contribution of primary care in reducing existing socio-economic and ethnic health disparities, and how healthcare best can be tailored to the needs of socially deprived patients, like migrants or persons with limited health literacy. To achieve this, person centred instead of disease centred healthcare is the key, with a focus on and in collaboration with the wider community, healthcare and social services – thus integrated care.