ACTION AGAINST AIDS, GERMANY – NOVEMBER 2020

IN FOCUS

COVID-19, HUMAN RIGHTS AND WHAT WE CAN LEARN FROM THE HIV WORK

WITH VULNERABLE GROUPS IN THE CENTRE!

Aligning public health activities with human rights and modern approaches to health promotion

Outlook

What measures can we take to overcome the corona-virus crisis, limit its effects and use scarce resources efficiently? Every day we experience uncertainties and contradictions regarding these questions among scientists, health experts, politicians, and in society. We must all strive for a broad consensus to overcome the global COVID-19 pandemic. With our IM FOKUS publications, we aim to stimulate discussion and encourage individuals to form their own opinions, whereby we write based on our experience of working on the HIV-response. Our intention is not to equate COVID-19 with HIV but to discuss which experiences from the work on HIV may prove helpful in dealing with COVID-19. We do not intend to replace scientific papers, nor are we in a position to comprehensively and conclusively represent the current state of scientific knowledge.

What is vulnerability and who is vulnerable?

The term vulnerability is derived from the Latin vulnerare, meaning 'to wound', and the corresponding adjective vulnerabilis, meaning 'susceptible to being wounded or hurt'. Vulnerability has several dimensions: we may speak of physical, emotional or social vulnerability. This term, however, not only describes the actual state of being vulnerable, it also encompasses social and political perspectives and underlying processes. One characteristic of the term 'vulnerability' is that it points to the context, i.e. to factors that increase vulnerability – as opposed to the mere detection of risk behaviour.

Individual factors of vulnerability

We must assume that any person without immunity to the disease can be infected with the SARS-CoV-2 virus. Whether persons who have overcome such an infection are protected in the long term, however, remains unclear. The probability of progressing to severe or even fatal forms of the disease increases greatly with advancing age and pre-existing health conditions. These conditions include diabetes and lung diseases such as asthma. The probability of progressing to severe disease also increases in the presence of factors such as smoking or overweight. Whether people living with HIV are more susceptible to coronavirus infection or complications has not yet been conclusively determined by scientific studies.

Vulnerability caused by structural and contextual factors

Substantial risks and associated vulnerabilities exist in workplaces and types of accommodation where it is scarcely or not at all possible to comply with social distancing and hygiene rules: e.g. in overcrowded, poorly ventilated or low-temperature indoor spaces. Locally, this has become known mostly through cases in industrial meat processing facilities. Greatly increased vulnerability also arose because of the cramped conditions in group lodgings for seasonal agricultural and harvest workers, in prisons, and in communal accommodation facilities or reception centres for refugees and asylum seekers. The factors that can lead to disease outbreaks include overcrowding, a lack of fresh air and inadequate air circulation, or sanitation that does not comply with hygiene standards. Examples such as these are evidence of the connections between precarious working and living conditions, social status and vulnerability.

The medical and care professions are associated with close physical and time-intensive interpersonal contact. Close contact in confined spaces and potential exposure to bodily fluids can result in opportunities for the transmission of pathogens by the staff, leading to increased vulnerability among residents and care professionals in nursing and aged care facilities. The implementation of social distancing rules in the care and social support sectors represents a great challenge – also with respect to emotional wellbeing.

Vulnerability and political responses

COVID-19 represents major challenges for policy makers, which they must – or should – face up to. These challenges consist, for example, of the fact that decision makers cannot draw upon lived experience, only upon historical precedent. Decisions must be made under time pressure while many questions remain unanswered by science. State-imposed restrictions of human rights and freedoms can lead to a weakening of democracy and confidence in the actions taken by governments. At the same time, public health system structures weakened by years of neglect are unable to implement regulations, which in turn puts politicians under considerable pressure.

How differently these challenges are either accepted or met with denial can be observed and analysed by comparing the policy responses of different countries. Effects on the vulnerability and wellbeing of citizens become obvious with respect to measures either taken or omitted, and can be detected e.g. in infection rates and mortality statistics. In some countries, we observe the misuse of the COVID-19 pandemic for populist political purposes. It undermines the trust of citizens in their governments when health policies targeting coronavirus are used for political purposes other than those intended, e.g. for delaying elections, barring access to legal representation and suspending basic rights, or for measures to control or discipline already discriminated or marginalised groups. Politicians should not use COVID-19 for election campaigning, to apportion blame to their political opponents, or to denigrate entire nations, as can be observed, for example, between China and the USA.

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Lessons learnt from the response to HIV

Only recognising these relationships and making a complete break from outdated disease control measures has made the response to HIV successful. Health promotion, prevention and comprehensive care for those affected are inseparably linked. Success is founded in the combination of concern for the individual needs of particularly vulnerable groups, and analysing and addressing problematic social conditions. In order to change individual behaviours, the surrounding conditions must also change. Only by combining these strategies can public health be promoted. The key concept to be taken from the HIV response is the inextricable link between behavioural and structural prevention.

Another lesson learnt from the response to HIV is a strong focus on the needs of vulnerable groups with poor access to prevention and care. In addition, those responsible for health services and care provision must make sufficient efforts to do justice to the aspects of vulnerability that are specific to their work. Here in Germany, gay men and people who use drugs were the main groups initially identified as particularly vulnerable. In other parts of the word, this was and is, depending on the socio-epidemiological situation, quite different: it includes sex workers, girls and young women, other LGBTI communities, seasonal workers, migrant workers, people wo use drugs etc.

Standards for the involvement of vulnerable groups

Instead of excluding disadvantaged or marginalised groups – termed 'key populations' in the professional discourse – it has become standard practice in the response to HIV to involve people living with HIV as equal partners in the implementation of programmes, and to support their civil society structures. This may sound simple enough, but is the result of a lengthy process of negotiation. Over the years, the self-confidence evident in the development of the GIPA principle (Greater Involvement of People Living with HIV) enabled the maxim 'Nothing About Us Without Us' to be articulated. The 2030 United Nations Sustainable Development Agenda's aim of 'leaving no one behind' is in part a result of the HIV activist movement's tenacious advocacy.

In comparison to policies in countries where people living with HIV and the groups they encompass continue to be discriminated against and sometimes persecuted – perceived as a threat and not as partners in health promotion – approaches that take this principle into account are more successful.

Applied to COVID-19 this means, for example, that in order to enable excessive hardships to be taken into account and avoided, people in the caring professions must be included in the development and implementation of any measures within their area of work. The same applies to primary school teachers, who surely know best under which conditions a humane form of teaching children can be put into practice. The perspectives of relatives, pupils and parents should also be taken into account in the implementation of such measures. All stakeholders and participants should have access to information. It is not sufficient, for example, that emergency response plans are developed for custodial settings: they must also be made available to detainees so that fear can be minimised and trust developed.

In order to respond appropriately to the COVID-19 pandemic, taking these complexities into account is essential. Vulnerability is modulated by structural, social, political and cultural factors. Merely looking at individual ('mis-') behaviour is missing the mark. Instead of focusing on 'culpable' behaviour that leads to chains of infection, circumstances where SARS-CoV-2 is spreading rapidly must be better analysed, also taking into account causal relationships with structural issues such as work processes and living conditions. Apportioning blame to individuals or groups leads to denigration and discrimination, and gets in the way of the necessary changes.

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What remains to be done and should be considered

The public health service must be changed, upgraded and promoted in a way that enables it – for the coronavirus crisis and beyond – to analyse vulnerabilities in sufficient detail and to implement effective countermeasures. Only then can it provide the greatest possible benefit to all. Success depends on the broad-based consent and participation of target groups.
We consider it essential that

- The specific factors of vulnerability of particular groups are analysed, forming the basis of efficient and comprehensive measures to be developed jointly with those directly affected In our view, for COVID-19 these groups include: care professionals, older people and care recipients, people with a disability, people living in asylum seeker accommodation and in custodial settings, the homeless, and people without legal residency status.
- Access to the health system, including prevention and treatment, is created for people without residency status.
- Targeted measures and programmes are developed according to the particular needs and vulnerabilities of groups affected by COVID-19.
- Representatives of groups particularly affected by COVID-19 and their expertise are included in programme planning and implementation.
- Measures are well justified and explained, also in order to avoid the impression of certain groups being favoured and others discriminated against.
- Excessive hardships are avoided – this applies primarily to measures of isolation or quarantine, e.g. in aged and nursing care facilities, in hospices and prisons – and that such measures are periodically and critically reviewed.
- Overcrowding in cramped mass accommodation facilities of any kind is avoided.
- Political and other decision makers constantly check that they are acting in the public interest and, even more importantly, that they are also held accountable.

No matter what the response or action taken: measures should be time limited, continuously reviewed, and revised as soon as the situation permits. Politicians and others with public responsibilities should base all measures that are to be introduced on current scientific evidence.

What should be avoided

The COVID-19 pandemic and the response to it are proving to have significant cross-border effects on many areas of life, and on social interaction. The resulting restrictions are leading to uncertainty and harbour the potential for conflict. At this point, nobody knows how the situation will affect public health, social relations, society, politics and the economy in the medium and longer term. State-imposed measures for the protection of public health must be based in scientific evidence, proportionate, and democratically legitimate, especially when they lead to the restriction of freedoms.

- The COVID-19 pandemic is primarily a challenge to global and public health. Politicising the epidemic, as can be observed in many countries, is unhelpful – it promotes distrust and undermines the implementation of countermeasures.
- Introducing measures to pursue objectives other than those proclaimed should be avoided. The emergence of new diseases must not be misused to criticise entire groups or types of behaviour. Otherwise, public health will not only lose its purpose, but also its credibility. In order to better prevent this, structural prevention must be afforded the same status as behavioural prevention, so that the danger of criminalising 'misbehaviour' and discriminating against certain groups is reduced.
- Taking the needs of different vulnerable groups into consideration has the potential to create envy and encourage prejudice. If, for example, homeless people or refugees are accommodated in hotels in order to reduce their vulnerability, it is helpful to provide a sound rationale, also as a way of pre-empting potential right-wing agitation.
- Apportioning blame to individuals or groups is not expedient, and should therefore be avoided. Instead of branding individuals or groups as (irresponsible) 'super-spreaders' or as (hedonistic) partygoers, and morally discrediting them, it must be insisted upon that faults in the system and structural causes of vulnerability are also taken into consideration.
- The role of law enforcement agencies and the police in enforcing COVID-19 countermeasures should be limited. This especially affects groups under police surveillance, who are not necessarily likely to trust that law enforcement agencies are contributing to the protection of their health.
- People who, on account of the way their live their lives, are more likely to be affected by exclusion – such as the homeless and people who use drugs – find it more difficult to access the health and social security systems. Prejudice and discrimination within the health system represent barriers that must be removed.

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If you want to know more

- Link RKI: https://bit.ly/2Rr2NDK
- 10 lessons from HIV for the COVID-19 Response: https://osf.to/32z351L
- GIPA Principles: https://bit.ly/3iugeP7
- Nothing about us, without us: https://osf.to/3hwqNjl
- Leaving no one behind: https://bit.ly/33rvLJd
- Structural prevention and health promotion in the context of HIV: https://bit.ly/2Fwepmr
- Key Populations: https://bit.ly/33w8Lc5
- Partnership for Evidence-Based Response to COVID-19: https://t1p.de/tbhp
- Competence Network Public Health Germany: https://t1p.de/2m92
- O'Neil Institute, Georgetown Law: https://bit.ly/3keQEOq

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