Emergency Treatment after Potential HIV-Exposure

A Neglected Right to Healthcare?

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In Western countries it is commonly assumed that quick emergency treatment is absolutely guaranteed. This, however, does not hold true for cases of possible acute HIV infection, particularly for men and transgender women who have sex with men. This is because an overwhelming majority of people are still unaware of the option of HIV post-exposure prophylaxis (HIV-PEP). Consequently, those who could have been infected with HIV through high-risk sex behaviours often do not consider their situation a medical emergency. As such, patients who could otherwise have begun a course of PEP after risk assessment fail to visit a clinic within the recommended 2 to 48 hours after exposure. Patients who do take the antiretroviral drugs for one month reduce their risk of HIV infection by around 80%.

1. Introduction: A Disturbing Observation in the »Western World«

It is difficult to understand that in the so-called »Western World«, a severe medical emergency may arise that can result in a life-threatening situation if not treated, or in the chronic infection of a virus, without affected individuals and those around them recognizing it as an emergency and obtaining access to immediate medication that could prevent the individual from

becoming infected.[1] This scenario, however, reflects the possible failure to obtain the HIV post exposure prophylaxis (HIV-PEP).[2] This paper discusses the problem of the ignorance surrounding HIV-PEP as a serious issue concerning the right to healthcare. The reasons for the low distribution of PEP will be investigated and ethically classified.

The available statistical data reveals a fairly poor adherence among patients to an initiated HIV-PEP[3] due to possible side-effects. No further research upon the question of HIV-PEP-knowledge in the population in general has been conducted. We have some results from specific research into particular target groups, such as men who have sex with men (MSM).[4] These results do not, however, extend to trans and inter individuals who may also belong to specific risk groups. However, there is reason to believe that with the exception of medical students, the younger generation of physicians, and doctors of infectiology, most people, at least in Germany, are not aware that there is a medication that can be used to prevent HIV-infection immediately after exposure.

My intention here is not primarily to focus on the question of who is responsible for the lack of knowledge regarding PEP amongst the majority of individuals. A mixture of medical, political, and economic reasons are behind the current state of general ignorance. The most disturbing explanation concerns the idea that certain actors could have a vested economic interest in avoiding HIV-PEP in order to benefit from the profit of lifelong drug therapy for HIV-infected individuals. What is for sure, however, is that »[t]he fight against HIV/AIDS is, above all, an economic issue.«[5]

An important preliminary mark must be made when discussing strategies to prevent HIV and AIDS. This severe virus and disease requires a life-

1 Doyal/Doyal (2013).

2 Whelehan (2009).

3 Ford et al. (2014).

4 The survey by Jochen Drewes and Martin Kruspe on behalf of the Deutsche AIDS-Hilfe of homosexual men and their sexual behaviour includes also a chapter on HIV-PEP. Although one special risk group, younger men, are underrepresented, the study collects and summarizes useful statistical data about the knowledge and use of HIV-PEP amongst MSM and detects fairly poor knowledge and usage of the treatment. See Drewes/Kruspe (2013).

5 Leoni (2010), ix.

long regimen of drugs while imposing a higher risk of contracting other diseases, such as Leukoencephalopathy or AIDS-related lymphomas.[6] In this connection, it must be stressed that the severity of the disease does not mean that already infected people are judged to be in a deficient state of human life. The struggle against sickness does not necessarily entail fighting against sick people, although the history of medicine provides plenty of examples to the contrary.[7] A sharp distinction between ethically permissible efforts against sickness and ethically not permissible efforts against sick people stems from the following philosophical observation: Diseases, according to traditional philosophy, are considered to be a natural evil (*malum physicum*). This is to say that diseases cause a »too much«, which occurs in pain, for instance, that individuals desire to overcome.[8] Thus, launching programmes against diseases does not constitute an assault against those infected, because the programmes seek to obtain the same situation for both groups (infected and non-infected). The goal is to prevent both groups from having to suffer from the »too much« of severe sickness through a) avoiding infection or b) through medication enabling a person to live like someone who is not infected. The »not being infected«, notably, applies to both groups. The human right to healthcare means both: Preventing people from being infected[9] and treating the infected, in the best scenario, so that they can live as if they had not been infected.

6 Wyen et al. (2004) and (2012).

7 Schmiedebach (2012).

8 Wirth (2015a); Wirth/Hurwitz (2016).

9 The Universal Declaration of Human Rights states in Article 25 that not only health care in the sense of treatment, but also in the wider sense, which includes prevention as the means of a certain standard of living, is a human right: »Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care […]«.

2. OVERVIEW OF HIV POST EXPOSURE PROPHYLAXIS

HIV-PEP is an antiretroviral treatment that reduces the risk of HIV-infection after potential exposure, both occupational and through sexual intercourse, by approximately 80% when treatment with drugs is initiated within 48 hours after potential exposition to the HI-virus.[10] A 28-day-treatment is recommended. Medication may be necessary to manage side-effects that occur among a number of users and include nausea, fatigue, diarrhea, and headache and that are often an issue affecting adherence.[11] These side-effects and possible effects on liver and kidney are usually reversible. All guidelines agree that HIV-PEP is indicated in cases of anal or vaginal sexual intercourse when one partner is HIV-positive and not on sufficient antiretroviral-medication or when men have unprotected anal sex with men, because this specific group is considered to have a higher prevalence of HIV than individuals exclusively practicing heterosexual sex.[12] Comparable use of antiretroviral medication occurs with pre-exposure prophylaxis and prevention of mother-to-child-transmission.[13]

The World Health Organizations' (WHO) Guidelines on HIV-PEP begin with mentioning the astonishing fact that since 1989, HIV-PEP has been prescribed after occupational exposure to HIV.[14] This guideline also mentions the failures of HIV-PEP and stresses that complete protection is

10 Jensen (2011).

11 Jones, S. G. (2009).

12 Benn et al. (2011); Deutsch Aids-Gesellschaft (2013). It is rather unclear how women who may have sexual risk contact with the one-fifth of MSM who also have heterosexual contact can be protected. Their number seems to be on the rise, cf. Drewes/Kruspe (2013). Concerning those 11% of MSM who have sexual relations with a woman, newer empirical work stresses the unlikelihood that these men are a bridge for HIV; although such studies admit that a closing result cannot be given on the question, cf. Sekuler et al. (2014). This is especially interesting, insofar as only a minority of women who have sexual relations with a bisexual man, as indicated by a German survey, are aware of their situation, cf. Drewes/Kruspe (2013).

13 Baggaley et al. (2015).

14 Drewes/Kruspe (2013).

impossible, and that therefore, sexual intercourse involving a high risk factor is still to be avoided. The WHO explicitly states that HIV-PEP should be easily accessible to all those who have been exposed to potential HIV-transmission, and also mentions children and their specific need for HIV-PEP, especially following incidents of rape. The WHO's guideline on HIV-PEP suggests training teachers, counsellors, police officers, and front-line healthcare workers on this topic.[15] The overall evaluation of HIV-PEP by the WHO is very positive: »Post-exposure prophylaxis […] is currently the only way to reduce the risk of the development of HIV infection in an individual who has been exposed to the virus«.[16] In addition, newer studies on the early use of antiretroviral therapy stress the overall benefit for the individual and society.[17] All in all, the WHO adheres to »strong ethical arguments support providing PEP for HIV infections«[18] and the guidelines' overall assumption puts HIV-PEP explicitly in the area of human rights by generally stating that »HIV-PEP can preserve life and health«.[19] Unfortunately, the strategy of a widened distribution of knowledge about HIV-PEP has not been successful, although a major goal of HIV-prevention is to inform about means of prevention.[20] This strategy should include the topic of HIV-PEP as well, which is not the case in all current works on HIV-prevention.[21] One of the most significant findings to emerge from the study by

15 World Health Organization (2007).

16 Ibid.,2.

17 Cohen et al. (2011).

18 World Health Organization (2007), 2.

19 Ibid., 5.

20 Corsten/von Rüden (2013).

21 One example is the work of Rolf Rosenbrock, a prominent voice in the academic approach to the HIV challenge during the last decades in Germany. In his work, HIV-PEP plays no crucial part. In a recent paper on societal and medical challenges surrounding AIDS prevention, HIV-PEP is not mentioned at all, although he quotes a campaign in Germany (»Ich weiß, was ich tu«), which focuses on PEP and other gay-related health issues, cf. Rosenbrock/Schmidt (2012). This is especially astonishing as Rosenbrock has dedicated much of his work to the politics and prevention of HIV and one of his first, still fundamental works is about how AIDS can be overcome more efficiently, cf. Rosenbrock (1987). Although his book was written before HIV-PEP, it is still unclear why

Drewes and Kruspe is that even special risk groups for HIV, such as MSM, either do not know about PEP at all or do not feel well informed about it.[22] Younger people are especially prone to being unaware that after a risk contact an HIV infection can be prevented,[23] while younger MSM show an increased vulnerability for HIV infection (see chapter 4). More broadly, an important implication of this is that so far, HIV prevention has failed to establish HIV-PEP widely, and consequently the right to healthcare of MSM and other risk groups is not fully taken into account. Thus, there is a definite need for tackling this issue as a serious human rights issue.

HIV-PEP never became a crucial topic in the prevention strategies of the last decades.

22 Drewes/Kruspe (2013). In 2007, only 17% of MSM knew about the option of a combination therapy – see Cohen et al. (2011) – that helps to prevent HIV infection after risky behaviour. Though the weakness of that study was that the term PEP was not mentioned, follow-up studies also revealed poor knowledge of HIV-PEP. These findings suggest in general that information politics since the beginning of HIV-PEP in 1989 have failed to reach the intended audience. Drewes and Krusper summarize the German situation and the knowledge about HIV-PEP as being differentiated and rather deflated: »Only a minority of the participants [of the survey] feel well informed about PEP, and amongst those participants who know about PEP, only a minority say that they know where to obtain PEP in case of an emergency. Although the probability of being familiar with PEP increases with the probability of needing it, gay men and other MSM who have sex with risky partners or with a high number of partners are, as a whole, rather poorly informed about PEP and where to find it. […] Although the number of gay men and MSM with PEP-knowledge is visibly increasing in Germany, knowledge about PEP must be judged as bad overall.« Drewes/Kruspe (2013), 241–242. This observation throws up many questions in need of further investigation, including the question of the need for general knowledge in society about HIV-PEP, which would not only be a support for MSM health but also for the currently rarer HIV risk for heterosexual individuals.

23 Drewes/Kruspe (2013).

3. HUMAN RIGHTS AND HIV-PEP

Access to healthcare is the bare minimum of the human right to health, as expressed in Article 25 of the Universal Declaration of Human Rights.[24] This is especially true in cases of medical emergency.[25] However, access to healthcare is dependent on knowledge of one's personal situation, of possible treatment and where to go when needed. In the case of HIV-PEP this is more easily said than done. The situation amounts to an offence under Article 27 of the Declaration of Human Rights, which is dedicated to »sharing […] scientific advancement and its benefits.«[26]

Another relevant international document concerning human rights and healthcare is the United Nation's Committee on Economics, Social and Cultural Rights' (CESCR) document entitled *The right to the highest attainable standard of health*. General Comment No. 14 (GC No. 14) and its para. 2 include what is known as the triple »A« and »Q«.[27] This AAAQ stands for availability, acceptability, accessibility, and quality of healthcare. Concerning accessibility for the purpose of evaluating HIV-PEP leads to a complete failure. According to GC No. 14, accessibility means, in detail, non-discrimination, accessibility of information, and physical and economic accessibility.[28] None of these fourth goals are reached, an observation which in some aspects also holds true for general HIV treatment.[29] HIV-PEP regulations tend to discriminate against people who are possibly infected but who are not in target groups. Access to information is also poorly managed. It is necessary to be aware that PEP exists in order to be able to search for further information in cases of HIV emergency. Since many people probably have a rather vague idea that a certain period of time is required before HIV can be detected in the blood, they would not see the need for immediate action. Physical access is also not sufficient because only specialized hospitals are able to offer expertise and treatment with

24 Farmer (2003); Lisk (2010).

25 Asher (2010).

26 Farmer (2003), 215–216.

27 Jones, P. S. (2009).

28 E/C.12/2000/4, 11 August 2000.

29 Jones, P. S. (2009); Lisk (2009).

HIV-PEP. In addition, economic accessibility is insecure where there is uncertainty as to whether health insurance covers treatment with HIV-PEP.

What is worth mentioning is that GC No. 14 puts special emphasis on vulnerable groups. Men who have sex with men might be considered a vulnerable group in the sense of GC No. 14 and need to be addressed specifically.[30] The General Comment also states that providing education and access to information is a core obligation in healthcare (GC No. 14, para. 44).[31] This again makes HIV-PEP-policies appear in rather a negative light.

Health is one of the unachievable but undeniable values people desire. It is a very fragile state that will be weakened over time and that can be lost in the case of chronic and severe sickness. Therefore, healthcare is a basic human right and implementing the right to healthcare is a political act. Thus, the human right to healthcare implies the right to timely and appropriate professional help. It is clear that if an individual does not know about the existence of HIV-PEP, recognizing the individual's need for timely and appropriate medicine is impossible and thus a human rights issue.[32]

4. ETHICALLY DEBATING HIV-PEP

The desirability of a widespread administration of HIV-PEP is medically and ethically debatable. The aim of this contribution is to stress the fundamental right to information regarding one's health and the means to prevent diseases. Having discovered that there is a lack of knowledge concerning HIV-PEP – which, as indicated, needs further statistical evaluation – medical ethics can participate in overcoming a hesitancy to promote the only existing and therefore ultimate therapy to prevent the HI-virus from infecting an individual after potential exposure.

When examining the ethical debate on the withholding of HIV-PEP in some parts, which can also, in this specific HIV-context, be understood as »structural violence«, as Paul Farmer did explicitly,[33] two items should be

30 Doyal/Doyal (2013).

31 Santelli et al. (2010).

32 White (2009).

33 Farmer (2003), 230; White (2009).

considered in more detail: First, the quest for medical paternalism or maternalism in the debate over HIV-PEP; secondly, the question of proportionality between risk and administering drugs.

First and foremost, the argument is that the knowledge of HIV-PEP could promote high-risk sexual behaviour. This has not only been emphatically refuted, it also seems to be a paternalistic argument exhibiting low regard for an individual's autonomy. Medical paternalism or maternalism more generally alludes to the conviction that individuals without academic medical education are unable to entirely understand their circumstances and therefore need professional guidance. A recurring theme of implicit paternalism is the conviction that popular knowledge about HIV-PEP could weaken behavioural discipline in terms of sexual intercourse, which is considered to be the best strategy to prevent HIV or any sexually transmitted infection. The efficacy of the entire abstinence strategy is highly debatable;[34] even in a theological perspective, since control over one's behaviour appears to be a never entirely accomplishable good. Religions and ethics deal with the torment of always being unable to overcome the juxtaposition of will and deed.[35] Humans are known for notoriously failing to realize possible moral convictions, while other people do not have any moral convictions (regarding their sexual practice) at all. Hence the »rational choice paradigm« in HIV-prevention[36] appears to be a fairly weak approach due to the weakness of rational choices, especially in the area of sexual desire. If HIV-prevention is to become more successful, medical aid without paternalistic or maternalistic judgment about patients is highly required, as these judgments are not a medical task in any way. Any cultural or sublime religious reason for hindering wide access of PEP therefore needs further and critical inspection.[37] Hence, the learning strategy aspect in HIV-prevention[38] should incorporate the issue of HIV-PEP, especially in terms of risk group-oriented approaches,[39] also because the gap between that

34 Altman (2010); Kovara (2012).

35 Wirth (2015b).

36 White (2009); Vollmann (1991).

37 Doyal/Doyal (2013); Lisk (2010); Jones, P. S. (2009).

38 Corsten/von Rüden (2013); Rosenbrock/Schmidt (2012).

39 Herrn (1999); Herrn et al. (2002).

which has been learned and that which is performed is especially evident in the domain of sexual pleasure.

Another core issue regarding HIV-PEP and medical ethics is the question of proportionality. The ethical means of appreciation of conflicting values (»Güterabwägung«) must also be conducted for the usage of HIV-PEP.[40] Since HIV is still an incurable and severely chronic disease,[41] much effort has been put into the attempt to find vaccines or medication that not only helps infected people to survive, but also seeks to cure HIV-infected individuals in the future.[42] Until such a cure is found, HIV-PEP should be administered widely, as side-effects are reversible and not as intolerable as they used to be. The cost of approximately 1.500 Euros for the 28 days of therapy with antiretroviral medicine is not astronomical, as well as being in line with the human right to basic good healthcare. Due to the severity of an HIV infection and the physician's mandate to cure, HIV-PEP should be prescribed whenever there is any danger of HIV-infection.

At least in Germany, one reason for the observable hesitancy on both the physician's and the patient's side is the unclear financial situation, as insurance companies could possibly refuse to cover the cost for HIV-PEP. Experiences seem to differ depending on the state and the concrete practice within the institution where PEP is administered. Although an unclear situation is likely to hinder patients from receiving adequate treatment, it seems as if compulsory insurance companies (»Gesetzliche Krankenkassen«) do generally cover costs for HIV-PEP, when the treatment is administered according to the aforementioned German-Austrian Guidelines. These differentiate between circumstances in which HIV-PEP should be »suggested« (e.g. anal or vaginal intercourse with a person with a known HIV-infection) and circumstances in which it should be »offered« (e.g. receptive or inserting anal sexual intercourse amongst men, especially when occurring in places visited by MSM seeking sexual intercourse). Although the likelihood of transmission is different, both indication groups are in what German insurance companies consider to be situations where an infection is very likely and thus cost should be covered.[43] There are other medi-

40 Whelehan (2009).

41 DiClemente et al. (2009); Whelehan (2009).

42 Ibid.

43 Marcus/Stellbrink (2013).

cal circumstances where there is no hesitancy to administer medication to potential patients without knowing beyond all reasonable doubt that they are needed. An example is meningoencephalitis. If a young child is suspected to have contracted the virus, acyclovir is immediately administered. Side effects are tolerated since avoiding a disease would be worth the mild discomfort occasioned by them.

Another aspect that might arise from the argument from proportion is that of the rather low risk of HIV infection and the relatively low number of new infections each year. For example, there were 3.525 registered HIV cases in 2014 in Germany,[44] and the argument claims that new PEP politics in medicine is too much effort for such a small amount of people, though infected people do not know their status early (late presenter).[45] Although it may be of minor importance compared to other diseases, the HIV prevalence amongst MSM in Germany is around 4,9–6,7%.[46] Moreover, HIV is still so severe that is it important to be prepared for every eventuality, also because the disease can affect any social group in society.[47] To underline this with an analogy: Anyone who boards a plane will be confronted with safety instructions pertaining to the well-known »unlikely event« of an accident. What's striking is that less than 30 individuals in Germany were involved in serious plane accidents in 2016. In other words, there is a notion that possible extremely harmful but rather unlikely situations need constant preparation through the distribution of information. A similar requirement should be in place for information on HIV-PEP, since contracting HIV in the territory of Germany is more likely than being involved in a plane crash.

5. CONCLUSION

The ethical debate about HIV-PEP indicates that much more information about HIV-PEP should be provided. Key players are policy makers, teachers, and healthcare professionals. A new HIV-PEP-strategy could begin

44 Robert Koch Institute (2015).

45 Whelehan (2009); Rosenbrock/Schmidt (2012).

46 Drewes/Kruspe (2013).

47 Whelehan (2009).

with the revision of biology books that are used in schools and would fall under the General Comment (GC No. 14, para. 44).[48] At present, the sexual education sections of biology books in Western countries generally contain detailed information regarding the prevention of unwanted pregnancies and emergency contraception, but there is no information about emergency post-exposure prophylaxis. This is despite the fact that the information on HIV prevention would appear to be the most important amongst other kinds of prophylaxis, for instance against hepatitis. The strategy of communicating the possibility of HIV-PEP in biology classes and sexual education would be especially important to the group of young men who have or will have sex with other men.[49] Perhaps surprisingly, the rates of infection and unprotected sexual intercourse among young men who have sex with men seem to be relatively high compared to those among older men,[50] whereas studies also show that about one third of MSM usually do not practice risky sexual interaction.[51] However, an open and unpretentious introduction to

48 Santelli et al. (2010). It is worth mentioning, that letter »b« of GC No. 14, para. 44 stresses the need to spread information when it is understood as an obligation »to provide education and access to information«

49 Newer infection rates in East Europe, however, indicate that heterosexuality may not necessarily provide protection against HIV. Statistical data indicates that there has been a slow but constant increase in HIV infection rates amongst the heterosexual general public in the last decade, cf. Rosenbrock/Schmidt (2012). The question regarding to what extent bisexual men are a bridge for transmission is not fully resolved, but on the basis of the available data, they do not seem to play a key part in transmitting HIV.

50 DiClemente et al. (2009); Vollmann (2001). Admittedly, it must also be considered that in actuality, men who have sex with men who are HIV-positive tend to be older, live in urban or metropolitan surroundings, more often define themselves as homosexual and judge their general health condition to be poorer than that of general populations, cf. Drewes/Kruspe (2013). However, 90% of those who know about their HIV-infection undergo antiretroviral therapy and 80% are not infectious any more, as the HI-virus in their blood is below the limit of determination, cf. ibid.; Cohen et al. (2013). Amongst older HIV-positive men, the tendency that they undergo successful treatment is higher than amongst younger MSM, as implied by the quoted study by Drewes and Kruspe.

51 Rosenbrock/Schmidt (2012).

the specific healthcare issues of MSM within school education, including information about HIV-PEP, could also help to normalize the self-awareness of young men who have or will have sexual relationships with other men. This is especially urgent as internalized homo-negativity is still widespread. Internalized homo-negativity refers to taking negative assumptions about homosexuality held by parts of society to be true, which leads to an (unconscious) negative self-picture. This again increases the susceptibility of MSM to healthcare issues.[52] The fear of informing one's general practitioner (GP) or another physician about same-sex intercourse will hinder a homosexual or bisexual man from obtaining adequate healthcare, including means of prevention.[53] There is also evidence that family and peer support help MSM to deal constructively with idiosyncratic needs, including a higher adherence to HIV-testing.[54] Treating special healthcare issues covering not only heterosexual concerns during school education is of paramount importance and can lead to a more open handling of specific needs that may otherwise be hindered by internalized homo-negativity. Discrimination and stigmatization not only lead to psychological harm but can also cause, apart from direct violence, severe physiological conditions, especially when MSM are too afraid to take sufficient care of themselves.[55]

Not only men who have sex with men, along with their friends and families, need to be informed about HIV-PEP. Women can also be exposed to situations where it is important that they be informed about HIV-PEP, as currently one heterosexual person in every 10.000 has tested positive for HIV. The number is increasing, especially in Eastern Europe.[56] Although bisexual men don't appear to be a »bridge« for HIV-transmission,[57] their role cannot be entirely disregarded.

52 Drewes/Kruspe (2013).

53 Ibid.

54 Ibid. Also due to the stigma of an HIV infection or expressed anxiety, the majority of MSM generally have a weak adherence to HIV testing. A recent German study revealed that only one third of MSM test their status regularly, although amongst the group of MSM who do it only once a year or never, many state that they engage in risky behaviour (ibid.).

55 Drewes/Kruspe (2013).

56 Rosenbrock/Schmidt (2012).

57 Sekuler et al. (2014).

Finally, in order to draw a more general lesson from the debates concerning HIV-PEP, the stereotype that in highly developed countries highly undeveloped areas in high-tech and medicine domains would not persist has been proven to be incorrect. The need for further developing HIV prophylaxis is obvious and should be addressed.

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