CHAPTER 12

Vulnerability around Health Issues: Trajectories, Experiences and Meanings

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In this chapter, we discuss how vulnerability takes on contrasting and ambivalent meanings when approached at different levels. More specifically, we are interested in how institutional approaches do not necessarily align with the perceptions and experiences of those who are defined as vulnerable. Over the last decades, scientific knowledge, and technical and medical measures have supported the development of the prevention and management of vulnerability. However, despite social and public health interventions, vulnerability reduction remains unequal across social groups. Starting from this mismatch, we focus our attention on how individuals in vulnerable circumstances develop their own strategies and meanings in the context of adversity, along but also against collective definitions of and responses to vulnerability.

In the introduction, Spini and Widmer contrast two main perspectives on vulnerability. The first focuses on individuals having difficulties coping with adversity due to their low resources and their subsequent need for support

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D. Spini, E. Widmer (eds.), *Withstanding Vulnerability throughout Adult Life*, https://doi.org/10.1007/978-981-19-4567-0_12

from social institutions through different categories of welfare. The second perspective starts from individuals' interpretations of their own circumstances at different stages of their life course, thereby connecting vulnerability with their own definitions of social citizenship and in relation to integration in society. This distinction suggests that '"vulnerability" means different things to different people' (Brown 2011, p. 313). Indeed, we propose that these meanings vary depending on people' s relationship with vulnerability: as a condition that they ought to protect others as part of their professional role (as health professionals or social workers) or as a personal condition reflecting one' s own life trajectory and aspirations. In this chapter, we tackle these contrasting meanings to better understand the complexity of the social processes taking place around vulnerability. We consider that institutional or professional views, on the one hand, and lay or ordinary meanings, on the other hand, are not fully independent. Rather, they are interrelated and mutually influential, notably through social norms.

This discussion will focus on health issues. From a medical and public health perspective, vulnerability tends to be defined through biological conditions, individual characteristics or behaviours (Armstrong, 2014). In this approach, contexts, interactions and life course effects are most often absent. However, the life course perspective invites us to consider how interpretations of vulnerability change over time at the individual level over successive life stages and at the societal level as a result of medical and social transformations (Delor & Huber, 2000; Wadsworth, 1997). These changes are not likely to occur synchronously across levels, thereby contributing to generating divergent views on what vulnerability actually means. In addition, focusing on how meanings and experiences develop over time sheds light on the intersection of agency and structural processes and emphasises the importance of contexts, social norms and interactions in people' s understandings of vulnerability.

Based on research conducted on health trajectories in the context of the LIVES research program, the first section shows the importance of paying attention to various understandings of vulnerability and emphasising its situated character related to actors' positions. The second section illustrates the argument in greater depth by using elements from a qualitative study on the experience of HIV-infected women's trajectories (Fargnoli, 2021) to highlight contradictions between their own understandings of vulnerability and its medical framing. In conclusion, we stress the importance to policymaking of defining vulnerability based on people' s needs and their own assessments.

Vulnerability around Health Trajectories

We approached vulnerability through the lens of health inequalities. Along with developments in life course epidemiology, we aimed to contribute to the understanding of why health inequalities remain persistent in high-income countries, despite an overall improvement in population health (Cullati et al., 2018a). Analysing health trajectories implies approaching health as a dynamic feature that, beyond biological ageing, is shaped by a number of exposures, including genetic and biological make-up, family and work conditions, and societal and environmental factors (Burton-Jeangros et al., 2015). Moving beyond associations between individual risk factors and specific diseases, epidemiology has endorsed a life course perspective to account for the long-term influence of lifelong factors on the evolution of health (Burton-Jeangros, 2020). Adopting a cumulative (dis)advantage framework (Dannefer, 2003), empirical analyses of longitudinal data were employed to assess the role of individual socioeconomic resources and institutional resources in how health evolves across social categories. In addition to the influence of childhood and adulthood socioeconomic circumstances over health trajectories later in life (Cullati, 2014, 2015; Cullati et al., 2014a, 2014b), the impact of welfare regimes in moderating health inequalities was also assessed (Sieber et al., 2019; Sieber et al., 2020). Such quantitative analyses inform us about general trends and describe how social determinants shape contrasting health trajectories. They provide important insights into the accumulation of vulnerability as a result of 'dynamics of stressors and resources across the life course' (Spini et al. 2017, p. 5). These processes matter not only for individuals' social life but also for their health. Current developments in epigenetics allow to analyse biomarkers and socioeconomic data jointly and thus to better understand the intersection of biological and social processes in shaping health trajectories (Landecker & Panofsky, 2013).

However, these analyses also present shortcomings. For one, they tend to adopt a top-down view of vulnerability based on definitions formulated by scientists and policymakers of what individuals should do to avoid being in a vulnerable condition. Furthermore, the medical perspective reflects modern individualism, emphasising the importance of individuals' characteristics and behaviours for health (Armstrong, 2014). In both welfare and public health actions, activation policies have become the preferred strategies to address vulnerability. Next to recommendations to promote social justice, vulnerable people are continuously encouraged to modify their 'inappropriate' behaviours to improve their social and health circumstances. The idea of risk, so common concerning health issues, has promoted this emphasis on individuals' agency: 'Being at risk therefore established the perfect machinery for placing the population in a constant state of readiness and awareness in regard their health' (Armstrong 2014, p. 167). Public health measures advocated in the context of the COVID-19 pandemic have reiterated this focus on individual responsibility regarding risk.

Against this institutional perspective, a number of findings suggest that meanings of vulnerability can vary along contextual and temporal circumstances. People interpret their life circumstances and their capacity to act upon them in light of their own life course, experiences, hardships, and aspirations. In support of this, research dedicated to well-being has shown that additional resources do not systematically improve individuals' quality of life, as revealed in analyses of the quality of life of successive cohorts of women born between 1916 and 1945 in Switzerland (Burton-Jeangros & Zimmermann-Sloutskis, 2016). Those born more recently reported higher resources but lower quality of life than those born earlier. This discrepancy could result from the contrasting levels of adversity experienced by successive cohorts; women born earlier having encountered more hardships. It could also reflect changing sociocultural expectations among more privileged populations with regard to health and life conditions, hence reducing their perceived quality of life.

In the Parchemins study on undocumented migrants' health and well-being (Jackson et al., 2019), the quality of life of newly regularised migrants was found to be approximately as high as the quality of life reported by local residents. However, the resources available to both categories are widely unequal (as measured, for example, by average income, ranging between 23,000 CHF/year for undocumented migrants and 83,000 CHF/year for regular local residents). In this context, the motivations underlying undocumented economic migration are likely to shape expectations and aspirations that are clearly distinct from those of people who have resided in Switzerland without having encountered the hardship experienced by migrants who remain undocumented for a long time. The latter are willing to accept their difficulties in regard to their capacity to support their families who remained in the country of origin (Burton-Jeangros et al., 2021).

These findings indicate that the definition of vulnerability is normative, based upon values and goals that are not systematically shared across societies, across groups and over time. This assertion is further evidenced by the fact that preventive activities tend to increase health inequalities rather than diminish them. For example, it has been observed that the higher uptake of preventive measures (such as not smoking, eating healthy food, and taking exercise) in higher socioeconomic groups tends to reinforce the gradient in health rather than to diminish it (Stephens, 2010). In other words, more privileged people, who are closer to those holding dominant positions in society, share similar worldviews and aspirations that contrast with those of less privileged people. Research on health care renunciation or social aid non-take-up has also emphasised such a clash of expectations and values across social groups. We observed this in the context of the first COVID-19 lockdown in Switzerland in spring 2020. Undocumented or newly regularised migrants engaged in only a limited use of institutional support, despite an important deterioration of their economic circumstances. Such limited use was motivated by their fear of being deported but also by their internalisation of the norm of autonomy and thus of not asking for any outside support, as well as by the shame associated with demanding help (Burton-Jeangros et al., 2020).

Health issues are particularly relevant in discussing contrasting views of vulnerability, since they typically encompass different framings of what it means to be healthy or sick. Medical and public health tend to approach individuals as autonomous, self-responsible agents who try to maximise their health (Petersen & Lupton, 1996; Armstrong, 2014). This framing has, however, been criticised for its overly limited consideration of individuals' socioeconomic resources and living conditions. Furthermore, the life course perspective invites us to consider not only contextual circumstances but also people' s own interpretations of what matters to them in terms of health (Burton-Jeangros, 2020). Self-rated health, a commonly used item in population surveys, acknowledges the importance of individuals' own evaluations, especially since many health conditions do not end up in contact with health professionals. Indeed, it appears that this indicator presents important overlaps with more 'objective' indicators of health across cultural contexts (Cullati et al., 2018b). In addition, qualitative anthropological and sociological research has provided useful insights into emic views of health and vulnerability and their contradictions with the perspectives of other social categories, notably those of individuals in professional roles. We consider that these studies, stemming from a different research tradition and usually using ethnographic approaches, are important to provide a more in-depth knowledge of vulnerability. Notably, they analyse how vulnerability changes over individual life stages, in tight connection with significant others, while considering individual strategies as well as the external constraints and social norms to which they are exposed.

In summary, longitudinal surveys are useful to show patterns in population health distribution and account for the dynamics of stressful experiences and resources available to individuals. However, they offer only a limited understanding of the mechanisms connecting social and biological conditions. The classical distinction among the medical definition of disease, the person's own experience of illness, and the policies framing sickness (Bjørn Hofmann, 2016) illustrates the variability and complexity of meanings attached to health-related vulnerability. In the next section, we elaborate on those contrasting understandings, with elements drawn from qualitative research concerning women living with HIV in Switzerland (Fargnoli, 2021). Health inequality research has shown how important resources are in facing stressors and remaining in good health (Burton-Jeangros et al., 2015). However, we want to emphasise here how vulnerability is also shaped by experiences and interactions and by the interpretation of vulnerable situations as elaborated by the people living them and by others around them (cf. Bonvin et al., in this volume).

Vulnerability Experiences of Women Living with HIV

In the early 1980s, HIV/AIDS emerged as a risk that threatened large segments of the population at a global scale. The first decade following its emergence focused on health education to reduce risk behaviours and thus limit the spread of the virus. In the mid-1990s, antiretroviral therapies (ART) normalised the epidemic by keeping infected people alive, thus reducing their biological vulnerability. A decade later, the acknowledgement that HIV-infected people under regular medical treatment were not presenting risks to their regular partner reduced collective vulnerability even further. Medically, the risk of HIV infection has thus been 'domesticated' (Rosenblum et al., 2012), moving from an unacceptable to an acceptable risk with the 'normalisation' of AIDS (Setbon, 2000). Over the last 20 years, the image of an HIV-infected person as capable of leading a 'normal' life has gained traction. While the biomedical approach did not succeed in curing people living with HIV, it does keep them alive in an intermediate status between health and illness—and thus, in a condition of vulnerability. Next to the medical and institutional framings, which emphasise the reduction of individual and collective risk, the narratives of women living with HIV who do not belong to targeted groups[1] have revealed how they experienced vulnerability over time.

'Treated Body': HIV under Control

In the Swiss context, the liberal health model protects individuals (confidential HIV status, access to social insurance in case of incapacity to work) and ensures care for everyone (treatment and medical follow-up reimbursed by mandatory health insurance). At the same time, this system makes individuals responsible for their own health: a 'good' HIV-infected patient or citizen is expected to take antiretroviral therapies, available in Switzerland since 1996. He or she takes care of himself/herself by adopting 'responsible' behaviours to avoid worsening his or her state of health and further disseminating the disease, since infecting others is sanctioned by law.

From the medical point of view, the 'treated body' (Pierret, 2006) represents an HIV infection 'under control'. Thanks to the efficiency of ART, the viral load becomes 'undetectable', which means that HIV has been reduced to such a small quantity that standard blood tests cannot detect it. 'Made undetectable through treatment' (interviewed doctor in 2015) has become a medical standard in Switzerland and elsewhere (WHO, 2016).

Medically, 'normalising HIV/AIDS' has meant that in high-income countries, the virus has been transformed into a 'manageable public health problem' (Rosenbrock et al., 2000). The promise behind ART is the guarantee for people living with HIV to survive and lead a life like everyone else (Squire, 2010). Overall, for the HIV specialists interviewed, 'being undetectable' implies that 1) the treatments are taken and effective; 2) there is no risk of HIV transmission, and the virus does not develop resistance to the treatments; and 3) serodiscordant couples[2] can have a child naturally. According to their views, based on the latest evidence, vulnerability is thus minimised thanks to medical treatments.

Next to this medical framing, the promise to be able to live a 'normal life' appeared ambivalent for the study participants. The notion of

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[1] Thirty in-depth interviews with women living with HIV, who do not belong to targeted groups as defined by the Federal Office of Public Health (FOPH), were collected between 2013 and 2016, and ten HIV/AIDS specialists were interviewed.

[2] One partner is HIV-positive and the other one is HIV-negative.

'undetectable viral load' remained vague and ambiguous for several of them. Their treated body still represented a 'weak, sick and intoxicated' body, and the perception of it as a 'dangerous body' for others remained.

'Dangerous Body': HIV as a Social Threat

For the interviewed women, 'being undetectable' did not necessarily mean being healthy but rather no longer representing a risk of HIV transmission, which they translated into no longer being 'dangerous' or 'monstrous'. Therefore, their views on vulnerability were foremost expressed in terms of a social condition that affects others—i.e., a body that had been previously dangerous had become safe for others—rather than as a physiological state. However, for some interviewees, the perception of 'contagiousness' persisted.

> 'It means that I can' t transmit "it" to someone. I am no longer contagious. Even that would scare me. What does that mean? That I am less dangerous than someone who is HIV-positive and who wouldn' t know it?' (Fanny).[3]

Although they were declared to have an undetectable HIV viral load and were living without symptoms, they remained perceived as potentially dangerous to others and to society.

> 'Not many people today would drink from my cup, lick my spoon, when we know very well nobody can get AIDS like that! The fears are just as deep as they were back then. People get along intellectually, but fear is just as deep.' (Adèle).

The infectious nature of HIV remained strongly embedded in social norms and was perceived by interviewees as a powerful driver of their rejection by others.

The impact of HIV on the interviewees' feminine identity was evinced by their perception of their body as 'dirty', a view that nurtured negative feelings towards their intimacy. Being HIV-infected underpinned the idea that, somehow, they had failed to meet female social obligations and roles as 'good' mothers and wives and had transgressed the sociosexual norm of virtue typically assigned to women (Héritier, 2013; Théry, 1999).

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[3] Quotes are associated with a pseudonym to respect participants' anonymity.

Therefore, HIV-infected women' s perceptions and experiences appeared to be strongly influenced by the social and gender construction of HIV/AIDS as a 'moral disease'.

> 'It is still stigmatised: either you are an ex-drug addict or a whore.' (Rose).

Some emphasised that their noninfectious status as a result of their treated body did not convince everyone; their body was still associated with representations of 'death transmission'. Indeed, two-thirds of the interviewees had been tested HIV-positive before the introduction of effective ART, at a time when this diagnosis was synonymous with death. Their infection and diagnosis thus took place in a context of medical powerlessness that particularly marked them then and continues to fuel their fears even today. Hence, for most of the interviewees, their current minimal risk of HIV transmission remained an unacceptable risk:

> 'I am still reluctant to have unprotected sex even if I have a steady partner. I' m never 100% ok. To say that we can have sex without a condom, there is always a little doubt about not infecting a third person.' (Tina).

Moreover, if these HIV-infected people were not themselves convinced of their low risk, nor were the health professionals they had worked with or contacted. Indeed, some participants claimed having experienced discrimination in those interactions. These elements indicate that living with HIV means living with the indelible imprint of the history of a threatening epidemic whose social representations have not been deeply altered by the development of medical solutions.

'Sick and intoxicated body': HIV as Personal Vulnerability

Descriptions of the 'infected body', 'dangerous body', 'sick body', 'vulnerable body', 'vegetable body', and 'intoxicated body' were present in the women' s narratives to express their body's fight against the virus and the medical treatments. They were concerned with the treatment's long-term side effects, viral resistance, interactions of ART with other treatments and comorbidities.

ART, by destroying HIV, also affects treated individuals' bodies. Most of the interviewees felt their bodies 'threatened' at some point. Some even mentioned having their bodies 'eaten up' by the treatments or 'being intoxicated'. In the long term, the treated body becomes a painful, sick and worn-out body, which has both psychological and social consequences. 'Being in pain all the time' limited these women's autonomy and social interactions. In addition, the irreversible nature of HIV infection, the continuing uncertainty about the course of the disease and long-term treatment weighed on their life course:

> 'You may be sick, but at the moment you are not sick. You don' t know how long you will not be sick and when you may or may not get sick.' (Valentine).

Discrepancies between participants' expectations and interpretations and those of their physicians also appeared in the explanations of the symptoms experienced. The interviewees considered the treatments exhausting, whereas the doctors never blamed the treatments. Participants complained about not being considered or taken seriously by specialists, who interpreted their complaints in light of the risks of treatment interruption.

According to the interviewees, in the absence of evidence—since their suffering, pain and exhaustion remained invisible—doctors would typically attribute their symptoms to something else, such as advanced age or psychological factors. Thus, the medical vision of an undetectable viremia (the presence of HIV in the blood) ensuring 'normal' experiences with HIV did not resonate with their lived experiences.

> 'What is the basis for saying that you' re "healthy"? Medical tests or how do I feel?' (Béatrice).

For doctors, undetectable viremia defined a form of normality and the absence of vulnerability. For the participants, however, normality was defined by the way in which the disease affected their daily lives. Through their interruption of treatments, pauses, refusal or reduction in dosages and use of alternative therapies, they expressed a need to exercise some control over the virus and to be an actor in their own health. By (re)appropriating medical standards, they claimed a certain expertise, agency and autonomy.

Conclusions

This case study of women living with HIV showed that vulnerability needs to be situated within the life course and social context of the persons concerned. First, if the vulnerability of people living with HIV is controlled from a medical point of view, they live ‘a normal life’ only under certain conditions: life-long treatment and fear of social rejection. Despite the effectiveness of current treatments, concerns about their toxicity and the development of the disease are still raised. Furthermore, people living with HIV do not have the status of legitimate patients: By making them ‘undetectable’, treatments take away their legitimacy as ‘sick patients’. They are neither fully ‘sick’ yet, nor fully ‘healthy’ since they are still HIV-positive and under treatment. Second, their HIV-related vulnerability persists in its social and relational dimensions. Indeed, based on their past experiences, these women’s fears of discrimination from potential sexual partners, health professionals, and relatives remained high. Whereas medically HIV has been considered a chronic disease since the end of the 1990s in high-income countries, the treatments have not, to date, achieved ‘social normalization’ (Poglia Mileti et al., 2014). Furthermore, the transmissibility of the disease is highlighted in the law. This perception of risk makes HIV/AIDS not only a biological but also a social condition.

The medical point of view has emphasised how treatments have transformed HIV into a manageable public health issue thanks to compliant individuals endorsing the official definition of vulnerability. However, such normalisation of HIV is questioned by the experience of those who are infected. Indeed, women living with HIV reported encountering numerous obstacles in their emotional, sexual, professional and social relationships. Overall, their accounts showed how vulnerability, as defined by institutional approaches, does not match the ‘subjective’ or lived experience and understanding of those described as vulnerable. Along with others, we consider it important to address the complexity of these contrasting views: ‘In emphasising the relational, contextual, and process aspects of the risk itself, we avoid the pitfall of considering vulnerability to be a stable, essential characteristic of individuals’ (Delor & Hubert, 2000, p. 1564). The life course perspective contributes to this effort by emphasising not only the temporal dimension—crucial in the context of the HIV epidemic—but also the role of life-long development, interactions and agency in the meanings attached to vulnerability.

The case of women living with HIV described above notably helps us understand how situated definitions of vulnerability are shaped by the exposures, resources and trajectories of those who formulate them. The medical definition of vulnerability, based on biomedical and epidemiological evidence, adopts a top-down perspective along specialists’ professional trajectories and positions, which do not match the perspective of the persons concerned. Their interactions, affected by divergent understandings, are thus potentially conflictual. In addition, people living with HIV remain exposed to social norms, which still define them as potentially dangerous. Consequently, they experience stigmatisation in different settings and interactions. Offering those who experience vulnerability the opportunity to characterise their experience in their own terms helps to uncover their agency regarding vulnerability amidst those multiple outside influences.

Thus, analysing the articulation of vulnerability across multiple levels confirms that it is not merely an individual experience. Rather, the understanding and experience of vulnerability are built along relations developed with others and institutions over time, through which people either consolidate or question their identity and their vulnerable position as assigned to them from outside. The difficulty and potentially damaging impact of defining 'vulnerable' groups or individuals have been made visible again in the context of COVID-19 pandemic measures. Official categories can deny people' s agency, since some elderly people have contested being labelled particularly vulnerable to the infection. Institutional responses can also potentially trigger discrimination, as observed across age groups in the COVID-19 context.

Considering the coexistence of multiple, socially anchored definitions of vulnerability also has implications for policymaking. Understanding people' s views, especially when these clash with the dominant definitions or with social norms, can definitely help to elaborate policies that are more likely to reach their goals since they are more in line with people' s needs. We therefore concur with the view that addressing vulnerability requires considering its implications in terms of social integration and citizenship. Findings from a number of studies reported here have suggested that the social sciences can contribute to a better understanding of the complexity of vulnerability processes in society. They can do so by comparing views and experiences across social groups and by paying attention to multiple levels, including institutions and social norms, as being either supportive of or detrimental to those who face different forms of adversity.

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