# Living with HIV in post-Soviet states: Rejecting individual stigma through social activism

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## Abstract

This article addresses the continuing resilience of two post-Soviet governments – Azerbaijan and Lithuania – against community-based engagement and social protection of HIV-positive people by exploring the challenges of two social activists. The analysis shows how basic social and medical needs of people living with HIV/AIDS remain unmet, while stigmatisation informs the local health policies and manifests as a protective mechanism against contrary promotion effects. The findings call for urgent policy changes to prevent the further suffering of these people because of poor state strategies. The aim is to help further intervention practices and improve social care services for HIV-positive people in the two countries.

## Keywords

Azerbaijan, discrimination, HIV, Lithuania, self-empowerment, social activism

> Social change can start with an individual.
>
> (Kam, 2014: 734)

## Introduction

In most post-Soviet countries, the basic medical and social service needs of people living with HIV remain unmet. The main purpose of this article is to explore the role of individual advocacy and social activism in post-socialist welfare systems for addressing such basic needs. To do this, our article identifies similarities and differences in the struggles of two HIV-positive activists within the socio-political context of Azerbaijan and Lithuania as exemplar of post-Soviet states. The

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purpose for the comparison emerged from the experiences of the authors living and conducting research in Azerbaijan and Lithuania. This comparison highlights the urgent need for political advocacy for the rights and necessities of people living with HIV in post-Soviet states, with overlapping characteristics in public health policy and historical background. Furthermore, with the exception of a few studies in Lithuania (Gurevičius et al., 2009; Stonienė, 2015; Vainoriūtė et al., 2010), social scientific literature as well as poorly updated reports on HIV and AIDS in both countries have barely touched stigma and discrimination issues. This article also aims to contribute to the literature in this regard.

At first, Azerbaijan and Lithuania may not seem comparable or share explicit similarities. Located in Eurasia and Eastern Europe, with Muslim-majority and Christian-majority populations, respectively, Azerbaijan and Lithuania nonetheless share a common history of being under Soviet hegemony. Health policies inherited from the Soviet regime are thus the converging point of these two nations. Both states have relatively low HIV prevalence rates in comparison to their neighbouring countries (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2014a), although public awareness and political engagement are also low due to the concentration of the incidents mostly among heterosexual injecting drug users, the so-called bridging population (AIDS Healthcare Foundation, 2017; Centre for Communicable Diseases and AIDS (CCDA), 2015; United Nations Office on Drugs and Crime [UNODC], 2015). While generally insufficient coverage for HIV testing could explain the low prevalence, other factors such as religion, repressive politics and heteronormative attitudes are also strongly influential (Gluhovic, 2013). Authors Vainoriūtė et al. (2010) revealed that people with HIV in Lithuania experience stigma and discrimination in the healthcare system in the form of negative attitudes, disrespect and lack of empathy from medical staff. The authors acknowledge that the negative attitudes of wider society towards people with HIV are manifest in healthcare systems by connecting the disease with 'immoral' ways of living. In this regard, Chan (1999) wrote about young democracies in the post-Communist world, noting that 'ideological profiles range from traditional conservatism […] to the pre-Communist epoch, to Christian democracy and the neo-liberal strand of conservatism' (pp. 2, 8). It is also important that, in Azerbaijan, traditional conservative and Islamic values serve as a protective mechanism and carry individual meaning in times of social upheaval (Hunner-Kreisel, 2008). This string follows a conflict of traditions, views and values that draw on the heritage of dissent and opposition extending back to the pre-Communist period.

## Historical context

Although the Union of Soviet Socialist Republics (USSR) implemented free universal healthcare from 1930, the 'policy and funding favoured hospitals over ambulatory care and individual routine check-ups over community-oriented preventive approaches' (Tulchinsky and Varavikova, 1996: 313). Institutionalised and centralised public health policy established during the Soviet regime repressed individual advocacy and social activism that was provided by community-based organisations. Hence, the Soviet national healthcare system solely focused on medical treatment and 'social diseases' were also treated within this paradigm. Within the medical paradigm, people with HIV and AIDS are treated primarily as patients with a medical condition, thus their social care needs are not considered. This paradigm continues to dominate today because healthcare providers and practitioners perceive the social domain beyond the scope of their professional practice (Tulchinsky and Varavikova, 1996). In Lithuania, the tradition of giving preference to institutional care rather than community-based social services is evidenced by the distribution of social services through institutions and municipalities, with limited provision (Mažeikienė et al., 2014; Žalimienė and Lazutka, 2009). Thus, a great deal

depends on social workers, whose job includes advocating for the rights and needs of people living with HIV in both the clinical settings and community-based organisations and services. In both countries today, healthcare systems resemble each other to a certain degree. Both have two separate state systems operating in relation to HIV/AIDS treatment: the medical – provided by ministries of health – and the social – provided by ministries of labour and social services. Inpatient healthcare is still prevalent in Lithuania and alternative ambulatory services are not adequately developed (Kudukytė-Gasperė and Jankauskienė, 2014). Trying to better address patient needs and diminish the divide between health and social care sectors, Lithuania is currently set to promote a collaboration of specialists from both sectors (involving psychologists and social workers) and strengthen service delivery on a community level (Kudukytė-Gasperė and Jankauskienė, 2014). In practice, however, it is focused primarily on palliative and elderly care and on developing preventive approaches to general health issues. Meanwhile, in Azerbaijan, there has been a departure from the Semashko system that privileged collectivistic healthcare to households and community-based interventions (Habibov and Afandi, 2011). After hospital-level expenditures dropped drastically (Bonilla-Chacin et al., 2005), drug treatment and HIV/AIDS became marginalised. This is also visible in countries' action plans regarding HIV treatment and care where development of social services, together with support for community-based organisations, are not the target for future strategies, as outlined in recent progress reports (CCDA, 2015; Ibrahimov et al., 2010).

Current global plans to end the AIDS epidemic and introduce a cure for HIV – a New Era goal set for 2030 by UNAIDS (Nadkarni, 2015) – do not exactly reflect the definitions set by World Health Organization (WHO) in Azerbaijan's public health system (Ibrahimov et al., 2010). Here, most HIV programmes are aimed at monitoring and the evaluation and control of prevalence rates (UNAIDS, 2014b), while poorly executed formal legislation mainly focuses on anti-epidemic medical intervention strategies (Ibrahimov et al., 2010). Moreover, the majority of internationally funded health programmes in Azerbaijan 'are not integrated within the main statutory system' (Ibrahimov et al., 2010: 41). Making treatment available to every person living with HIV, reaching people who are unaware of their serostatus and may therefore unknowingly transmit HIV, and providing essential care for affected individuals are still indispensable necessities for Azerbaijan. Meanwhile, in Lithuania the allocated government funding remains insufficient to address the needs of people with HIV. This shortage of specialised services is similar to other post-Soviet countries where municipalities and local governments do not engage in protecting the rights of people living with HIV (e.g. Semigina, 2017). Azerbaijan's country reports mostly align with the worldwide guidelines and recommendations to protect the positive image of the country, while basic harm-reduction programmes are concentrated in only a few locations in Baku and close surroundings (Burrows et al., 2014). While Lithuania started signing up for international human rights requirements after regaining independence, many in relation to HIV/AIDS are yet to be implemented on a national level. For example, the Vilnius Declaration[1] requires 'universal, affordable, non-judgmental and non-discriminating access to effective, appropriate and safe care, support and treatment, including anti-retroviral treatment' (p. 2). Individual social assistance is a rare occurrence, and family or group therapies for concerned significant others are not commonly considered. In both countries people with HIV and AIDS can access social assistance, usually via organisations that provide help to former convicts and people who inject drugs.

## Theoretical framework

The cases discussed in this article relate to the public activities of social activists within the context of available resources and local healthcare policy and social discourse. Although these

cases are not nationally representative, the narrow scope of such activities in these two countries, and their being unique cases of their kind, justifies their consideration. Individual cases such as these contribute to understanding the diverse experiences of stigmatisation and social exclusion as well as the self-help domain across different cultural and economic contexts. The public health policies, in which stigma is an integral part of professional attitudes, restrain the possibilities for persons living with HIV to advocate for more rights and services than are already provided by the governmental institutions. The attitude of 'undeserving citizens' (Bernays et al., 2010) towards HIV-positive people regretfully informs health practitioner and national health discourse, per se. This article challenges the boundaries that inform local HIV/AIDS policies in the two countries, by reporting on the social stigmatisation experience by the social activists.

In the previous decade, concerns about HIV- and AIDS-related stigma and discrimination have seen a rise (see Bharat and Aggleton, 1999; Parker and Aggleton, 2003). However, in the light of social changes and harm-reduction movements happening across the world, HIV- and AIDS-related stigma seem to be receding from attention (Valdisseri, 2002). However, in many countries, stigmatisation of HIV-positive people remains a significant and continuing challenge. Because of this stigma, individuals affected by the virus face different levels of discrimination within their social surroundings (Letamo, 2005). For example, Parker and Aggleton (2003) conceptualise stigmatisation and discrimination not as processes, which involve only the infected person, but as a social and cultural phenomenon interrelated with the actions of whole groups of people. However, the level of stigmatisation varies in these countries. While in Lithuania individualist tendencies prevail in how social life is organised and personal problems are lived, in Azerbaijan, stigma is much more pronounced as collectivist approaches and the importance of public opinion exacerbate the experience of it.

For decades, HIV was regarded as a disease of gay men, sex workers and injecting drug users, restricted to behaviours that are considered 'value-laden' and thus form the complexity behind the stigma attached (Valdisseri, 2002: 341). This description has a particular relevance in post-Soviet states, where people do not receive treatment equal to that of other patients due to perceived negative HIV-associated lifestyles. Such intersectional inequalities associated with the pandemic exacerbate the experiences of affected individuals (Watkins-Hayes, 2014), creating additional social and psychological barriers in the context of an already challenging medical condition. Although some researchers have attempted to design a unified measurement scale for stigma and discrimination to apply across different countries and cultures (e.g. Genberg et al., 2008), it remains a topic without a commonly shared theoretical perspective (Deacon, 2006). For example, stigma can be seen as an experience of 'othering' and discrimination as one of negative outcomes of stigmatisation often exhibited in actions against stigmatised people (Deacon, 2006). Fear of being stigmatised, judged or isolated causes many HIV-positive persons to avoid disclosure, at least for some time. Some studies identified these processes within a structural approach, where political figures and institutional power organisations define life circumstances of less powerful individuals (e.g. Healy, 2001; Moreau, 1979). Parker and Aggleton (2003) present stigmatising attitudes towards people living with HIV as derivatives from the prejudices associated with HIV and AIDS. Prejudices precede and construct the stigmatising attitudes.

The literature has long discussed how social discourse on HIV/AIDS can directly influence and transform political discourse and subsequently healthcare and social services (e.g. Densham, 2006). However, there are two contradictory factors to be considered: one is that in countries where advanced medical treatment is available, HIV/AIDS is viewed as a chronic disease rather than an abrupt death, compared to countries where such medical treatment is not as accessible. In some countries, changes in societal structures and political strategies have

already happened, followed by a reduction in incidence. Nonetheless, in Azerbaijan and Lithuania, where prevalence rates are moderate, health and social policies still fail to address people's needs for better social services and advanced medical treatment. Yet stigma and discrimination exist not only in public but also among practitioners, and they define treatment strategies and lack of social services. In this study, we present the reason for governments' lack of interest in better healthcare and social services for people living with HIV. In addition, governments' restrictive policies and adversarial views towards individual agency and community-based actions are understood as limitations to possible wider outreach. Often social activism, harm-reduction initiatives and campaigns for inclusive policies are viewed as threats that could cause contradictory promotion effects. The analysis presented in the following sections thus expands on these observations.

## Data collection

This article focuses on one part of a larger study that consists of 13 semi-structured interviews and one focus group that were conducted in both inpatient and outpatient settings to understand the use and provision of HIV-related social and medical services, as well as the role of stigma and discrimination in Azerbaijan, Germany and Lithuania. The data collection took place during 1 year between March 2012 and 2013. The informants were interviewed in Baku, Braunschweig and Vilnius. Two individual cases were then selected for the analysis of social activism in resource-limited settings. The selected cases were distinguished from the rest of the sample due to the social statuses of the informants and their subsequent engagement in political activism and advocacy within the context of post-socialist nations. Permission to conduct interviews with the patients of the centre in Baku was obtained after a personal meeting with the director. The following period included several visits to the centre with two interviews being conducted per day, lasting a minimum of half an hour. The recruitment process in Lithuania included kick-off meetings with the director of a governmental public health organisation (who was also later interviewed together with another medical doctor from the centre) followed by online research which lead to a telephone interview with the chairman of a non-governmental public association in Lithuania.

The interviews took place according to availability and communication accessibility of the two informants: face to face at the inpatient treatment centre in Baku and via telephone in Vilnius. Both interviews lasted approximately 60 minutes.

There are several limitations of this study. First, the sample size withdrawn from a bigger study provides limited insights and requires further research in line with later developments in both countries. Moreover, fieldwork in other regions of the two countries could help provide a more inclusive and broader picture. Second, unfeasibility of follow-up interviews restrains the time-relevance of the data, given the constant developments in the HIV and AIDS field. Finally, the data do not provide sufficient insight into the discrepancies between rural and city social attitudes that also underpin the level of social activism in different regions of the countries.

The analysis section will also briefly discuss the views of two medical doctors from the focus group interview as complementary data to that from the two key informants.

### Ethical considerations

Undertaking qualitative interviews on such a sensitive topic comes with challenges both on practical and emotional levels (Dickson-Swift et al., 2007). HIV/AIDS remains a highly stigmatised disease and one that may reveal too much of person's 'private sphere' (Lee, 1993: 5). Some of the

potential informants found it baffling to talk about their health conditions and obstacles that life with HIV had brought them. The key informants whose cases are presented in this article were informed about the study purposes and confidentiality agreement orally before setting up an interview date. One informant gave written informed consent and the other gave his assent orally during the interview that was limited to a telephone call. The interviews were tape-recorded and transcribed verbatim afterwards. Information included in this article about the participant from Lithuania is not anonymised at the request of the interviewee due to his public activities. The treatment centres and other locations are anonymised due to the small latitude of the geographical area where informants were recruited.

## Findings

The study explores the cases of Jurgis and Rasul, who represented social activism for the rights of people living with HIV. The analysis based on the qualitative interviews addresses the possibilities of service implementation within the existing gaps of the two current systems.

### Background

Jurgis Andriuska (41 years) – the chairperson of the 'Pozityvus gyvenimas'[2] Association – was one of the first public figures in fighting HIV/AIDS in Lithuania. He requested that his name and affiliation be openly mentioned in the study, due to his public work. Personal lived experiences of discrimination and indifference from the governmental institutions to his needs other than medical provided momentum for Jurgis to start his socio-political activism. His ultimate purpose was to make the necessary social and support services accessible for the HIV-positive community. Aiming towards the unity of HIV-positive people and offering them a space for safe disclosure and acceptance, Jurgis created a movement of people who have been experiencing similar challenges.

### The case of Jurgis (Lithuania)

The NGO lead by Jurgis Andriuska was established in 2003 and is in Klaipeda, the third biggest city in Lithuania. According to the statistics, the highest prevalence rate of the virus by 2014 was registered in Klaipeda (CCDA, 2015). This is largely attributed to the high prevalence of sex work in the area and related risks of sexually transmitted diseases. 'Pozitivys Gyvenimas' offers low-threshold services to most affected populations, organises public awareness marches and fund-raising, campaigns, and promotes HIV testing. However, government interventions often create problems for NGOs implementing their own projects and mobilising the community of HIV-positive people. For example, according to Jurgis, publicly open testing failed several times because the government establishment restricted testing despite being arranged by the organisation's own sources and staff. Jurgis refers to medicalisation of the HIV treatment and lack of social care towards people living with HIV as the 'heart of the problem': 'They [the government] see us – [people living with HIV] – as helpless, weak, asocial people, who cannot take care of themselves without an intervention of the government.' There is a political clash between the state-funded AIDS programme and the community-based NGO lead by Jurgis, due to conflicting views on how care for people living with HIV should be provided. Interviews carried out with two medical doctors from the government-sponsored medical centre underpins this clash vividly. According to Jurgis, the centre leads a policy of closure, where it is believed that the

HIV-positive persons need not publicly disclose their serostatus in order to receive more attention. A medical doctor from a state-supported healthcare centre in a focus group interview provides an example of one of her patients:

> He is an extraordinarily handsome man, with good reputation and outstanding financial possibilities. He has many friends, beloved job and beautiful life and he keeps his serostatus in a secret, which just makes his life easier. People ought not to know, and everybody is happy.

With such a simplified description on how to live a 'happy life as an HIV-positive person', the interviewee points out that social activism for better conditions and acknowledgement of needs of people living with HIV is unnecessary. Moreover, the description of 'outstanding financial possibilities' lacks consideration of the needs of a less financially fortunate HIV-positive population and thus reveals the gaps in the state's healthcare and welfare policies. Congruently, another medical expert during the same interview session speaks of the 'protective role of stigma':

> I would not review stigma as a negative notion, because it has important advantage for the society since it prevents rise in number of deviant or asocial behaviour of community members. This is a judgement for behaviour that is hazard and not considered normal for the society, and it is vital for stigma to exist, for own good of people.

Such an approach to stigma is reflected in Goffman's (1965) concept of 'information control' which defines maintaining distance and control of contact with the stigmatised group. The interviewee here points to the 'usefulness' of such a distance as a shield not only in a moral sense but also against possible social activism. In contrast to these statements, we further focus on how, in most cases, stigma exacerbates the lived experiences and isolation of HIV-positive persons.

Jurgis finds emancipation from such structural limitations in his social activities and individual growth after HIV:

> We would like to provide health-care support, advocacy and assistance to people with HIV positive status. However, we simply do not have the conditions to provide such services. There is a huge need for additional community services, as the governmental hospitals accept HIV positive patients only twice per week and that means, if somebody needs a consultation or urgent intervention on other days than established by the law, he must either wait or try to find support from somewhere else, which is quite hard, considering the existing situation.

One of the aspects of empowerment in the frames of critical social work indicates that social work does not only educate, advocate and support the oppressed, but at the same time it has a function of reconstructing the social reality by implementing changes (Fook, 2016). For Jurgis, this self-initiated leadership served as escapism from both external and internal suppression, as well as a powerful source of inspiration to live the best life possible despite the virus. Jurgis speaks of stigma as 'cutting chances of people living with HIV for full-fledged life'. Social activism and the popularity of a leader may reduce explicit discrimination because of one's health condition, while others with precarious living conditions are more likely to encounter discriminatory attitudes if their serostatus is known. Jurgis saw his life with HIV as a possible way for bigger changes in the society, starting almost two decades ago with his initiatives of community-based action to combat the government's oppressive system. Jurgis passed away in February of 2016 – 3 years after this interview was conducted.

## Background

Rasul (a pseudonym, 42 years) is the first person to have received anti-retroviral therapy in Azerbaijan since 2006. Rasul had been providing palliative social care to HIV-positive patients and people who inject drugs in Baku for 5 years at the time of this interview. As a patient himself, he provides inpatient and outpatient palliative care and consults patients on their treatment and appointments, as well as methadone maintenance therapy. While being an active member of a third-party-funded non-governmental organisation (NGO), he simultaneously carries out his activities within the governmental treatment centre. As an ex-injecting drug user and an HIV-positive person himself, Rasul is an important figure to other patients due to his first-hand practical knowledge and skills.

## The case of Rasul (Azerbaijan)

Rasul has no professional degree in social work, neither has he attended any other special training courses. Nonetheless, he has been building up experience in palliative care (for about a year at the time of the interview) for injection drug users (IDUs) and patients suffering from physical pain or other somatic problems related to HIV and AIDS. As an adjacent staff member of the treatment centre, Rasul is the only HIV-positive individual among the personnel. In addition to his everyday job at the hospital, he is affiliated with an NGO where he also provides healthcare and social assistance services for people living with HIV. After being imprisoned in Moscow, he learned about his serostatus in a detention facility. This is where he started his social activism by joining an NGO initiative – a drop-in centre that provided harm-reduction services to people living with HIV. Empowering others to be hopeful and to maintain a positive attitude about their status is the key determinant of Rasul's interactions with other patients he takes care of. Nonetheless, he depicts his experiences in a different reality:

> My observations show that as soon as people find out about their infection, first they experience certain psychological changes. Many go back to drugs and die from an overdose, others keep thinking that there is no treatment for this disease, and sooner or later they will die anyway and that even speeds up the process of death.

Having received medical care both in Russia and in Azerbaijan, Rasul is better informed regarding his health condition. This position granted him a lead role at the treatment centre, where other patients could rely on his previous treatment and knowledge. It is this knowledge capital that he could transfer from one context to another, by signing up for responsibilities that helped to transform his position from a dependent patient into an empowering social activist. Once regarded as a staff member, Rasul could more broadly advocate for patients' needs as well as his own. Nevertheless, due to the high level of stigma in the society, and lack of civic support, he confronted challenges in taking his social services and other related activities outside of the facility's frames to a broader community. In his job he frequently encounters official state representatives at different health and prevention events, as well as local police administrations:

> I can tell you how different structures [institutions] react to AIDS. I will tell you examples; for example, the police. They are afraid of AIDS patients; even to touch them. Recently, one policeman found documents of one of our patients, in the street. He brought it here, to us and asks a question […] 'did I get infected because I held the documents in my hands?' Can you imagine? The policeman asks such a question.

The case of Rasul demonstrates empowerment as a structural context when hierarchical facilitation of changes is the prerequisite. The fact that the director of the AIDS centre has created an opportunity for Rasul to provide care for others is an empowering prospect.

The reasons for fear are the product of much more sophisticated complexities. For instance, one causal aspect of stigma is fear of becoming infected due to casual contact (Genberg et al., 2008). Such fear among the general population is a strong indicator of lack of HIV/AIDS-related public education even among the administrative organisations engaged in support of HIV/AIDS policy. Rasul has observed such behaviour on several occasions:

> I was taking part at one of the gatherings of our community. One of the sponsors who is also the government official, shook my hand. […] As we parted, I saw him reaching for a napkin and cleaning his hand.

To produce inclusive health policies and allow social changes to happen on a community level, policy-makers need to develop different viewpoints as well as overcome stigmatising barriers themselves. Community actions and changes in the sociocultural environments are important measures to make individual actions occur (Rhodes, 1996). For example, indirect influence of international worldwide organisations such as the Global Fund in promoting health actions (e.g. palliative care) in communities served as an empowering opportunity for Rasul to embark on his social activism.

Neither in Azerbaijan nor in Lithuania do the dominating medical models allow the combating of stigmatising attitudes among the public about HIV and AIDS. However, structural discrimination is itself an influential force. In fact, discriminatory treatment towards people living with HIV and moralisation of treatment is the case within the medical institutions themselves. For example, because of their serostatus, patients in Azerbaijan reported being asked to provide their own essential equipment for an examination, such as medical apparel or instruments for taking blood samples. Such cases of health inequalities affect efficiency of healthcare provision and cue the existence of bigger social inequalities in the society (Kojoué, 2016), along with economic disparities and institutional corruption like in many post-Soviet transitional countries (Stepurko et al., 2015). Drawing on his experiences on working with other patients in the treatment centre, Rasul told,

> Last week I supervised one of our patients to the narcological centre for a biopsy. I took him there, so that they could take analysis from him. But they made him buy medical apparel, instruments and even sheets with the patient's own money, in order to do the biopsy; which is like a drop, you need only a tiny sample …

Cases of social activism discussed in this article draw upon the self-identified professional field within the context of aspired to structural changes. Jurgis and Rasul fought against the disabling effects of institutionalised and medicalised treatment with lack of accessibility and provision. Rasul, having had fewer opportunities for independent advocacy compared to Jurgis, experienced more explicit oppression due to the system. Thus, he committed to certain responsibilities to alleviate his own and his family's struggles in the first place. The same can be attributed to Jurgis, too. However, NGOs such as 'Pozitivys Gyvenimas' in Lithuania meet fewer constraints imposed by the government than in Azerbaijan. As a result, one sees the difference between the issues at stake. Within this context, we are looking at the transformation of 'powerlessness' into gaining control over the disease and its effects on one's life. As experts of their situations, Jurgis and Rasul fought powerlessness in the way that they know and experience it themselves, thus carrying out self-empowerment in an individually tailored manner. Jurgis, acting in a less constrained environment, both politically and socioculturally, nonetheless managed to assemble and mobilise a bigger community. The Lithuanian government does

not support the harm-reduction initiatives pioneered by Jurgis financially nor through other means. Nonetheless, he was still able to attract the public attention and support of private sponsors, as well as affected individuals. Despite the medicalised approach and highly stigmatising attitudes in Lithuanian society, he received better support from general public and other HIV-positive individuals. Differences in the limitations and achievements (both protagonists could only reach as far as it was 'permitted' within their environments) correspondingly were governed by the existing circumstances.

## Discussion

By depicting the struggles of selected activists, this article connects to social work's primary purpose of highlighting internal political situations and portrays the ways in which social change can affect individual lives (Abramovitz, 1998). The article has shown that histories as well as social and political discourses in both countries do not yet allow advocating for acceptance, inclusion and protection of the rights of people living with HIV/AIDS. Instead, the kind of social activism carried out in the two countries are exemplars of people striving for basic medical care and what Epstein (1996) called 'treatment activism' (p. 18).

This article has also drawn connections among sociocultural, political and individual forces to illustrate the collective enactment of the stigmatisation of people living with HIV and AIDS in the two countries. The cases of Jurgis and Rasul were examples of emerging critical consciousness, which is an important prerequisite for critical social work. Activities of the NGO founded by Jurgis is a case of new social support services for people with HIV are awareness-raising, emancipatory practices of critical social work (Fook, 2016; Howe, 2009). The activities of Jurgis' NGO and the emancipatory attitudes of its leader are examples of fostering solidarity and mobilisation of communities of people with HIV when they are encouraged to empower themselves – to understand their needs and problems, overcome fears of disclosure and search for solutions together. The role of social workers is to help activists and communities realise the potential to go from passive consumers of welfare services to producers of appropriate responses to the needs of their communities, and to help the activists acquire the interpersonal and political skills that will assist them in performing their role (Makaros and Itzhaky, 2013; Zanbar and Itzhaky, 2018).

These activities of collective acting intertwine with awareness raising by encouraging people to see their participation in the stigmatising discourse. While both informants were primarily committed to reducing stigmatisation and discrimination as well as to advocating for their rights and needs through the public activities and services, they also created a space for disclosure and self-expression of other persons living with HIV. Acting as social activists, Jurgis and Rasul not only provided care to other patients and carried out responsibilities, but also contributed to and accompanied the process of change by establishing an environment of mutual peer support. In both countries, HIV-related stigma and knowledge deficiency govern people's attitude and subsequent stigmatising behaviour towards people living with HIV. Both activists started paving the way for a better enlightenment of what living with HIV in restrictive welfare systems means. It is important to underpin the necessity of socio-structural interventions in reducing HIV vulnerability (Platt et al., 2015) and fighting innate structural discrimination to enable compassionate health and social care policies. Furthermore, the central focus of this article has implications for social work education as well, when specific advocacy and activism skills need to be developed in post-Soviet states. The article raises a necessity to help students learn to provide skills to advocate for improved services and influence the development of social policies. Further research is needed to address the possible collaboration between the government and community-based organisations to reveal potentials for further development.

## Notes

1. 'Vilnius Declaration' on Measures to Strengthen Responses to HIV/AIDS in the European Union and in Neighbouring Countries, 2005.
2. 'Pozityvus gyvenimas' (Positive Life) is a community-based organisation established in 2003 by HIV-positive people. The association provides social care and support to HIV-infected people and their families and organises educational events for the general public.

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