

Nursing women living with HIV in Europe

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Introduction

Back in September 2013 I attended my first European AIDS Clinical Society (EACS) conference. One of the presentations that I found troubling was Stigma and Discrimination in Health Care Sector in Belarus [1]. The presentation included grave results from the Belarus stigma index [2]. It also included results from further studies and training for health care workers (HCWs) that the researchers had organised and carried out the previous year. The stigma index showed that 47% of the respondents were advised not to have children while 11.4 % were coerced into sterilisation. Furthermore, although the research conducted in HCWs showed that 100% of HCWs had received some training on HIV/AIDS and universal precautions, 25% of them were still not willing to provide services to people living with HIV (PLWH), 96.4% had negative images of PLWH, and 68% would discriminate against PLWH outside their professional duties (change hairdresser if HIV positive, change schools if child's classmate was living with HIV). I wanted to believe this was only happening in Belarus and that other countries would never allow such discriminatory practices. This particularly seemed like a death sentence for women with an HIV diagnosis. At the same time BHIVA standards in the UK were providing the following guidance: 'People living with HIV should have access to safe, effective, and acceptable methods of fertility regulation, both for conception and contraception. Women living with HIV must be able to access appropriate healthcare services for a safe pregnancy and childbirth which provide the best chance of having a healthy infant' [3]. That provided some relief ... the problem was mostly located in Eastern Europe! Correct? Not so fast!

Some epidemiological data

Women globally represent 51% of the HIV epidemic. Right now it is estimated that 18.6 million women and girls aged ≥ 15 years are living with HIV [4]. In Eastern Europe and Central Asia women accounted for 31% of new HIV infections; in the younger ages of 15–24 years, the number reached 46% [5]. Eastern Europe is currently leading the epidemic within the European region according to the European Centre for Disease Control (ECDC) [6]. Nevertheless, there are no accurate figures available from Eastern European countries and especially Russia where a silent epidemic seems to be in development. The available figures mention a rise of 60% in recent years (2010–2016) in new diagnoses in Eastern Europe and Central Asia [7]. At the same time global numbers are falling. In Western and Central Europe, and North America women still account for

22% of new infections; in the age group 15–24 years, they represent 29% of the new infections [5].

Specific vulnerabilities of women living with HIV

Several socio-economic and cultural vulnerabilities have been identified in different settings and countries. We know, for example, that women with unstable housing conditions, who are unemployed, or don't always have money to meet their basic needs are facing the risk of non-adherence and, therefore, can present with detectable viral loads [8]. The study concluding this, by O'Connell, was conducted in the UK, but I suggest that any woman (or person) fighting for economic survival would become negligent of their treatment, especially if they need to present at a hospital once a week to pick up medications as is the case in many European countries that experience stock-outs. Moreover, specific risk factors identified for women are: increased concerns, responsibilities and priorities, such as carer duties and motherhood compared to their male counterparts. Other risk factors include migration status, injecting drug use, sex work, intimate partner violence and stigma.

Caring for women living with HIV

In the era of the UNAIDS 90-90-90 target the healthcare settings and professionals seem to focus on starting treatment as soon as possible after diagnosis (ideally straight away); retaining women in care, and achieving an undetectable viral load. The campaigns of TasP (Treatment as Prevention) and U=U (Undetectable=Untransmissible) are working and have been delivering good results, depending on the country of residence. Nevertheless, ECDC reports that only three countries within the WHO 53 Europe have managed to achieve at least 73% in the three areas of interest (know ones status, started treatment, achieved undetectable viral load): Denmark, Sweden, and UK [5]. In other countries the epidemic is fuelled by 'outdated treatment threshold policies and, in some places, legal and policy barriers, health system resource challenges, and social and cultural factors' [6]. Finally, great differences exist between achieving undetectable viral load in EU and non-EU countries: two out of three people living with HIV have achieved viral suppression in EU/EEA countries, while only one in four people living with HIV in non-EU/EEA countries have achieved viral suppression [6]. Unfortunately, the above evidence has not been distinguished by gender.

In February 2016 the European AIDS Treatment Group (EATG) ran a week-long online survey about the experience PLWH have with HIV clinicians [9]. The

survey received 357 responses from 34 countries of the Europe 53 area. The groups represented in the survey were aged 18–81 years, while 23% of the participants were women. Among the results presented, 88% of PLWH clearly stated they trust their HIV clinicians and most of the participants mentioned that nurses are involved in their HIV care. Nevertheless, only 36% of the participants were comfortable discussing sexual health issues with their doctors and only 11% their reproductive choices. The above results signify that nurses can play a vital role in starting and carrying out those discussions, something that can prove very difficult in some countries and settings where nurse-led practice is not recognised.

Moreover, as healthcare professionals, we often forget that women living with HIV are actually *women*. They don't only care about viral load and CD4 counts and in some cases they are exasperated with HCWs talking to them about adherence and organising their lives around their medication administration. My experience from working with women who live with HIV is that you can only establish a relationship with them when you actually treat them as individuals with feelings, beliefs, opinions and personalities. I had very good results, for example, when I started talking to my patients about their taste in music, clothes, or past and planned vacations. It is important for HCWs to share their own experience in this process. Sometimes, as healthcare professionals, we forget that we are people as well. My best results came from sharing some of my vacation experiences with women I had established a relationship with.

Nurse training

Depending on country, HIV is included more or less in the nurse training curriculum.

Nevertheless, structural changes in the teaching of HIV can help fight stigma within the nursing community (or even better the HCW's community). PLWH should be included in nurse training from the start: in drafting the curriculum and in course delivery. The following is a description of my personal experience and journey in the field to demonstrate this point:

I graduated in 2002 from the National and Kapodistrian University of Athens. This university is still considered among the top universities in Greece, nevertheless, the training we received in HIV/AIDS was very basic. The information provided described a very grave picture for PLWH, which was to be expected to a degree as highly activated antiretroviral therapy had just become available in 1996. As I had not practised nursing for long my interaction with PLWH was limited to a volunteering role within a non-governmental organisation in Greece. The people I met had nothing to do with the descriptions in the books.

In 2013, I started working for OKANA (Greek organisation against drugs), which is the only organisation working in harm-reduction providing syringe exchange services and opioid substitution treatment (OST) programmes. This was during an HIV

outbreak that was ongoing since 2011 in Athens among people who use drugs (PUD). For the first time I witnessed the situation described in my university books. PUDs were only gaining access to HIV treatment if they were receiving OST. The waiting time for OST was about 9 years and the list 4000-people long. Exceptions were being made for the PUDs that were diagnosed with HIV as huge efforts were being made at the time to limit the outbreak. The staff attitudes including my own were, to say the least, misinformed. Misconceptions and prejudice were influencing our practice. My colleagues and I attended several training sessions and read as much as we could in order to address our knowledge gaps. It was mostly information on counselling, drug use, and safe injecting advice, whatever we could access.

HIV training was not available in Greece back then, so I searched outside Greece and found that all available programmes were impossible to attend owing to financial or time constraints. Subsequently, I found STEP UP (Skills to Empower Patients) training organised by EATG. This was a five-module, year-long training course that brought together activists, healthcare workers and PLWH from all over Europe (WHO Europe 53). Among our trainers were PLWH. For me this was a very intense experience, different to any other training I had ever attended before. The instructors were extremely knowledgeable – more knowledgeable than any of the healthcare professionals attending the course. This humbled me and of course filled me with respect for PLWH. I noticed that PLWH within EATG were very well educated and empowered, more than any other patient group I had contact with before. There was an emphasis on collectiveness and community responses, a passion with which these groups were driving their response to HIV. STEP UP informed and, in essence, changed my nursing practice. It made me a knowledgeable, understanding and compassionate nurse and liberated me from my misconceptions and prejudice to a large degree.

Community initiatives

Looking at the community of PLWH one realises that it is mostly represented by men who have sex with men (MSM). Of course there is a very good explanation for this as MSM still seem to be leading the European epidemic. Women are not so visible or vocal, mostly due to stigma. Community initiatives have been proven to engage women and provide them with the support they need, for example the SHE programme that initiated and enhanced peer-support groups; and the mentor-mothers programme in Africa that helped minimise perinatal transmission. Peer support increases adherence and retention in care, and community testing initiatives have better diagnosing rates than established medical services, especially among key and marginalised populations.

In an effort to give a voice to women the EATG established a portfolio dedicated to women 2 years ago; EATG4Women has managed, in a very short time period, to bring together women and men living with

or affected by HIV, who work on transforming the HIV response for women in Europe. EATG are presently running a project entitled 'Metrodora', which intends to specifically investigate the involvement of women (cis and trans) in the research and development field. The project is structured in three phases: in the first phase a literature review will be conducted, which will guide us to draft a position paper. Our experience so far indicates that there is a great difference in women participation when protocols are developed by women principal investigators (PI) and when patient/community representatives have the opportunity to review those protocols. The next two phases of Metrodora include training specifically designed for women who are living with or are affected by HIV and a stakeholders meeting that will bring together participants from industry, science and policy, and PLWH to discuss and hopefully come up with an action plan to increase women's involvement in research and development. In my opinion, more women need to be trained to review protocols. Trials need to enable women in their several roles (career, mother, wife, or carer) to participate and attend. Simple things, practical solutions and provisions could enable women to participate. For example, the availability of childcare makes it easier for women to attend clinic appointments, which may be more frequent during a clinical trial. The patient leaflets of the trial and informed consent should always ensure that women who participate in clinical trials have the support to adhere and stay in the clinical trials. I expect all the aforementioned to be presented in discussions with the stakeholders and the position paper produced.

Conclusion

In the UK nurses are considered the patient's advocate. Although I wholeheartedly embrace that role and encourage the advocacy on behalf of our patients, whichever country we are practicing in, I more strongly believe in the need to empower PLWH to speak up and stand up for themselves. Education and training are critical in that respect both for the healthcare professionals as well as PLWH. Women living with HIV are a significant proportion of PLWH. Among the healthcare professionals involved in their care, nurses are in a unique position to raise and address concerns, help them adhere to their treatments, retain them in care and help them manage their own well-being. Recent efforts, especially community efforts, highlight the need for women's empowerment within healthcare settings (either as patients or healthcare workers) and are taking steps to address that need. Nurses need to be in the front lines of those efforts.

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References

1. Ilyenkova V, Kunitskaya S, Eramova I. HIV/AIDS Stigma and Discrimination in Health Care Sector in Belarus. *14th European AIDS Conference*, October 2013, Brussels. Abstract PS11/6.
2. *People living with HIV Stigma Index: Belarus*, 2013. Available at: www.stigmaindex.org/belarus (accessed February 2018).
3. BHIVA. *British HIV Association Standards of Care for People Living with HIV 2013*. Available at: www.bhiva.org/standards-of-care-2012.aspx (accessed February 2018).
4. UNAIDS. *International Women's Day 2017*. Available at: www.unaids.org/en/resources/infographics/girls-and-women-living-with-HIV (accessed February 2018).
5. UN Women. *Facts and Figures: HIV and AIDS*. Available at: www.unwomen.org/en/what-we-do/hiv-and-aids/facts-and-figures (accessed February 2018).
6. Noori T. *Thematic report: continuum of HIV care. Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia: 2017 progress report*. ECDC. Available at: ecdc.europa.eu/en/publications-data/thematic-report-continuum-hiv-care (accessed February 2018).
7. UNAIDS. *Ending AIDS: progress towards the 90–90–90 targets*, July 2017. Available at: www.unaids.org/en/resources/documents/2017/20170720_Global_AIDS_update_2017 (accessed February 2018).
8. O'Connell R, Burch LS, Anderson J et al. Do Socio-economic Factors Explain Gender Differences in Virological Response to ART in the UK? *15th European AIDS Conference*. October 2015, Barcelona. Abstract 114982.
9. Kelly D, Jachnowitsch L, Raskevich Y. European survey on doctor-patient relationship. *HIV Drug Therapy Conference*. October 2016, Glasgow. Abstract P320.

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