

Challenging stigma and improving understanding of reproductive issues for women with HIV: Belarus

What was the issue?

The GNP+ Stigma Index research in Belarus indicated particular difficulties faced by women with HIV. Of the 273 female respondents, 62% had decided not to have more children and 27% not to marry. Over 14% had not disclosed their HIV to any friends or family. Some 38% had received no information on their reproductive options since their diagnosis and of those who had become pregnant since then, 25% reported being coerced to have an abortion. Just over half had discussed treatment options with a health professional and only a third had discussed personal topics such as sexual and emotional health in the past year.

Why was change needed?

Heterosexual women with HIV who are of reproductive age need clear advice on their sexual health and reproductive options in order to make healthy choices and life decisions. Clinicians who are unfamiliar with treatment advances in HIV may not give appropriate advice and women may be afraid to access reproductive health because of perceived or actual stigma about their HIV. The view that “reproductive health is not for HIV+ women” is often met among doctors and decision-makers. In such circumstances women do not go for counselling and instead remain in fear, in some cases contributing in their suicidal intentional and other depressive disorders.

What were the barriers to change?

Project participants reported previous negative experiences of reproductive counselling services, which had made them reluctant to seek help. Medical officials were often reluctant to engage with peer counsellors, seeing them as “non-professionals” and there are legislative limitations to peer counselling in medical settings.

How long did change take and who was involved in making the change?

The project took around 18 months from start to finish and involved:

- supportive clinical staff and officials
- activists, both HIV+ and HIV- women and their families
- HIV+ women motivated to explore the possibility of motherhood
- HIV+ parents who had poor previous experiences in family health settings

How was change made?

Change was made via a series of meetings, round table discussions, networking among specialists and mass media communications.

A core group of 18 participants was identified, all of them women with HIV who wanted to

understand sexual and reproductive health better and potentially to have children. They met regularly in group sessions and were given psychological support as well as peer support and information. In this “safe space” they were able to openly discuss their experiences and concerns.

Because it was important not only to have this space with each other but also to make some safer space in the outside world, a series of meetings and special events among doctors, gynaecologists and paediatricians were also run to influence and improve their understanding of the situation for these women. A supportive clinic with good staff was identified and a “mother and child” team formed including doctors and peer support, which provided counselling and information to the women. The core group also communicated regularly on social media through Viber.

As a result of this focussed support, 12 of the 18 participants made a decision to have children in the next two years and five became pregnant while in the programme, with two births. All project participants managed to become regular clients of medical specialists in reproductive health and to raise their understanding of the issues. None among those pregnant during the project indicated coercion to undergo an abortion or reported coercion in relation to birthing method and infant feeding practices.

Are there any ongoing issues?

While this project was successful in reaching its goals, additional support is needed to reproduce the programme and raise awareness amongst both women with HIV and reproductive health clinical staff in other regions.

What lessons have been learnt?

Activism among doctors in Belarus causes serious challenges for them in an atmosphere where it is considered a career risk to challenge the assumption that everything is already being done well and that change is unnecessary. The most effective challenge involves the patients and their stories which show that this is not always the case, but patients need support to do this as it can be a frustrating and even abusive process. Activist citizens and NGOs are able to influence this situation to some extent but it is important to persuade the state to accept the need for change or it will not last. Even in a difficult political context there are doctors brave enough to support patients and advocate for their rights. It was important to use their expertise and their influence for the dialogues with officials. Bringing change into the system is impossible without engaging the decision-makers. We organized a round table where the acute issues were discussed in an accurate but acceptable manner.

It is possible to increase the knowledge and confidence of women with HIV through groupwork, peer support and information. Within the project women required ongoing psychological support and, coming from quite complicated backgrounds, they were sceptical at the beginning regarding support. However, the safe space with other project participants provided the basis for quite rapid development. The participants not only supported each other but formed an intention to bring change for others by quite aggressive advocacy. However, in Belarus it is important to go step by step balancing between the wishes of the patients and the abilities of decision-makers to process the information and requests.



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