



MMS Bulletin #97

Memory Work

Overcoming Lazarus Syndrome

Psychosocial support in the context of antiretroviral treatment

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I would like to share the experience of Médecins Sans Frontières (MSF) in the psychosocial support of adherence for people living on antiretroviral treatment and stimulate psychosocial treatment support action by other NGOs.

In my contribution, I would like to present the psychosocial problems influencing adherence to antiretroviral treatment in resource limited countries, to discuss the psychological impact of starting antiretroviral treatment in the life experience of people living with HIV and AIDS, to present the MSF approach to Memory Work (rediscovering the past to go forward) and its limits, and to identify possible complementarities of approaches among different NGOs.

What does it mean to be HIV infected?

There are several psychosocial problems influencing adherence to antiretroviral treatment of HIV/AIDS such as the relationship between care providers and patient, some disease characteristics, the treatment regimen and the therapeutic context. Becoming HIV infected often means living under a suspended death sentence, losing job and friends, stigmatisation, and, on top of all that, the abandonment of life projects.

An example from Cameroon: Mrs B. is a 30-year old woman. She is married and mother of six children. She is a seller in the market. She had a quiet life with her husband, family, and friends. But one day, she was informed that she was HIV positive. She was shocked, could not believe it. She revealed the situation to her husband who denied the reality. He decided to take a second wife. Some months later, she had opportunistic infections. In her family and neighbourhood, she was stigmatised, she stopped her business, also because of health problems. She was desperate, with no hope.

During this period of time, she was lost to society and lost to herself. And then came the time to take antiretroviral treatment.

What does it mean to be on antiretroviral treatment?

Once Mrs. B began her antiretroviral treatment she recovered her good health situation (regaining of weight, no more frequent illnesses, and reconstitution of physical capacity). But she was afraid to realise that now there was a possible future for her; and she told me that she had been very lucky. She was a survivor and facing what in psychology is called the Lazarus syndrome. As everybody knows the story of Lazarus in the Bible, Lazarus was ill and then died, but Jesus rescued him from death. The reappearance of Lazarus on the one hand affected his community and on the other it affected himself too. The community had anticipated its period of mourning and therefore reorganised itself without the presence of Lazarus. But the reappearance of Lazarus changed this entire situation. Lazarus needed to get back his position in society. Likewise, antiretroviral treatment rescued this woman from death and recreated a situation of the same kind as Lazarus'. There had been an improvement of health but not yet an improvement of quality of life.

Regaining health – and quality of life?

It is fairly easy when following the right antiretroviral therapy to find good health. In medical terms good health means maximal and durable undetectable level of viral load and the steady increase of CD-4 cells. This also would include reducing opportunistic infections. However, for patients the improvement of quality of life is a more complex procedure. In this woman's case, her objectives to follow the antiretroviral treatment consisted in coming back to a normal life. That meant having a job, being reintegrated in different social groups and being accepted and loved as any other human being.

Our intervention is the following: we provide medical support by giving antiretrovirals. AND we provide psychosocial support.

In the context of psychosocial support, one of our objectives is to go back into the past of this woman in order to rebuild a future with hope, a life plan for her. In other words, to rebuild a bridge between the past, before the announcement of seropositivity and the present, with its benefits thanks to antiretrovirals. This bridge between past and present should be considered as another form of Memory Work.

We will therefore work with Mrs. B. on the following issues:

- What were her life projects?
- What were her resources?
- What happened? With what impact?
- How can she restart the project that she previously had to abandon ?
- What is the actual situation of resources?
- How can we mobilize them?

Our limits

Like many people under antiretroviral treatment that we followed up, Mrs. B. benefited from psychological support provided by the MSF treatment team: She regained confidence in herself, she began to create new relations with other patients, she began to smile, she moved out of depression. But as Lazarus, she still has some bandages – which need to be removed.

We have tried to elaborate solutions with this woman but we could not help her to implement all of them. In this case, other actors' help could be essential, in order to encourage her husband to keep supporting his wife, to work with this woman's neighbourhood, and to create new job possibilities for her to start working again in her community. These are some interventions beyond the possibilities of the MSF treatment project. That is why we are looking for further collaboration with other organisations working in the psychosocial domain.

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