



From the patients' perspective

How does this compare with your clinical
setting?

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Context

- Qualitative study amongst PLHIV and service providers on their HIV treatment experience
- Very little qualitative research yet conducted on treatment experience in the SEE region
- Specific case study: how does this resonate with your experience in the region?

Presentation outline

- Outline study design and methods
- Findings
- Conclusions about treatment experience in this setting

Study outline

- Conducted by LSHTM in partnership and with support of HPVPI Secretariat in Belgrade
- DfID funded HIV prevention intervention and research programme.
- Advised by Study Advisory Group [key stakeholders]
- Designed to document the experiences of PLHIV to inform policy and advocacy for HIV service provision

HIV in Serbia and Montenegro



- **Cumulative HIV/AIDS cases to Dec 2005: 2,078**
- **December 2005: 1,157 registered PLHIV**
- **Approximately 600 PLHIV currently receiving medical care**

Methods

- In-depth interviews
- 42 PLHIV
- 18 service providers (key representatives of treatment supply chain invited to participate, medical and NGO staff)
- Conducted via translation, or in Serbian or English
- Interviews transcribed and where necessary translated
- Preliminary coding- thematically driven analysis

Sample: 42 individual PLHIV



Place of Residence

Belgrade - 25

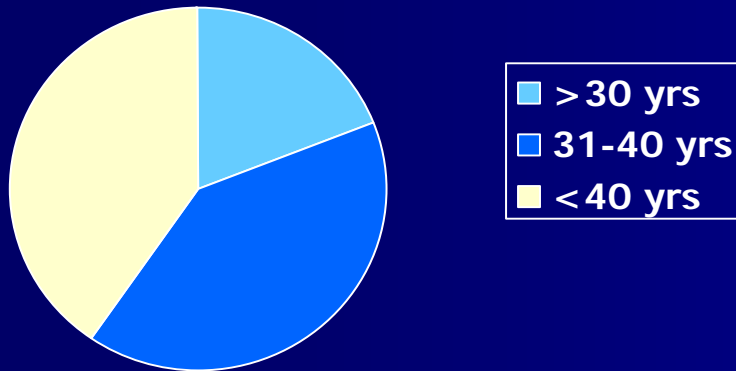
Vovjvodina - 8

Nis area - 4

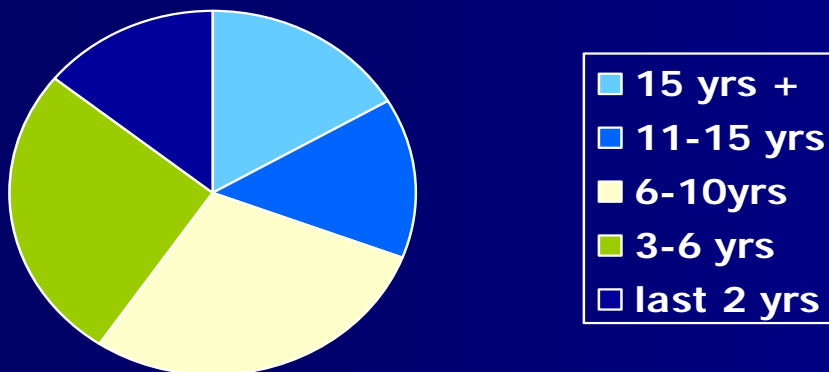
Montenegro - 5

PLHIV sample

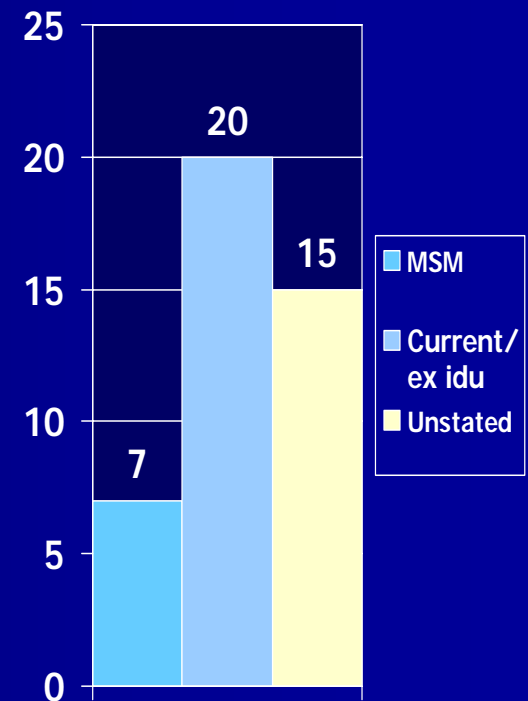
Age



Time since diagnosis



Vulnerable group



Qualitative methodology

- Qualitative study: this limits the ability to generalise the findings
- Findings: key themes emerging from participant accounts
- Study conducted 2005-6 and HIV treatment access and delivery has changed since due to:
 - Decentralisation policy: planned in 2005 and commenced mid 2006
 - Independence of Montenegro: May 2006

Treatment access and delivery

- 100% access to HIV treatment funded by state
- Study found not <100% delivery of HIV treatment
- Shortages of drugs and monitoring tests were reported resulting in
 - Unstructured treatment interruptions
 - Need to alter regimens
- Cause of significant concern among PLHIV

Impact of uncertain treatment supply

'The treatments are just each month what they have in the pharmacy...without any medical check you know, without any check of blood or some support so that you can see those tests say, 'OK you can take that'. It is a very big problem. Now my treatment is available at the pharmacy but I don't know for how long. Now in the meantime, I have to find some connection to go somewhere, outside of the country to see what other possibilities for treatments there are so that I can plan my life. Everything is so expensive and so uncertain.'

quote from PLHIV

Praise for doctors at HIV clinic

Almost universal praise for the doctors within the HIV clinics

'The doctors who are working with us have really good experience. They really give all of their power to help the people here. I mean the doctors do what they can, with what the system gives them.'

quote from PLHIV

Lack of information

- Anxiety of PLHIV exacerbated by lack of easy to understand and clear information
- Rumours around treatment availability prevalent
- Accessing treatment particularly difficult for those outside of Belgrade

Lack of information- anxiety

'It's really difficult to get an explanation or an answer and as I've said this is psychologically really bad, and even the doctors don't or can't give the right information, they don't even know and the patients don't really know whose job it is to know.'

quote from PLHIV

Perceived lack of support

- Little formal support available for PLHIV
- HIV Clinic counselling was praised but overstretched
- Few NGOs working with PLHIV on HIV treatment advocacy
- Insecure funding and weak sustainability of PLHIV services - low life expectancy
- 'A blink of hope' - PLHIV

Consequences of uncertain HIV treatment delivery

- Implications for treating HIV as a chronic manageable illness
- Very difficult for PLHIV to manage anxieties around shortages of therapy despite improvements in drug supply over the course of study
- Fears of sustainability of supplies
- A few patients chose to stop or even not start treatment

Consequences of perceived lack of support

- Low treatment literacy
- Undermined trust in support of system and NGO sector
 - Increased pressure on HIV clinic to manage HIV treatment problems and patient's anxiety
 - Negative influence on PLHIV's participation in community action
 - Impact on pace of social change and efforts to reduce stigma

Why do HIV treatment supply problems occur? [1]

- Funding issues with financial constraints affecting all national health care
- Problems with effective management and accountability within systems increase responsibilities of doctors
- Ineffectual planning in:
 - Licensing
 - Forecasting of long term supply needs
 - The event of drug supply difficulties

Why do HIV treatment supply problems occur? [2]

- Slow registration of new drugs
- Small market with lack of regional cooperation
- Poor Structure for writing and consulting concerning implementation of Treatment Guidelines
- Lack of alternative means of procurement for PLHIV

Conclusion

- The study showed praise for Serbia's 100% access, improvements in treatment delivery and for response to study.
- Recommendations:
 - Treatment system review needed
 - Guidelines to be established [see new EACS guidelines]
 - Information provision needs to improve- hub linking treatment and PLHIV services
 - NGOs to increase treatment advocacy efforts to support service providers and PLHIV
- So do these findings resonate with your experience?
- There are opportunities for regional cooperation in strengthening treatment and community action.

PLHIV study report

- Report available today or contact sarah.bernays@lshtm.ac.uk
- Ongoing prospective qualitative study [end 2007].
- Data to be used for to support treatment advocacy and anti-stigma resources