



Press Release

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European Men's Health Forum calls for steadfast action against stigma and discrimination to improve the quality of life of people living with HIV in Europe

New Europe-wide survey data reveals HIV-positive respondents believe their quality of life can be further improved

Rio de Janeiro, 25/07/05; New data from the European Men's Health Forum's (EMHF) *European HIV-related Quality of Life Review*, presented at the 3rd International AIDS Society Conference on HIV Pathogenesis and Treatment, revealed that almost half of respondents reported dissatisfaction with their quality of life. Whilst respondents believed that many aspects of drug treatment had dramatically improved since they first started receiving therapy, they nonetheless felt that areas of emotional wellbeing, work and social life needed attention. In particular, many respondents still hold concerns about the potential effects of status disclosure on their ability to maintain social networks and to pursue career opportunities.

The EMHF wishes to call for a greater focus of national and local governments on fighting stigma and discrimination, and on improving the overall quality of life of people living with HIV in Europe.

EMHF particularly recommends:

- Further health promotion and information campaigns to fight HIV-related stigma amongst the public.
- Increased assistance to people living with HIV in maintaining or restarting employment, particularly in terms of achieving new qualifications, and flexibility of work schedules.
- Developing research aiming to lessen the visible signs of HIV status through the reduction of treatment side effects and of the frequency of daily medication intake.

"Satisfaction with quality of life is determined by a great many factors and, with the collaboration of HIV advocacy groups across Europe, the EMHF hopes to develop policy recommendations to improve quality of life", stated Erick Savoye, Director of EMHF. "In our survey, respondents showed some satisfaction with treatments but it was also very clear that side effects and difficulty in taking medicines are still an enormous burden. The results also showed that the effectiveness of health and social policies in this area depends on gender-specific needs being met. The EMHF believes that a greater understanding of men and women's differing health behaviours, and respective priorities for quality of life improvement, should inform the development and implementation of future plans."

Reported Experiences

Treatment

Respondents felt that, since taking their first drug regimen, some aspects of treatment had dramatically improved, such as the effectiveness of medication at controlling disease progression, convenience and reduction of side effects. However, respondents did feel that there is still a need for improvement in these areas.

Consistently rated amongst the top three most important aspects of treatment were ease of medication intake (78%), visible side effects (73%) and silent side effects (65%).

Healthcare Services

A trusting relationship with their doctor was rated as the most important factor to maintaining a good quality of life. Many indicated being highly satisfied with their involvement in clinical decisions, doctors' knowledge of the latest medical technologies and doctors' concerns about treatment impact on quality of life.

Physical Wellbeing

Pain, fatigue and disrupted sleep were the most reported day-to-day consequences of HIV and respondents felt that the areas of life most affected by these consequences were work and social activities.

Almost a quarter of respondents (22%) reported moderate to a lot of pain, nearly half of respondents (45%) reported moderate or a lot of fatigue and 42% reported moderate to much disrupted sleeping patterns.

Emotional Wellbeing

More than half (51%) of respondents felt conscious of their HIV status some of the time whilst 44% answered most or all of the time. Future body shape changes, increased symptom visibility and physical disability ranked among the top three causes of concern for both men and women.

Fear of Disclosure and Impact on Relationships

98% of respondents had already told a partner, wife or husband about their status. The HIV diagnosis was felt by the majority of respondents to have the most impact on their relationship/marriage. Respondents felt that the ability to provide for family/care for children and the ability to maintain social networks or employment were negatively affected by their HIV status.

Actual reactions from friends and work colleagues often appeared more positive than originally anticipated by respondents, highlighting that fear of disclosure and discrimination still runs high.

Employment

370 respondents (69%) were in employment of which one quarter worked part-time. Of these, almost one third (30%) previously had to quit employment due to HIV-related medical reasons and almost one quarter (22%) had to change jobs and/or learn new skills. Over one third (34%) needed to reduce their working hours.

Over a half of all respondents (58%) felt their diagnosis could affect their career opportunities and a further 24% were unsure. Only 18% did not think their HIV status would impact on their career. Interestingly, 53% of respondents perceived they would receive a negative reaction from their employer whereas in reality only 7% of respondents experienced a negative reaction from their employer.

Gender Specific Experiences

Across all measures of quality of life (experience of health services, treatment, physical and emotional wellbeing, work and social life), at least 10% more women than men expressed more dissatisfaction/less satisfaction. Women were particularly dissatisfied with social life and work aspects.

Aspects men and women most wish to see improved:

Rank	Men	Women
1	Treatment side effects	Emotional wellbeing
2	Emotional and physical wellbeing	HIV discrimination
3	Ease of medication intake	Treatment side effects
4	HIV discrimination	Ease of medication intake

The study is supported by an educational grant from Bristol-Myers Squibb and falls under the umbrella of the One Vision European Photographic Competition, designed to reduce HIV-related stigma in Europe. The full report is available from www.emhf.org

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Notes to Editors:

The study was initiated in mid 2004 and was aimed at examining expectations of men and women living with HIV towards quality of life and the effect of gender-based factors. The questionnaire was made available through the website of the EMHF. A number of global and international websites publicised the existence of the study and posted links from their site to the EMHF site.

The EMHF received the support of HIV patients' organisations in France, Germany, Italy and Spain to publicise the existence of the survey and to disseminate questionnaires in their native language.

- Approximately three quarters of respondents (76%) were male and one-quarter (24%) female. 534 people in total responded to the questionnaire.
- The mean age of respondents was 39.02 years.
- Over half the respondents (55%) were gay/lesbian, 30% were heterosexual/straight and approximately 14% bisexual. Analysis of the results by gender showed that 71% of men were gay, 17% bisexual and 10% heterosexual/straight. 92% of women were heterosexual/straight, 3% gay/lesbian and a further 2% bisexual.
- 85% of respondents were West European with a further 9% being African. No other ethnic grouping accounted individually for more than 1% of the total.

European Men's Health Forum

The EMHF is an independent, non-governmental, non-profit making organisation established to promote male health across Europe. It is a membership organisation managed by a board of directors and an executive committee, which represent the diversity of its stakeholders. These include national men's health organisations, EU policy makers, organisations representing health professionals, academics and women's health and patient's organisations. www.emhf.org

Bristol-Myers Squibb

Bristol-Myers Squibb is a global pharmaceutical and related health care products company whose mission is to extend and enhance human life. www.bms.com

One Vision

One Vision is a campaign sponsored by Bristol-Myers Squibb to encourage new and positive ways of looking at the lives of people living with HIV and AIDS. Through this competition, Bristol-Myers Squibb will contribute essential funds to community HIV and AIDS groups across Europe. For more information about the One Vision campaign, visit www.onevision2005.org

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