Women with HIV/AIDS described several forms of positive change resulting from their illness


QUESTION: What are the perceptions of illness related positive change among women living with HIV/AIDS?

Design Qualitative study.

Setting New York City, New York, USA.

Patients 54 women (mean age 36 y) were recruited through advertisements, flyers, and community outreach to health, social, and advocacy organisations. Inclusion criteria were HIV antibody seropositivity or diagnosis of AIDS; residence in metropolitan New York City; if Hispanic, were Puerto Rican (of any race) and living on the mainland for ≥4 years, or if African-American or white, were native born and non-Hispanic; and no IV drug use in the previous 6 months. 18 were African-American, 19 were non-Hispanic white, and 17 were Puerto Rican. 56% had AIDS, 23% were symptomatic, and 21% were asymptomatic.

Methods Women participated in 2 semistructured interviews within a 1 month period, with each session lasting about 2 hours. Interviews began with a general question about changes because of HIV/AIDS, and then specific changes in behaviour, relationships, spirituality, goals, and how the person had changed from before infection. Interviews were audiotaped and transcribed verbatim for thematic analysis.

Main findings Although women acknowledged the negative consequences of their illness, most reported that HIV/AIDS had changed their lives in some positive way. 6 forms of stress related growth were identified. HIV/AIDS was seen as a motivating factor for women to make positive behavioural changes, including long standing, problematic health related behaviours such as substance abuse, smoking, and risky sexual behaviours. Women with a history of drug abuse reported the most profound changes. Many women described how HIV/AIDS had contributed to their religious/spiritual growth, and they returned to previously neglected religious roots to find meaning, spiritual support, or a deepening of faith. Women described growth in relationships, as over time, relationships with children, family, friends, and lovers became closer and more important. HIV/AIDS was seen as a catalyst for resolving past differences and using their remaining time to express and affirm their love for one another. Women described positive self changes as a result of HIV/AIDS. They felt stronger, more responsible, and more caring. Their illness decreased their dependency as they were forced to stand up for themselves, advocate for services, and manage new challenges. Many women felt that HIV/AIDS resulted in changes in the value of life. They had a greater appreciation of life and the time they had left. HIV/AIDS often led to positive goal related changes, usually related to helping others through AIDS advocacy, education, or care provision. They focused on educational aspirations that would enable them to serve the HIV/AIDS community. HIV/AIDS was a setback for some women as they had to stop their careers because of symptoms; others felt, however, that leaving their jobs was a positive change that allowed them more time to relax and take care of themselves.

Conclusion While acknowledging their experiences of the negative sequelae of HIV/AIDS, women described 6 types of positive changes that often emerged as part of the process of coming to terms with living with HIV/AIDS.