

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

Siegel K, Schrimshaw EW *Perceiving benefits in adversity: stress-related growth in women living with HIV/AIDS. Soc Sci Med* 2000 Nov;51:1543-54.

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.

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COMMENTARY

The secondary analysis by Siegel and Schrimshaw is an interesting addition to the field of stress related growth. The researchers suggest that one explanation for perceiving positive outcomes or growth associated with the AIDS experience might be that it represents an emotion focused coping strategy. Such coping strategies allow individuals to find positive meaning in difficult experiences by reappraising their stressors more favourably.¹ This is consistent with the notion that these women were "trying to find a silver lining so that they would feel less victimized" (p1551).

The suggestion that the identification of positive outcomes might be a coping or adapting strategy is consistent with reports from long term survivors who attributed their survival to similar conceptualisations.² For example, focusing on behaviours to enhance physical and mental health (*taking care of oneself*), and believing that having AIDS was a blessing (part of *triumphing*) were offered by AIDS survivors as important dimensions of adapting to this illness experience.³ The combined results suggest that the perception of positive outcomes associated with HIV/AIDS might have important implications for survival.

The interpretation of these perceived positive outcomes as part of an emotion focused coping strategy raises the question of whether the reported positive outcomes are "real" or not. For patient focused clinicians, it might not matter as both have adaptive value. Nurses should, however, be careful in assuming that emotion focused strategies will lead to positive behavioural changes such as stopping illicit drug use or practising safe sex. Firstly, in this study, only women who had stopped using drugs were part of the sample. Secondly, no corroborating data were collected to confirm the changes in health behaviours. Nevertheless, the results suggest it might be important for nurses to support strategies that enhance a positive reappraisal of the situation. Consequently, nurses would benefit from becoming familiar with ways to foster emotion focused coping strategies.

Overall, it is important to remember that a perceived positive effect can co-exist with the stressful component of an illness experience. Nurses should pay attention to both when guiding HIV/AIDS patients along the illness experience.

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1 Folkman S. Positive psychological states and coping with severe stress. *Soc Sci Med* 1997;45:1207-21.

2 Barroso J. Reconstructing my life: becoming a long-term survivor of AIDS. *Qual Health Res* 1997;7:57-74.