

To say or not to say: a qualitative study on the disclosure of their condition by human immunodeficiency virus-positive adolescents

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PURPOSE: Human immunodeficiency virus (HIV)-positive adolescents face a number of challenges in dealing with their disease, treatment, and developmental tasks. This qualitative study describes some of the reasons why, and the extent to which, adolescents may or may not disclose their condition to others. METHODS: A semistructured interview lasting 40-110 minutes was conducted with each of 29 adolescents 12-20 years old, 22 female and seven male) living in Switzerland. Interviews were tape recorded and transcribed verbatim. The analysis of the content of interviews allowed us to identify salient topics (e.g., disclosure), which were then explored in detail. RESULTS: Of 29 participants, eight had not disclosed their condition to anyone outside the family, 19 had disclosed it to good friends, and 16 had disclosed it to some teachers. Four participants had engaged in public disclosure, and six of 10 sexually active teenagers disclosed their status to their partners. The attitudes toward disclosure among younger adolescents were mostly related to those of the parents, particularly the mother. Older adolescents, engaged in their search for autonomy, tended to decide independently what to say and to whom. Although foster/adoptive parents would often encourage disclosure, biological parents, especially HIV-positive mothers, insisted on not disclosing the adolescent's status for fear of stigma. CONCLUSION: The health care team should systematically address the issue of disclosure with the adolescent and his family (or foster parents), the aim being to balance the right of the adolescent and that adolescent's family to maintain privacy against the concerns of sexual partners, as well as the adolescent's interest in divulging HIV status to relatives, school staff, and friends.

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