

Coping with an HIV infection

A multicenter qualitative survey on HIV positive adolescents' perceptions of their disease, therapeutic adherence and treatment

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Summary

HIV-positive adolescents face a number of challenges in dealing with their disease and its treatment. In this qualitative study, twenty-nine HIV-positive adolescents aged 13 to 20 years (22 girls), who live in Switzerland, were asked, in a semi-structured interview (duration of 40–110 minutes), to describe their perceptions and experiences with the disease itself and with therapeutic adherence. While younger adolescents most often thought of their disease as fate, older adolescents usually knew that they had received it through vertical transmission, although the topic appeared to be particularly difficult to discuss for those living with their HIV-positive mothers. Based on their attending physician's assessment, 18 subjects

were judged highly adherent, 4 fairly and 7 poorly adherent. High adherence appeared linked with adequate psychological adjustment and effective coping mechanisms, as well as with the discussion and adoption of explicit medication-taking strategies. The setting and organisation of health care teams should allow for ongoing discussions with HIV-positive adolescents that focus on their perceptions of their disease, how they cope with it and with the treatment, and how they could improve their adherence.

Keywords: HIV; AIDS; adolescent; development; coping strategies; treatment; therapeutic adherence

Introduction

Adolescence is a complex developmental process that includes the progressive adoption of autonomy and identity [1, 2]. Like other individuals suffering from chronic conditions, HIV-positive adolescents undergoing highly active antiretroviral treatment (HAART) face a number of challenges related to these two developmental tasks [3–5]. On one hand, HIV-positive adolescents have to develop their identity, a sense of personal sameness and continuity paired with some belief in the meaning of their life and their role in the community [1]. HIV-positive adolescents have to integrate the fact that they are not as “normal” as their peers, that they have to take medication, and they have to accept life in a context of uncertainty about whether they will survive and for how long [6, 7]. Thus, beyond providing the medical follow-up for the HIV infection, health professionals caring for these young people must assist them in developing their autonomy as well as a stable identity by discussing the impact of the disease and its treatment on their everyday lives [8, 9].

On the other hand, as they progressively strive to gain their autonomy, which can be reflected in their capacity to manage their treatment without parental/other caring adults' support, it is inevitable at times that their adherence to treatment weakens [10–14]. The risk of low adherence is increased by the fact that an HIV infection is often “silent” meaning that, contrary to asthma or rheumatic disease, not taking medication is not immediately followed by observable consequences [15, 16].

To shed further light on the situation of these adolescents, a qualitative study was designed focusing on their health, lifestyle, treatment adherence and psychosocial characteristics. The objective of this paper is to describe the adolescents' perceptions of their illness, of their therapeutic adherence and of their participation in decisions regarding their treatment, with the idea that a better understanding by health professionals of these perceptions will assist them in improving the outcomes, both in terms of the adolescents' coping capacities and how to improve adherence to treatment.

Coping With Hiv Infection

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Table of Contents Coping With Hiv Infection

1. Understanding the eBook Coping With Hiv Infection
 - The Rise of Digital Reading Coping With Hiv Infection
 - Advantages of eBooks Over Traditional Books
2. Identifying Coping With Hiv Infection
 - Exploring Different Genres
 - Considering Fiction vs. Non-Fiction
 - Determining Your Reading Goals
3. Choosing the Right eBook Platform
 - Popular eBook Platforms
 - Features to Look for in an Coping With Hiv Infection
 - User-Friendly Interface
4. Exploring eBook Recommendations from Coping With Hiv Infection
 - Personalized Recommendations
 - Coping With Hiv Infection User Reviews and Ratings
 - Coping With Hiv Infection and Bestseller Lists
5. Accessing Coping With Hiv Infection Free and Paid eBooks
 - Coping With Hiv Infection Public Domain eBooks
 - Coping With Hiv Infection eBook Subscription Services
 - Coping With Hiv Infection Budget-Friendly Options
6. Navigating Coping With Hiv Infection eBook Formats

- ePub, PDF, MOBI, and More
- Coping With Hiv Infection Compatibility with Devices
- Coping With Hiv Infection Enhanced eBook Features
- 7. Enhancing Your Reading Experience
 - Adjustable Fonts and Text Sizes of Coping With Hiv Infection
 - Highlighting and Note-Taking Coping With Hiv Infection
 - Interactive Elements Coping With Hiv Infection
- 8. Staying Engaged with Coping With Hiv Infection
 - Joining Online Reading Communities
 - Participating in Virtual Book Clubs
 - Following Authors and Publishers Coping With Hiv Infection
- 9. Balancing eBooks and Physical Books Coping With Hiv Infection
 - Benefits of a Digital Library
 - Creating a Diverse Reading Collection Coping With Hiv Infection
- 10. Overcoming Reading Challenges
 - Dealing with Digital Eye Strain
 - Minimizing Distractions
 - Managing Screen Time
- 11. Cultivating a Reading Routine Coping With Hiv Infection
 - Setting Reading Goals Coping With Hiv Infection
 - Carving Out Dedicated Reading Time
- 12. Sourcing Reliable Information of Coping With Hiv Infection
 - Fact-Checking eBook Content of Coping With Hiv Infection
 - Distinguishing Credible Sources
- 13. Promoting Lifelong Learning
 - Utilizing eBooks for Skill Development
 - Exploring Educational eBooks
- 14. Embracing eBook Trends
 - Integration of Multimedia Elements
 - Interactive and Gamified eBooks

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