Chapter 11

A Narrative Description of Disclosing Sensitive Information to Empower an HIV/AIDS Infected or Affected Child

Mmule Magama  
University of Botswana, Botswana

Motshedisi Sabone  
University of Botswana, Botswana

Pelonomi Letshwiti-Macheng  
University of Botswana, Botswana

EXECUTIVE SUMMARY

Failure to disclose sensitive information to a child is a source of emotional trauma. The consequences include inability to respond to life challenges and impaired productivity. In this case, concealing sensitive information is a form of disempowerment that can result in poor adherence to therapy and resistance to the use of existing support systems. Disempowerment is displayed through disruptive behaviour, low self-esteem, and inability to make constructive decisions. This behaviour flourishes within traditional cultures in which disclosure of sensitive information to a child is considered a taboo in the pretext of protecting the child from emotional pain. Contrary to this view, it is demonstrated in this chapter that disclosure can be empowering. It can lead to self-acceptance and positive thinking that will enable a client to approach life with a positive attitude, and willingness to learn and succeed. Evidently, the child in this chapter demonstrated normal processes of child development, appreciated parental advice, and behaved more responsibly following disclosure of his and his parent’s positive HIV status.

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INTRODUCTION

The chapter addresses the importance of issues related to the disclosure of HIV infection. Disclosure here is considered a critical step in the empowerment of an HIV and AIDS affected and infected child. Empowerment, on the other hand simply implies personal acceptance which opens up for other positive attributes such as accepting therapy and approaching life with a positive attitudes and willingness to learn and succeed like others. The stigma surrounding HIV has made it difficult for parents to open up and discuss HIV and AIDS issues with their children especially in cases where either the parent or the child is infected. The case presented in this chapter involves a child who is infected with HIV and parents who are reluctant to discuss the HIV status with the affected child. A number of reasons are normally proffered towards this reluctance. In Botswana, children are considered “the buds of society” and parents must incorporate them into society, feed them, bring them up, educate them, and in many ways, protect them from anything that stands in their way of development (Mbiti, 1988, p.110). It is for this reason that at times parents fear to disclose information about HIV and AIDS infection to their children because of the consequences that may accompany such a disclosure. Quite often, people who discover their HIV status become demoralized, depressed, and feel rejected. To a certain extent, these types of feelings are disempowering. Disempowerment here may manifest as disruptive behaviour such as denial, low self-esteem, resistance to help and inability to make constructive decisions. It is therefore important that a critical consideration of the consequences of both disclosing and failing to disclose sensitive information is made before either decision can be taken.

Literature underscores the importance of disclosing HIV status to affected people over withholding such information from them (Monahon, 1993; Rotenberg, 1995). Whereas the authors support this widely held view about HIV status disclosure versus non-disclosure, they also acknowledge the difficulty and potential psychological risk in HIV status disclosure, if the process is not well managed. In this chapter, therefore, the authors present a case study that illuminates the challenges in disclosing HIV status to affected children and how the psychological risks inherent in the process can be reduced. Disclosure is used in the case study to mean revelation of concealed HIV and AIDS information to a child who is infected or affected. It is very important that disclosure is done because of its empowering effects. A number of approaches can be used to disclose sensitive information to children. In this case, storytelling has been found to be effective. The story-telling in this regard refers to conveying a message through a detailed narration of information as it unfolds. This mode of information gathering was adopted because of its thrilling and readily appealing nature to children since they enjoy story-telling.
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