

CIRCLES OF SECRECY: CAREGIVER CONFIDANTES AND PAEDIATRIC HIV DISCLOSURE

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Introduction

- Disclosure of children's HIV positive status is critical to enabling them to take responsibility for managing their own care as they age
- The process of disclosure is often delayed due to a lack of appropriate training and support for those responsible for children's care and treatment
- Current approaches to paediatric HIV disclosure focus almost exclusively on the child-caregiver-health worker relationship
- This study explored caregiver attitudes towards paediatric HIV disclosure, focusing specifically on the role of caregiver confidantes in assisting caregivers in managing paediatric HIV

Methods

- In-depth interviews were conducted with 51 caregivers in the Western Cape and Limpopo
- Interviews were recorded and transcribed
- An adapted grounded theory style analysis was used to identify key themes

Results

- The majority of caregivers viewed disclosure as a one-to-one process between themselves and the child, or between health workers and children
- Caregivers generally had not begun the process of disclosing to their children
- In spite of not disclosing children's status to them, 75% of caregivers reported telling their immediate families about their child's HIV status, while 39% reported telling friends, neighbours, or other community members
- The primary reason for disclosing to family and friends was to assist in maintaining children's adherence on ART
- This created 'circles of secrecy' around children, with various people in their lives simultaneously managing their care, and withholding the fact of their HIV positive statuses

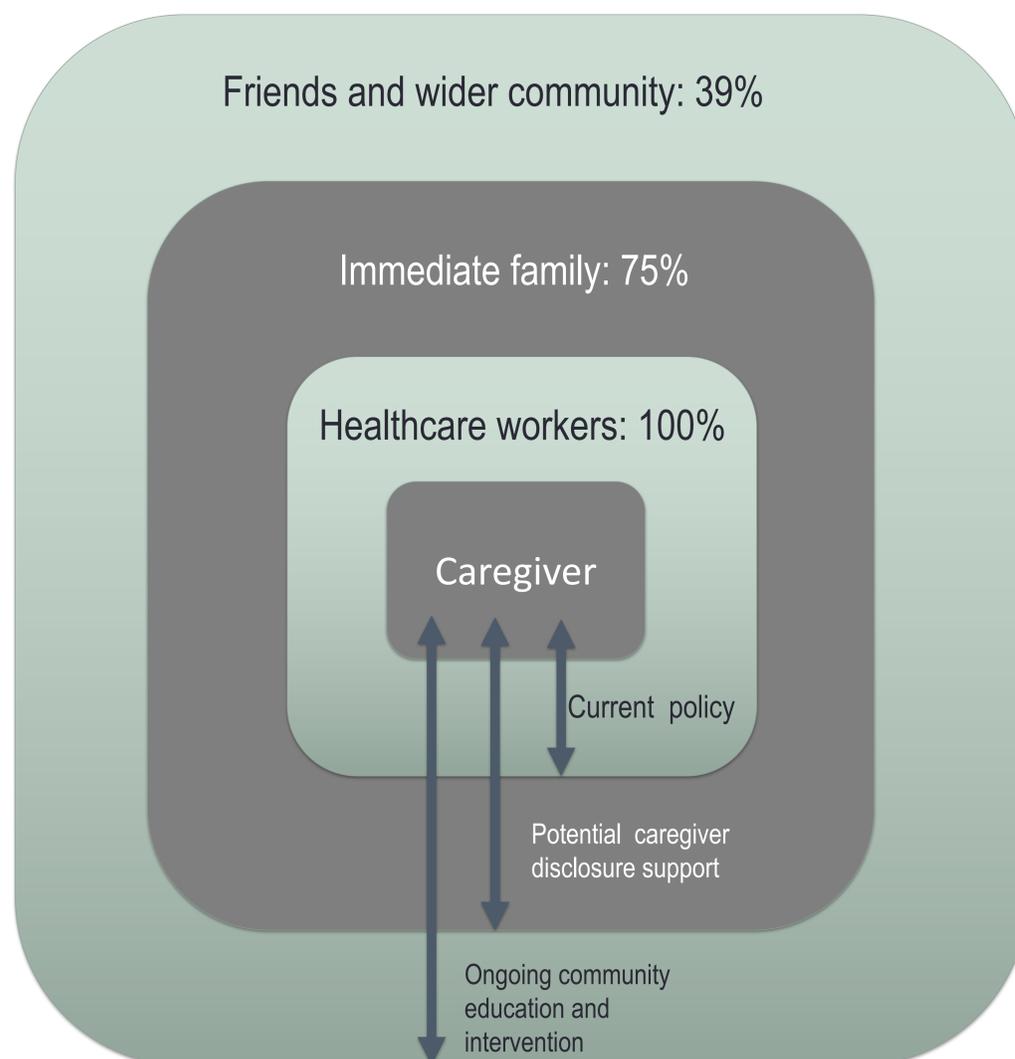


Figure 1: Percentage of caregivers reporting disclosing children's HIV statuses to family members, friends, neighbours and the wider community

Conclusions

Given that existing research on individual disclosure shows positive impact of supportive peers on the disclosure process (cf. Kalichman et al. 2003), it may be possible to utilise these social networks to provide support to caregivers through the process of disclosing to children.

References / Notes

1. Kalichman, S. C., DiMarco, M., Austin, J., Luke, W., and DiFonzo, K. 2003. Stress, Social Support, and HIV-Status Disclosure to Family and Friends Among HIV-Positive Men and Women. *Journal of Behavioural Medicine* 26(4):315-332.

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