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Summary

The studies described in this thesis provide a comprehensive understanding of adherence to ART, disclosure of HIV status to the child, home-based treatment of tuberculous meningitis and we determined the cost-effectiveness of home-based treatment of this program compared to in-hospital treatment. In addition, a treatment-support intervention was developed, implemented and evaluated in collaboration with a diverse group of stakeholders involved with the care for children with HIV infection and tuberculous meningitis.

Chapter 1 is the general introduction to this thesis. South Africa is considered a middle-income country in terms of its economy, however, has health outcomes that are worse than those in many lower income countries. The country's history has had a pronounced effect on the health of its people, and the health policy and services of the present day. There are strategic plans in place to address the HIV and TB pandemics in particular, however there is inadequate capacity to deliver critical healthcare interventions.

South Africa has the largest paediatric HIV program in the world. Although South Africa has guidelines and strategic plans in place that address adherence, this information is not specifically tailored to children. Many patients experience difficulties following treatment recommendations. Poor adherence to long-term therapies severely compromises the effectiveness of treatment making it a critical issue in population health, both from the perspective of quality of life and of health economics. Understanding the factors associated with paediatric adherence can help inform clinical practice, strategies and policies to improve adherence. In addition, increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments. To date, the extent of disclosure of HIV status to children and adolescents and context facilitating their disclosure process has received little attention, although widely perceived to be important. For children and young adolescents, disclosure is the first step in a successful transition to manage their own HIV care. In-hospital treatment of children with tuberculous meningitis is not a feasible option in many resource-poor countries such as South Africa. Home-based treatment has shown to be a viable alternative under certain conditions. The cost-effectiveness of home-based treatment compared to in-hospital treatment had not yet been evaluated. The difference in healthcare structure, treatment regimen, duration of treatment and effect of the condition on daily functioning between HIV infection and tuberculous meningitis provided for a diverse population to study paediatric home-based treatment.

Chapter 2 describes a comprehensive analysis of factors associated with adherence in children with HIV infection. We included 195 children aged 2 to 13 years. Adherence depended on definition and measure which ranged between 20-55% for pill count, and 80-

89% for self-report. In addition, 67% of children were virally suppressed and 92% had a CD4 count >500 copies/mm³. We found that boys were less adherent according to caregiver self-report, girls were less adherent according to pill count. The social construct of gender roles seems to affect the measure of adherence within a paediatric population which needs to be taken into account when addressing adherence in clinical practice, research and when developing interventions.

Non-adherence was not merely defined by low pill counts; upper levels were as high as 192% and should therefore be considered when defining adherence both in clinical practice and in a research setting. Caregivers ensured medication was taken when the condition directly affected daily life. On the other hand, well-functioning families and families with high SES provide a context supportive of adherence. Non-disclosure and difficulties administering medication negatively affected adherence and viral suppression. Monthly clinic visits represent a convenient and appropriate time to address these difficulties and can resolve these problems while reducing socially desirable answers and stigmatisation.

In **chapter 3** we investigated disclosure of HIV status to the child and aimed to provide a comprehensive analysis of factors associated with disclosure. For this study, we included 190 children from the population described in **chapter 2**, who were three years and older. The HIV status was disclosed to 24% of the children (partial disclosure 15%, full disclosure 9%). Disclosure was strongly associated with older age of the child. When children do well on treatment, caregivers feel less need to disclose. Well-functioning families, with higher educated caregivers and children from households with better SES, provided an environment enabling and promoting disclosure. Non-disclosure can indicate a sub-optimal social structure which could negatively affect adherence and viral suppression. Low disclosure amongst young children demonstrates an urgent need to address disclosure thoughtfully and proactively in long-term disease management. For the disclosure process to be beneficial, an enabling supportive context is important. Families within such context provide a great opportunity for future interventions.

Barriers to adherence and caregiver perceptions of home-based treatment of tuberculous meningitis are discussed in **chapter 4**. A qualitative study describes 11 in-depth semi-structured interviews based on the principles of the health belief model. Caregivers showed good appreciation of the adverse effects of non-adherence and benefits obtained from taking treatment in the home environment. Barriers of adherence identified included poor understanding of the disease and transmission route, difficulty with medication administration and side effects, lack of access to the healthcare facility, long waiting times and hidden costs of transportation. Improved doctor–patient communication, information brochures, structural changes to hospital settings, provision of financial and peer support all contribute to optimal tuberculous meningitis home-based treatment.

In **Chapter 5**, the societal costs and cost-effectiveness of home-based versus in-hospital treatment of paediatric tuberculous meningitis were described from a societal perspective using probabilistic analysis. Healthcare, informal care, lost-productivity costs and costs in other sectors, health-related quality of life and family impact were assessed during interviews with caregivers, children, medical staff and management. Societal costs of home-based treatment are lower compared to in-hospital treatment (USD3857 versus USD28043). Children treated at home have a better health-related quality of life (91% versus 85%) and family impact-scores (95% versus 73%). Home-based treatment is a highly cost-effective alternative for in-hospital treatment of drug-susceptible tuberculous meningitis.

Chapter 6 describes a randomised-controlled evaluation of a paediatric treatment-support intervention for home-based treatment of HIV infection (population described in **chapter 2 and 3**) and tuberculous meningitis (home-based treatment group described in **chapter 5**). The intervention was developed based on qualitative research (**chapter 4**) and combined adherence-education (information brochure), -reinforcement (sticker-puzzle), and -monitoring (calendar). The low-cost, cultural friendly treatment-support intervention had beneficial effects on health-related quality of life, family functioning and caregiver disclosure of HIV status to the child. Treatment adherence was not significantly affected in both the HIV and tuberculous meningitis groups. The intervention resulted in an increased caregiver reporting of medication non-adherence and caregiver reporting of difficulties experienced with administering medication.

Chapter 7 reviewed the main findings and implications of these studies and provided recommendations for paediatric HIV and tuberculous meningitis care. The current home-based setting for treatment of HIV infection in children provides opportunities for improvement. It is important to address adherence to ART and the disclosure process of HIV status to children before the health of the child deteriorates. Recommendations for clinical practice, research and the development of interventions include the consideration of gender roles within the societal context, and defining adherence measured with pill count including upper limits. Monthly clinic visits represent a convenient and appropriate time to address difficulties administering medication (a good indication of adherence) and an opportunity to resolve these problems. The effect of the condition on the child's life, caregiver's life and family life affect paediatric adherence and the disclosure process. When ART is tolerated well, and no condition-related difficulties are experienced, the urgency to remain adherent or disclose the child's HIV status, are not as prominent. When daily life is affected by the condition, caregivers ensure medication is taken and children more likely receive disclosure. Well-functioning households and households with high SES provide a context supportive of treatment adherence, viral suppression and the disclosure process. For the disclosure process to be beneficial, an enabling supportive context is important.

Families within such context provide a great opportunity for future adherence and disclosure interventions. Healthcare provider-caregiver communication is crucial in the facilitation of good adherence behaviour, and successful disclosure process. High levels of adherence in a home-based setting for treatment of paediatric tuberculous meningitis are possible. Home-based treatment is highly cost-effective compared to in-hospital treatment. Provided a strict selection procedure, a structured follow-up system including a dedicated program nurse and with the commitment of the healthcare providers involved, we recommend the implementation of home-based treatment for tuberculous meningitis at scale. The treatment-support intervention enables an environment supportive of adherence and the disclosure process. We therefore recommend the use of the intervention to support home-based treatment for children embedded within existing treatment-support structures.