

An interpretive investigation of perinatal HIV  
transmission:  
From the population to the personal

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A thesis submitted in fulfilment of the requirements of  
Doctor of Philosophy

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University of Technology, Sydney**

### **CERTIFICATE OF AUTHORSHIP/ORIGINALITY**

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

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## ACKNOWLEDGEMENTS

I wish to express my gratitude and thanks to several people who have provided me with comment, guidance and support during my candidature. Firstly, grateful thanks to my supervisors, Professor Jackie Crisp, A/Professor John Ziegler and in particular to Dr Cheryl Waters; to my friend, Tina Kendrick; to my friend and fellow student, Alison Hutton; and to my children and family from whom nursing and study have taken up so much of my time. Thank you also to Michelle Goode and Mary Jo O'Hara for reading sections of the thesis and for their general and kindly encouragement.

I would also like to acknowledge the scholarship from National Health and Medical Research Council that allowed me to devote uninterrupted time to the study. I would also like to thank Professor Jackie Crisp and A/Professor Ziegler for periods of paid employment during my candidature.

I would also like to thank the many nurses, particularly the paediatric nurses at Sydney Children's Hospital for the encouragement of 'one of their own' in undertaking a doctorate.

Special thanks must also go to the children with HIV, their parents and families who have taught me to listen to their stories and who have shared such intimate moments with me during my work as CNC and during this research study.

I would like to dedicate this thesis to the two Clyties who sadly are no longer with us. Firstly, to my aunt, Clytie Stevens, who fostered in me a love of learning and secondly, my sister, (Clytie) Anne, who taught me to find goodness in everyone.

## Abstract

While there have been many studies investigating perinatal HIV infection, few have addressed the complexity of the disease. The complexities of HIV infection are compounded for families affected by the disease where several family members are infected. HIV infection is a particularly challenging disease when it affects children and their families as it has the potential to extinguish whole families, placing an infected family under extreme stress. The multigenerational impact of the disease, where several family members are infected and where multiple losses may have occurred as a result, severely affects the family's ability to cope with existing problems.

This dissertation explores the experience of children with perinatal HIV and their carers using an interpretative methodology to synthesise understandings from three separate epidemiological, case study, and interview studies. A review of data from the National Perinatal HIV Register provides information on perinatal transmission of HIV in Australia; a case study demonstrates the medical complexity of the disease from diagnosis to treatment while interviews with parents and children provide insight into the effects of the disease. The study is predicated not only on the research undertaken for this study but also on clinical experience of the researcher.

The findings demonstrated that although HIV is a relatively rare disease in Australia transmission continues despite strategies which have demonstrated efficacy in preventing transmission from mother to child. Perinatal transmission continues to occur especially when women give birth before a diagnosis is made. The experiences of parents caring for children with HIV infection, although varied, demonstrate the complex nature of HIV. Once diagnosed with HIV, parents find themselves undertaking a fine balancing act during which they must negotiate to strike the right equilibrium for their family to endure the circumstances as best they can. They are faced with contradictory decisions in which, for example, they must disclose their HIV status to others to receive the support necessary to survive the emotional turmoil created by the disease.

Children's experiences of living with perinatal HIV infection are an ongoing process. Most of the children who were interviewed for this study had been affected by HIV either through severe ill health or by the death of one or both parents. Thus, for all the children, HIV was a very real entity even though at the present time all were now well and attending school full time.

Across all major themes is the cumulative effect of HIV disease on the child and family. It is the cumulative effects of HIV that presents the greatest challenge for families and clinicians and it is this challenge that underpins the study.

This study represents the beginning of a systematic approach to an examination of how and why Australian children have been infected through mother to child transmission and explores the perceptions and experiences of children and their families. It is hoped that this research will provide health care providers, managers and researchers an understanding with which to guide the care of children and their families living with perinatal HIV.

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