

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

A BOY OR A GIRL?
Parental, Family and Whanau Information Needs When a Child is
Born with an Intersex/DSD Condition

A thesis presented in fulfilment of the requirements for the degree of

MPHIL
in
Nursing
at Massey University, Auckland, New Zealand

Gabrielle Leigh McCarthy
2008

ACKNOWLEDGMENTS

Firstly I would like to thank the women and men who shared their stories with me. These were personal and emotional narratives and most often hard stories to hear. I respect the courage these people displayed in contacting me and their willingness to share their experiences in the hope that others would have an easier path.

Thank you to my supervisors Denise Dignam and Suzanne Phibbs for your help and guidance as I negotiated a way to present these narratives.

To my work colleagues Robyn Wilkinson and Simon Rowley, thank you for the opportunity to talk through the issues and dilemmas involved in writing about a controversial subject especially within the medical community.

Lastly to my wonderful partner, and my three children, for your love and support, and for being there for me as I completed this work.

ABSTRACT

Is it a girl or a boy? This is a question that new parents assume will be answered at the birth, or even in the months leading up to the birth of their baby. To have a baby born where gender is not certain or to discover your child has a condition where their chromosomes and/or genital anatomy are not what are considered 'normal' for males and females shatters the expectations parents have for their child. While dealing with their shock and accompanying grief parents are caught up in major clinical decisions which impact on their child's future. Over the last fifty years there has been a medical paradigm of care that has recently been questioned in terms of the ethics and clinical treatment these families and children have received. This debate is ongoing and new parents are still being caught up in trying to make decisions with major implications for their child's life while negotiating their own, their family and friends, and the medical community's interpretations of major questions around what makes us male or female.

This study used a qualitative exploratory methodology to interview twenty one representatives from four key stakeholder groups in order to explore the information needs parents, families and whanau have when their child is diagnosed with an intersex/DSD (disorder of sexual development) condition. The groups were adults who self identified as having an intersex condition, parents of children with intersex/DSD conditions, representatives from advocacy and support groups and medical professionals these families would come in contact with.

Data was analysed looking at themes which arose from the narratives of those who spoke to the researcher and excerpts from the transcripts are used throughout the data chapters to illustrate the themes. 'Finding Out and Finding Information' examines the experiences of parents and families as they discover their child has an intersex/DSD condition and how this is impacted by the way health professionals talk with them and the information they receive. It reviews the internet as a source of information and the challenges the internet provides for parents. 'The Hard Issues' examines some of the dilemmas, ethical, legal, social and personal, brought up when making decisions for a child and the issues which parents confront in their day to day parenting. It also looks at the experience of growing up with an intersex/DSD condition. The Chapter on 'What is Helpful Information? Conclusions and Recommendations' reviews the advice and information parents would have liked to

receive when their child was born, and that they would offer to others. Finally recommendations are made for health professionals in terms of education and the information and help they can offer to parents, families and whanau.

This thesis explores the experience of those adults, families and children who have been treated under an existing medical paradigm, the work of those who want to effect change for these families and the information needs expressed by those who were willing to share their stories. It makes recommendations for improving the future experience families have within the healthcare system as they face the challenges and joys involved in having a child with an intersex/DSD condition.

TABLE OF CONTENTS

Acknowledgements	ii
Abstract.....	iii
Contents	v
Glossary	vii
Chapter I: Introduction to the Research	1
Debates Over Nomenclature	2
Research Aims, Objectives and Contribution to the Field.....	5
Thesis Overview	7
Chapter 2: Literature Review	11
Anatomy and Physiology	12
A Brief History of Clinical Management.....	13
Other Voices and Ethical Debate.....	19
In the Child's Best Interests?.....	25
Clinical Management- Contemporary Issues.....	31
Information Needs.....	37
Summary.....	39
Chapter 3: Notes on Methodology.....	41
Parents	43
Adults with Intersex Conditions.....	44
Health Professionals.....	44
Advocacy Groups.....	44
Ethical Issues.....	45
Recruitment and Interviews.....	47
Data Collection and Management.....	49
Thematic Analysis.....	51
Dissemination and Implementation of Findings.....	53
Chapter 4: Finding Out and Finding Information	54
How We are Talked To	56
What we are Told... Or Not Told.....	62
Congenital Adrenal Hyperplasia	63
The Internet.....	65
Summary.....	70
Chapter 5: The Hard Issues	72
Introduction.....	72
Nomenclature.....	72
Surgery	74
Gender Identity.....	82
Genetics.....	87
Growing Up.....	92
Summary.....	98
Chapter 6: What is Helpful Information Conclusions and Recommendations?	100
Introduction.....	100
Participants Answers.....	100
Written Explanations	102
In Depth Discussions	103
Honesty	103

Surgery	104
Practical Information	105
Sources of Support.....	107
Recommendations.....	109
Education for Health Professionals	109
Written Information for Parents	110
Condition Specific Information.....	113
A Team Approach.....	115
Conclusions to the Thesis.....	116
References	121
Research Appendix.....	134
Participant Consent Form.....	1
Information Sheet.....	3
Advertisement for Express Newspaper	6
Advertisement for parenting Magazines.....	7
Interview Guidelines for Adult Intersex People	8
Interview Guidelines for Health Professionals/Advocacy Groups.....	9
Interview Guidelines for Parents/Families.....	10
Maori Research Review Committee Approval.....	11
Massey Human Ethics Committee Approval.....	12
Northern X Regional Ethics Committee Approval.....	13
Table 1	14
Table 2	15

GLOSSARY

Ambiguous Genitalia Term used to describe outer genitalia which do not have the typical appearance of either a boy or a girl.

Complete Androgen Insensitivity/CAIS A genetic condition that makes XY fetuses insensitive (unresponsive) to androgens (male hormones). Instead, they are born looking externally like typical girls. Internally, there is a short blind-pouch vagina and no uterus, fallopian tubes or ovaries. There are testes in the abdomen or the inguinal canal

Congenital Adrenal Hyperplasia/ CAH Congenital adrenal hyperplasia refers to a group of inherited adrenal gland disorders. People with this condition do not produce enough of the hormones cortisol and aldosterone, and produce too much of androgen. Some forms of congenital adrenal hyperplasia are more severe and cause adrenal crisis in the newborn due to salt wasting. In this salt-losing form of congenital adrenal hyperplasia, newborns develop severe symptoms shortly after birth, including vomiting, dehydration, electrolyte changes, and cardiac arrhythmias.

Disorders of Sexual Development/DSD Term introduced in 2006 following the International Consensus Conference on Intersex as an umbrella term for conditions in which a person is born with a reproductive or sexual anatomy that does not seem to fit the typical definitions of female or male.

Gender While “sex” usually refers to a person’s physical anatomy, the term “gender” usually refers to mental, social, and cultural characteristics, regardless of anatomy, related to being a boy, girl, man, or woman in our society

Gender Identity A person’s innermost sense of himself or herself as boy or man, girl or woman. How one thinks of one's own gender: whether one thinks of oneself as a man (masculine) or as a woman (feminine.)

Gender Role Arbitrary rules, assigned by society, that define what clothing, behaviours, thoughts, feelings, relationships, etc. are considered appropriate and inappropriate for members of each sex. Some clothing, behaviours, etc. are considered appropriate for members of both sexes. Which things are considered masculine, feminine, or neutral varies according to location, class, occasion, and numerous other factors

Gonadal Dysgenesis/Swyer Syndrome Gonadal dysgenesis also known as Swyer syndrome is characterized by "streak gonads" in a phenotypic female with a 46XY karyotype. This condition is due to a mutation which inhibits the function of the Y-borne determinant that would normally cause the indifferent embryonic gonad to differentiate into a testis

Hermaphrodite and Pseudo hermaphrodite Terms introduced by medical authors in the Victorian period. The term "true hermaphrodite" was used for an individual who had both ovarian and testicular gonadal histology, verified under a microscope, "male

pseudo-hermaphrodite" for a person with testicular tissue, but either female or ambiguous sexual anatomy, and "female pseudo-hermaphrodite" for a person with ovarian tissue, but either male or ambiguous sexual anatomy. The terminology is now considered problematic with ISNA recommending that all terms based on the root "hermaphrodite" be abandoned because they are scientifically specious and clinically problematic. The terms fail to reflect modern scientific understandings of intersex conditions, confuse clinicians, harm patients, and panic parents.

Intersex Intersex is an umbrella term used for a variety of conditions in which a person is born with a reproductive or sexual anatomy that does not seem to fit the typical definitions of female or male. Intersex is a socially constructed category that reflects real biological variation

Klinefelter Syndrome 47, XXY or XYY syndrome is a condition caused by a chromosome aneuploidy. Affected males have an extra X sex chromosome. The principal effects are the development of small testes and reduced fertility

Partial Androgen Insensitivity/PAIS Partial or mild androgen insensitivity syndrome results when tissues are partially sensitive to the effects of androgens. XY individuals may have a variety of phenotypic expression

Prader Scale Staging system for the degree of virilisation of the external genitalia.

Sex One's anatomical designation as either male or female based on the presence or absence of primary sexual characteristics.

Sexual Orientation How one thinks of oneself in terms of whom one is sexually and romantically attracted to, specifically whether one is attracted to members of the same gender as one's own or the other gender than one's own. The inclination or capacity to develop intimate emotional and sexual relationships with people of the same sex (lesbian, gay), a different sex (heterosexual), or either sex (bisexual).

Starship Starship Children's Health, located in central Auckland, is part of Auckland District Health Board

Sources used for developing these terms; <http://feminism.eserver.org/>, <http://www.senecac.on.ca/hr/redc/psp/glossary.html>, <http://www.endosociety.org/>, <http://en.wikipedia.org>, <http://www.dsdguidelines.org/>, <http://isna.org/>.