FROM GENERAL DEVELOPMENTAL DISABILITY TO 22Q11.2 DELETION SYNDROME: UNDERSTANDING PARENTAL EXPERIENCES

A Mixed Methods Analysis

“I was meant to have him on this journey, whatever this journey is going to be”

Jane Goodwin, BPsych (Hons)
Thesis submitted to the University of Newcastle for the degree of Doctor of Philosophy
Submitted 6th February 2017
Declarations

Statement of Originality

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to the final version of my thesis being made available worldwide when deposited in the University’s Digital Repository**, subject to the provisions of the Copyright Act 1968.

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Signed,

Jane Goodwin
Statement of Authorship

I hereby certify that the work embodied in this thesis contains a published paper of which I am a joint author. I have included as part of the thesis a written statement, endorsed by my supervisor, attesting to my contribution to the joint publication. See below.

Signed,

Jane Goodwin

I attest that Research Higher Degree candidate Jane Goodwin has contributed to publications for which I am a co-author. For all publications, where applicable, Jane has:

- Contributed to the development of research questions
- Contributed to research design and methodology
- Contributed to the development of data collection tools
- Managed data collection procedures
- Conducted interviews
- Cleaned data
- Led all data analysis
- Led the writing of each manuscript

Signed,

Dr Linda Campbell
Acknowledgements

First and foremost, I would like to extend thanks to my wonderful primary supervisor, Dr Linda Campbell. The gratitude I have for the positive impact you have had on me and my career is difficult to put into words, but I can say that I feel honoured to work with you. You have shared your time and expertise completely generously, and have gone beyond your duties in providing support throughout my PhD – thank you. I would also like to thank my other supervisors: Dr Lynne McCormack for demanding excellence; and Dr Tracy Dudding-Byth for guiding my studies to best answer the questions I was asking. You have remained engaged and enthusiastic throughout – this was an instrumental support which did not go unrecognised.

Thank you to my family for always valuing and encouraging my education, and being so understanding of the PhD experience – especially my parents Richard and Deborah, and my Auntie Jill. Thank you to Ralph and Betty who have supported my education for many years all the way from England. Also, thank you to Dr Kylie McIntyre for inspiring and nurturing my interest in psychology. This strong foundation from all of you has offered immeasurable opportunities that would otherwise have never been available to me.

My friends always get excited for me when things are going well, pick me up when things are going badly, and understand the life-halting impact of a PhD. Eliza, Catherine, Kate, Marissa, Rebecca, Steffie, Shelley, Shem: thank you for being the most perfect friends imaginable. Further, without my “PhD buddies”, this experience would have been long and lonely. Thank you to Danielle, Justin, Christy, and Kalyce for making the office a fun place to be. Your academic input has been invaluable, but I would like to thank you most for all the laughter, celebrations, and empathy about the sacrifices and joys of PhD life.

Finally, I would like to thank all the people that participated in the research that forms this thesis. Thank you for sharing your experiences of such an emotional topic so freely, and giving me the privilege of entering and attempting to interpret your lives.
Publication Status of Chapters

Below are the details of thesis chapters that have been published or are under review for publication.

Chapter 3

Chapter 5

Chapter 6
List of Additional Publications

1. Goodwin, J., Alam, S., Campbell, L. E. (under review). “At the end of the day it is more important that he stays happy”: An interpretative phenomenological analysis of people who have a sibling with 22q11.2 deletion syndrome. *Journal of Intellectual Disability Research*.


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“Those who have a 'why' to live, can bear with almost any 'how’.”

— Viktor E. Frankl, Man's Search for Meaning

« Les plus belles choses dans le monde ne peuvent pas être vu ou touché, ils se font sentir avec le cœur. »

— Le Petit Prince d'Antoine de Saint-Exupéry
Abstract

The negative psychological impact of having a child with a developmental disability has been well-recorded. Although positive psychological constructs (e.g., psychological growth) are beginning to receive more attention, they are relatively unexplored in parents who have a child with a developmental disability. The aim of this thesis is to describe the experience of parenting a child with a developmental disability, particularly the more positive aspects. One developmental disability that offers unique challenges and is poorly researched is 22q11.2 deletion syndrome (22q11DS). Therefore, this thesis specifically focuses on 22q11DS and uses a concurrent mixed methods design. Although children with 22q11DS have a characteristic neurocognitive and behavioural phenotype, the disabilities experienced by these children and the challenges faced by their parents can be extrapolated to the wide range of developmental disabilities.

Considering the wider experience of parents of children with a variety of developmental disorders, predictors of psychological growth were examined through a cross-sectional survey. Many participants experienced at least some psychological growth as measured by the Psychological Wellbeing - Post-Traumatic Changes Questionnaire (Joseph, Maltby, Wood, Stockton, & Hunt, 2011). A regression model demonstrated that increased: a) use of positive reappraisal as a coping mechanism; b) parental perceptions of coordinated and comprehensive health care; and c) child’s age were associated with greater psychological growth.

Given these findings, the thesis then sought to understand whether psychological growth despite potential distress was possible from parenting a child with a poorly understood and often tardily diagnosed developmental disability, 22q11.2 deletion syndrome (22q11DS). Semi-structured interviews informed by the methodology Interpretative Phenomenological Analysis (IPA) explored the experience of parenting a child with
22q11DS at two different stages of parenting: a) a young child with 22q11DS; and b) an adult child with 22q11DS.

As 22q11DS is a condition that has wide variability in presentation, with little knowledge about the impact it has on parents’ psychological wellbeing, IPA informed a detailed and open exploration of this phenomenon. Parents who had a young child with 22q11DS provided rich data that was interpreted as anticipatory traumatic distress, systemic stigma, confusion at professional smoke screens, and ‘not knowing’. However, they were able to redefine their unanswered fear, guilt, loss and grief in these early years through hope for the future and a perceived opportunity to become better people.

Similarly, for the interpreted experience of parents whose children were now adults with 22q11DS, stigma remained a constant distress, and feelings of guilt, loss and grief persisted throughout the years. Progressively, stigma undermined independence, friendships, and instinctual judgement. Ill-informed hierarchical structures experienced as layers of obstruction and ignorance pragmatically replaced hope and triggered angry advocacy for their child, which was used proficiently in educational, health and societal contexts. In time, looking backwards, they came to value their unique accomplishments collected on their journey with 22q11DS, and in turn, consciously valued authentic ‘self’. Psychological growth was viewed as part of the journey that juxtaposed ongoing distress. It was identified through a metamorphosis of empathy, humility, gratitude, and pride.

This thesis provides a unique contribution to the literature by delineating factors that contribute to psychological growth in parents who have a child with a developmental disability. Further, the under-explored journey of these participant parents who have a child with 22q11DS is uncovered, highlighting both negative and positive psychological outcomes. In conclusion, this thesis highlights a number of areas for further investigation and intervention. It demonstrates: a) the need for clarity in positive psychological research; b) that
positive psychological outcomes are realistic for parents whose children have a developmental disability and should not be neglected; c) that hierarchical and medical frameworks often poorly support the long-term biopsychosocial needs of families living with lesser known developmental disabilities; and d) healthcare professionals are well-placed to promote positive psychological outcomes.