

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.

School Support for Siblings of Patients with Cancer

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

Master

of

Educational Psychology

At Massey University, Albany, New Zealand

Erika Lamb

2015

Abstract

This research project investigated the importance of providing support structures within school communities for siblings of patients diagnosed and treated for cancer. A cancer diagnosis is traumatic and devastating for the child or young person with cancer but what sometimes gets lost is the impact such a medical event can have on siblings whose need for a range of emotional, social, academic, and physical support tend to be overshadowed by the focus on the patient and how the parents/caregivers cope. Sibling members of CanTeen New Zealand (an organisation which supports young people living with cancer and their siblings) were invited to participate in a nation-wide online survey or a focus group session in Auckland, both exploring siblings' perceptions of school based support. Both methods of data collection were created with the support of CanTeen staff and were informed by the literature surrounding support for siblings living in families affected by cancer. Participants responded to questions regarding who supported them at school, how they were supported, what they wanted members of the school community to understand, and what supports they wish had been available while they were on their cancer journey. Highlighted in the research findings were that different school communities fulfil different sibling needs, siblings' everyday lives are disrupted by their brothers' or sisters' cancer diagnoses, every cancer journey is different (shaped by a sibling's unique familial and community circumstances), and there is a need for home-school partnerships to ensure the best outcomes for siblings. By having siblings express their thoughts and feelings regarding the cancer journey in their own words, this research can provide valuable insight for schools who have students living in families affected by cancer and can act as a guide for how to best support the needs of this population.

Acknowledgements

Hei whāngai i te harakeke

To nurture the harakeke/flax

I would like to acknowledge the guidance and support from my supervisors, Tracy Riley and Wendy Holley-Boen. I am incredibly grateful for all of their advice and words of encouragement throughout this year. Thank you for sharing my enthusiasm every step of the way.

This research project would not have been possible without the cooperation and support from CanTeen New Zealand, with a special thank you to the staff at CanTeen Auckland who provided me with great insight into the cancer journey of siblings and were invaluable in the recruitment phase of my research. I am forever grateful for the CanTeen sibling members that took time out of their busy lives to complete my survey or participate in the focus group session. I have been blown away by their strength and generosity in wanting to help others facing similar journeys.

Thank you to my family and friends for their unconditional love and support. I am lucky enough to have parents who have always believed in my ability to achieve and encouraged me to pursue higher education, but always impressed the importance of finding a healthy balance in life. Thank you to Mary for helping me create a research topic which I have loved exploring, and thank you to Warwick for being my editor and making sure this thesis is free from split infinitives and mis-placed apostrophes. I am also grateful to Lynda for her editing services and for being a constant source of support from the other side of the world. Thank you to Timothy for helping me search for articles, for comforting me when things were not going the way I wanted them to, and for being an all-round amazing partner and friend.

Last but not least, a massive thank you to my good friend, Jess, who is one of the strongest women I know. You are such an inspiration. Thank you for sharing your story with me and for helping me shape my research. I know Ella would be so proud of you.

Table of contents

Abstract	i
Acknowledgements	ii
Table of contents	iii
Chapter 1 – Introduction	1
Chapter 2 – Literature Review	4
The impact on family systems	4
Post-traumatic stress and negative effects	6
Post-traumatic growth and positive effects	9
School counselling in New Zealand	12
Teacher support	15
Peer support	17
Home-school partnerships	19
Community and national support	22
Study rationale	23
Chapter 3 – Methodology	24
An ecological approach	24
Research design and rationale	25
Survey methodology	25
Focus group methodology	26

Participants	27
Criteria	27
Recruitment	28
Consent	29
Ethical considerations	30
Data collection	30
Online survey	30
Focus group	31
Data Analysis	32
Chapter 4 – Results and Discussion	34
Different school community members fulfil different sibling needs	35
The role of school peers	35
The role of teachers	37
The role of school counsellors	39
Disruption of everyday life	42
Change in routine	42
Change in family systems	44
Every journey is different	46
Length of treatment and other demographic variables	46
Address individual needs	48
An ongoing journey	49
Need for home-school partnerships	50

Importance of parental involvement	50
Need for supportive school climates	52
Chapter 5 – Conclusion	54
Limitations	54
Conclusion of findings	56
Recommendations for future research	57
Implications for practice	59
References	60
Appendices	69