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Understanding the cancer-related distress and coping of men from provincial New Zealand:

'Bullet proof' meets radical prostatectomy.

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

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New Zealand

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ABSTRACT

Men suffer inequities regarding their health which may largely be attributed to masculine culture. The present study sought to better meet men's needs for psychooncological care by describing men's cancer-related distress and coping, and deriving from that knowledge suggestions for intervening more effectively to address their distress.

The study used participant action research methodology. Twenty-one Pākehā and six Māori men from rural provinces of New Zealand with lower socio-economic statistics, were interviewed in depth about their cancer-related distress and coping using a semi-structured format. Interviews were recorded, transcribed, and thematically analysed, producing preliminary descriptions of distress, coping, and a distress processing metaphor. These were discussed with small teams drawn from the original participants for verification and adjustment. Suggestions for intervention consistent with the findings were also discussed with these men.

The description of distress summarises a wide range of matters under superordinate themes of: distress featuring a lack of control; anxiety or despondency at anticipated or actual loss; 'black' feelings (degradation, anger, self-pity, guilt and regret); and empathic distress. It includes the reporting of 'no distress' and ambiguous reporting. Dynamics associated with each of these groupings is discussed, notably the association of traditional masculine norms with 'no distress' reporting and with more sources of distress, and the wide range of distress associated with sexual dysfunction as a side-effect of cancer treatment.

The description of coping lists four widely used coping strengths, namely: a positive attitude; an active and practical orientation; rationality and control; and social support/helping others. Use of social support varied with ethnicity and allegiance to traditional masculine norms.

The processing metaphor describes a trajectory of suddenly losing and then gradually regaining control, which is likened to being overwhelmed by a rogue wave while paddling at the beach.

Common to both descriptions and highlighted by the metaphor is the significance of control, which is underpinned by information. Accordingly, a new paradigm regarding the provision of information as part of standard treatment pathways is suggested. This features relevant, timely, and accessible information orienting men to the disease, its treatment and side-effects, the medical system, and social services.

DEDICATION AND ACKNOWLEDGEMENTS

Dedicated to the men who participated in this study, with deepest thanks for their generosity and courage in sharing their hearts in the service of others.

Particularly to those who knew, at the time of their interview, that they had not long to live, yet still gave of their precious time and energy.

I hope that the survivors among you, and the families of those of you who have passed on, will be satisfied that the contribution you made has been respected and will be put to good practical use.

Nga mihi nui. Arohanui.

Sincere appreciation is extended to those health and social service professionals who went to lengths to assist with this study in practical ways, such as persuading the management of their organisation to provide ethical sign-off, and finding participants from among their caseloads. There are always a few people who make a big difference. I hold their mahi, in the interests of men's health, in the utmost respect. The longer I associate with people who work in cancer, the more I notice that in disproportionate numbers they are fine human beings who are a joy and privilege to know and work with. Kia ora koutou.

I was particularly fortunate to have the support of Movember and the Cancer Society of New Zealand for this project. Research funding originated from Movember and was allocated through the Cancer Society, who monitored its use while also providing every practical support and encouragement possible. These funders brought a wonderful flexibility to their provision, allowing me to re-draw the budget twice and spend the surplus on dissemination in a bid to encourage practical application of findings. The Cancer Society also provided me personally with a most generous training scholarship. The personal encouragement of individuals from these funding bodies along the way meant a great deal to me. I found it a particular pleasure working with Mr Roger Twentyman, of the Palmerston North office, as one of my 'critical friends', and take this opportunity also to acknowledge the assistance of the two men from the men's support group who helped with piloting the interview schedule. Management and

organisational members of the Central Cancer Network have also been wonderful supporters, taking the project seriously and promoting it at every opportunity. I can only hope that all of these parties ultimately feel satisfied with the practical benefits that flow from the project, and that the privilege of working with them will continue!

I am also grateful for the funding support awarded by the Genesis Oncology Trust towards disseminating findings and my own professional development. This is now the second time Genesis has supported my psycho-oncology research in this way.

Finally, I am indebted to Massey University and to an exceptional set of supervisors. Massey provided personal support in the form of a doctoral scholarship, and pedagogical support in the form of my 'dream supervisor', Professor Christine Stephens. In earlier years I had the privilege of learning in research courses taught by Chris, so was really thrilled when she accepted the role as lead supervisor. Not only does she 'know her stuff', but she brings the integrity, reliability, and quality feedback that a student needs to make the most of the opportunity provided by postgraduate research. I felt spoilt also to have the supervisory support of Dr Don Baken and Dr John Waldon. Don has supported my research work for years now, having co-supervised my Masters thesis and co-authored three articles arising out of that. He is a warm and dedicated psycho-oncology clinician with considerable expertise, and it is always a privilege to work with him. I was also privileged to make the acquaintance of John, a big-hearted tāne Māori researcher. He brought his broad experience in cancer to the project, and, of course, the needed challenge to my Pākehā worldview together with his connections in Te Ao Māori. However, it will be John's generosity in sharing practical tips about research and career generally that will stay with me.

As the reader can deduce from these credits, I have enjoyed the experience of a lifetime. When I started studying psychology part time more than a decade ago, I would have stopped in my tracks at the thought of doing a PhD. After a long hard slog through law school in my earlier years, I was barely game to return to university at all, let alone to stay for a moment longer than was necessary to qualify for practice. But it only took a few weeks of Masters research for me to realise how enjoyable and satisfying this creative work can be. Then my other Masters research supervisor, Dr Shane Harvey, suggested the PhD. An aside from Head of School, Professor Mandy Morgan,

regarding what a privilege it is to do PhD study, sealed the deal. By this time I knew she would be right. And so she was. But I am acutely aware that the joy of the creative experience is almost entirely dependent upon the support of all the other people and organisations involved. And, what can I say? There cannot be many students who are so fortunate as I have been with the participants in, and many other supporters of, their research. Once again, nga mihi nui. Kia ora kotou katoa.

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