

**DEVELOPING STRATEGIES TO IMPROVE THE MANAGEMENT OF
CHRONIC ILLNESS**

**A Focus on Disability and Psychosocial Aspects in an Illness with an
Organic Cause (Cancer) and an Illness with a Non-Organic Cause (IBS)**

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Thesis submitted for the degree of

Doctor of Philosophy

School of Psychology

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ABSTRACT

Models of health care concentrate on acute conditions yet the major cause of disease burden is chronic illness. An emphasis on biomedical, as opposed to bio-psychosocial models, underestimates psychological disability and fails to explain burdens resulting from illnesses with no known organic cause. Topics explored were: quality of life, chronic and acute stress, emotion regulation, communication, support services, patient expectations, satisfaction with medical treatment, and health care seeking. Using grounded theory (Glaser, 1992) and active patient participation (Susman & Evered, 1978), the major objective was to develop strategies to improve the management of chronic illness.

Two groups were studied: 20 patients with an organic cause (cancer) and 21 patients with a non-organic cause (Irritable Bowel Syndrome). Using quantitative and qualitative measures, observational studies (N=29), interviews (N=41), focus groups (N=12), and a case study (N=10) were conducted. IBS patients reported greater disability (increased distress and reduced quality of life) than the cancer group and other chronic illnesses. Cancer patients showed impaired quality of life but they reported levels of distress up to 50% lower than the general population and 75% lower than another chronic illness group. Some cancer patients appeared to under-report levels of distress; however, when applying Pennebaker's (1997) written disclosure method, emotional expression was not uniformly associated with beneficial outcomes.

Interviews with IBS patients revealed that determinants of dissatisfaction involved a lack of acceptance and/or understanding of an IBS diagnosis and an expectation that consultants would find an organic cause. Cancer participants reported no need for participation in decisions concerning treatment. Evaluations of the quality of health services received were distinct from evaluations of the quality of care received by specialists. Fighting spirit and

positivity were linked with emotional inhibition and a lack of uptake of support services. Patients became more pro-active in seeking emotional and social support later in their illness experience. These findings were interpreted within the Conservation of Resources Theory (COR; Hobfoll, 2001; 1999; 1998).

Results in this study challenge public policy recommendations that focus on encouraging consumer participation in health care. Recommendations for intervention and future research with cancer patients focus on application of the COR theory. In IBS, patient education, improvements in communication and the adoption of Drossman's (1998) bio-psychosocial model are advocated. Finally, recommendations for improvements in methodology involve suggestions to incorporate quantitative and qualitative measures using longitudinal assessments with the grounded theory (Glaser, 1992) approach being an excellent methodological template.

DECLARATION

This thesis contains no material that 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 of the thesis.

I give consent to this copy of my thesis, when deposited in the University Library, being made available for photocopying and loan.

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ACKNOWLEDGEMENTS

I thank all of my supervisors for their feedback and advice. To Professor Deborah Turnbull, I thank you for your feedback and support particularly early on when establishing the direction of the research. I especially would like to thank Professor Anthony Winefield who for many years has given me encouragement and support in all academic pursuits. I also thank Professor Ian Olver: Your professionalism, support, encouragement and interest in my work helped me achieve my dream. I will be eternally grateful to you. Thank you also to Dr Jane Andrews and Professor Gerald Holtmann for your support and advice during the conduct of the interviews with the IBS patients.

Thank you to all the cancer patients and ‘survivors’ who let me share a part of their cancer journey. I have learned so much from you and appreciate your efforts and contributions made to this research. Thank you to the gastroenterological patients who participated in this research. I appreciate your willingness to be open and honest when discussing your illness with me.

I would also like to thank my partner Rob and my 9-year old son, Noah who continued on with family life despite my absence whilst working on this thesis. Their support and encouragement through difficult times kept me going. Also thanks to my neighbours, Bonnie, Paul and the 5 boys (Blaze, Indiana, Cassidy, Harry and Jordon) who kept Noah entertained during the school holidays and weekends. To my parents for always believing in me and supporting me no matter what career path I chose. Also, to my beloved pets who kept me company throughout the writing process, Zeus (deceased), Millie and India.

Finally, I thank School of Psychology Administrative staff who assisted me at various times throughout the course of this thesis (Lynda, Carmen, Jessica, Geoff, Carola and Wanda).