THE BENEFITS OF HEALTH CARE BEYOND HEALTH: AN EXPLORATION OF NON-HEALTH OUTCOMES OF HEALTH CARE

M. R. Haas

A thesis submitted in fulfilment of requirements

for the degree of Doctor of Philosophy

Department of Public Health and Community Medicine

Faculty of Medicine

University of Sydney

May 2002

Preface

The sources of written information used in this thesis are the publicly available databases MEDLINE, CINAHL, PSYCHINFO and ECONLIT. Ethics approval for the research described and reported in Chapter 5 was obtained from the Central Sydney Area Health Service Ethics Review Committee and for that described and reported in Chapter 6 from the University of Sydney Human Ethics Committee. All research participants received written information sheets regarding the objectives and process of research and signed consent forms were received from all participants. I declare that the entire thesis is original work carried out by me, Marion Ruth Haas. None of the work carried out for this thesis has been submitted for any other degree.

Summary

Recent interest in identifying and measuring health outcomes represents an advance in our understanding of how health care for individuals should be evaluated. However, the concept of health outcomes has mainly focussed on improvements in health status. Non-health outcomes of health care may also be important to patients. In this thesis, four tasks were undertaken with the aim of identifying non-health outcomes and establishing the extent of their relevance and importance to patients. First, the illness experience literature was reviewed to identify potential non-health outcomes. Seven categories of non-health outcomes were identified: information, being treated with dignity, being able to trust the health care provider, having distress recognised and supported, participating in decision making, legitimation and reassurance. Second, to gain an in-depth understanding of these concepts, topic-specific literature was reviewed and synthesised. Third, in order to confirm how relevant and important the concepts were to patients, a qualitative study was conducted with each of two different groups of health service users. Broadly, patients considered that all the non-health concepts were relevant, although the extent to which they were important varied. Fourth, to test the relative importance of the seven concepts, a Stated Preference Discrete Choice experiment in the context of general practice was conducted. This study showed that most people thought their GP demonstrated behaviour likely to result in the production of non-health outcomes. The results showed that although all the non-health outcomes were, to some extent, preferred by respondents, trust was most important, followed by legitimation and recognition of and support for emotional distress. Once again, these results point to the importance of context in the evaluation of health care from the patient’s perspective. While still being perceived as positive aspects of health care, the provision of information and acting autonomously or participating in decisions about their health care were the non-health outcomes considered least important by patients.

Acknowledgments

Peter Sainsbury provided support, guidance and encouragement as my supervisor for the entire period of the PhD. His thoughtfulness, professionalism, friendship and sense of humour are much appreciated. Gavin Mooney provided supervisory support for much of the time I spent researching and writing the thesis. Jane Hall, as well as being a valued colleague and friend, stepped into the breach to act as a supervisor at a crucial stage of the thesis. She gave me both encouragement and challenge in exactly the right amounts.

My colleagues at CHERE were a continuous source of support and understanding as well as practical assistance. In particular, Liz Chinchen assisted with literature searches and referencing as well as cheerfully and carefully editing a number of chapters, Richard De Abreu Lourenco was always able to help with computing enquiries and Rosalie Viney provided much needed encouragement, advice and critical appraisal. Jordan Louviere gave freely of his expertise in facilitating the design of the SPDCM experiment and assistance with analysis was generously given by Peter Sainsbury, Jordan Louviere, Patsy Kenny and Paul Burke. The staff of Surveys Australia with whom I dealt, Ben Dixon and Peter Blansjaar, were a pleasure to work with.

A number of clinical staff at Westmead and Royal Prince Alfred Hospitals provided advice on the empirical aspects of the thesis and assisted in recruiting research participants. I would like to acknowledge the support of the following people: Gerry Wain, Tish Lancaster, staff of the Westmead Hospital Gynaecological Oncology Team, David Tiller, Adrian Gillin, Liz Ray, staff of the Department of Renal Medicine at Royal Prince Alfred Hospital and Karen Bedford.

I am most grateful to the nearly 200 patients and members of the public who voluntarily gave their time and effort to participate in the research. Personal contact with them was a source of great pleasure for me, not just the means of obtaining information. Finally, my very special thanks go to my family, in particular to Eleanor, who kept my feet firmly on the ground and Katherine who, as ever, handled the ups and downs with tolerance and love.

Contents

List of Tables

List of Figures