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GETTING ON WITH LIFE: THE LIVED EXPERIENCE OF FOUR ADULTS WITH CYSTIC FIBROSIS

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ABSTRACT

Cystic fibrosis (CF) is a progressive, life limiting disease that requires relentless life long management. Although there are a small number of adults with CF in New Zealand, the disease is significant because of the duration and intensity of the health care they require.

A phenomenological hermeneutic approach has been used to explore the lived experience of a small group of adults with CF. Their experience is primarily one of getting on with life rather than dwelling on illness. Knowing that they have the disease all their lives leads to a difference in experience from people who are diagnosed with a chronic illness in adulthood. They experience a gradual realising of CF when they begin to understand the meaning of the disease, and after they have experienced significant disease related changes in their bodies. Adolescence and young adulthood are times of learning to live with CF. They learn their own limits, learn to look after themselves and manage their illness. The desire to get on with life leads people with CF to minimise illness to themselves and to others, and to reject aspects of the patient role. They see themselves as being relatively healthy much of the time. This is a different way of looking at health and illness from the traditional disease focused approach.

Nurses and other health professionals can use this new understanding of living with CF to better support these people to lead meaningful and purposeful lives rather than to simply look after their disease. As a consequence of this study, an increasing move to home care with an enhanced continuity of care across of hospital and community settings by health professionals who understand the illness experience are advocated.

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CONTENTS

INTRODUCTION

This study uses a phenomenological hermeneutic approach to uncover and reflect upon the experience of a small group of adults who are living with cystic fibrosis (CF). The aim of phenomenology is to gain a deeper understanding of the nature and meaning of our everyday experiences. In practice this approach meant gaining knowledge of the experience from people with CF, and using their accounts to describe and understand the way they live in the world as an adult with this disease.

Nursing is about caring for people when they are sick but also about helping them in their response to illness. The small number of adults with CF in New Zealand means that most nurses and other health professionals have a limited understanding of the disease itself, let alone the patient's illness experience. The aim of this study is to gain a greater understanding of how adults live with CF, how they create meanings and cope with their disease. It is hoped that as a result of this study, health professionals will gain a greater awareness of this illness experience and will incorporate this understanding into their practice.

CF is a genetic condition. Therefore adults with CF have been living with a chronic disease from birth. The disease is progressive with a reduced life expectancy. Until relatively recently, it was rare for people with the disease to survive to adulthood. In addition to its effects on the body, an ongoing experience of this kind can have a profound effect on the person and family, both economically and emotionally, and on the way they conduct their everyday lives.

Management of the disease is unrelenting and lifelong. It includes frequent chest physiotherapy, daily dietary supplements, pancreatic enzymes and vitamins, antibiotics as required, and regular medical check ups. Despite improvements in therapy and diet, CF remains a significant health problem,

and most adults with the disease are "high users" of health care services. Although there are only a small number of adults with CF in New Zealand, the disease is significant because of the intensity and duration of health care they require. Information collected on the New Zealand National Cystic Fibrosis (CF) database reveals that 94 people out of a total of 302 with the disease are older than 15 years (Wesley, Dawson, Hewitt & Kerr, 1993). Because of the small number of people with CF, viable specialised clinics have not been established on a regional basis in this country. Wesley and Stewart (1985), in their discussion of New Zealand's poorer survival rate compared with some overseas centres, project that in New Zealand there is a 47% probability of survival to 20 years compared to 80% in Victoria, Australia, 67% for Canadian males and 62% in England, Wales and Denmark. Also, they comment on the variable level of expertise available in the settings where people with CF currently receive their medical care.

The experience of living with CF would be expected to have some aspects in common with other chronic illness experiences, but also to have distinctive features specific to this disease. Like other chronic illnesses, management of CF mostly takes place in the patient's home, and it is only during acute exacerbations or progressive deterioration that the person is hospitalised. Adults, who have lived through childhood and adolescence with a life-threatening disease, must learn to cope with the interrelated demands of their illness and their social circumstances, and to create a meaningful life for themselves.

As a result of nursing adults with CF, I became aware that there are distinctive features to their illness experience and the strategies that they use to cope with their illness. In many ways they did not appear to be like other patients. In particular, their medical treatment was distinctive because of the special diet they required and the type and length of time they received intravenous antibiotic therapy. What was even more

noticeable was their approach to hospitalisation; they did not want to lie in bed and passively receive their treatments; they wanted to continue their normal activities and, at times, this created conflict with health professionals. I also became aware that the care provided in acute wards did not seem to meet many of the needs of people with a lifelong respiratory disease. It was not considered possible to provide some medical treatments at home, and there was little understanding or support for the psychosocial impact of the disease. It seemed to me that some readmissions to the ward could be prevented, or the length of stay could be reduced, by providing specialist respiratory nursing in the community.

As part of a small study[1] of how people live with chronic illness, I interviewed some adults with CF. They had a strong desire to be treated normally; they had lived with this disease all their lives and did not want to be treated as sick people. Hospitalisation was required for intravenous antibiotic administration but this did not mean they considered themselves to be sick. Issues about the progressive nature of the disease were touched on but not elaborated. I wondered whether this strong urge not to let the disease make them into sick people underlay their coping and provided the impetus for their prolonged survival. It also appeared that some improvement could be made in the health care received by both the person and their family.

From the outset, some aspects of living with CF discussed by some of the fieldwork participants were expected to be significant in this study: fulfilling an adult role in society, coping with infertility, bringing up children, relationship to spouse and socio-economic aspects of living with a chronic illness. However, this study has revealed other aspects of living day by day with a chronic and progressive illness and does not focus strongly on the above topics. It is important to note that this study does not encompass the

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[1] A fieldwork, exploring the experience of chronic illness, completed as an assignment for a Masters' paper in 1993.

very progressive phase of the disease. While this study does not attempt to define the lived experience of all adults with CF, it has uncovered some patterns in the responses of four adults with CF, and suggests strategies nurses and other health professionals should consider when working with this group of people.

This introduction has provided an overview of the study. Chapter One will review selected literature about CF and the experience of chronic illness. Chapter Two will explain the research method and the way this research was conducted, and includes information about the participants, the ethical considerations, and the method used to obtain and analyse the data. Chapters Three to Six will describe the research findings with themes and associated subthemes in each chapter. Chapter Seven contains a discussion of the key findings in the light of current literature and addresses the implications and limitations of the study.