

**AN INFORMATIONAL SUPPORT PROGRAMME WITHIN THE CONTEXT OF
HEALTH PSYCHOLOGY AND ITS IMPACT ON ASPECTS OF
PSYCHOLOGICAL FUNCTIONING OF PARENTS
OF CHILDREN WITH CYSTIC FIBROSIS**

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DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and that I have not, in its entirety or in part, submitted it at any university for a degree.

SUMMARY

This thesis focuses on the emergence of the psychologist in health psychology and the application of psychological skills in a multidisciplinary context, with particular reference to cystic fibrosis. Modern health care provision is being influenced by the consequences of improved medical treatment as well as a move away from the model of medical dominance. The concept of parental empowerment (Melnyk, Feinstein, Moldenhouer, & Small, 2001) is being promoted in an age of biomedical reductionism (Campbell, 1994).

With pressure to innovate in a climate of cost-containment, health care is taking on new forms of service delivery, with the psychologist experiencing greater acceptance in general hospital environments but, at the same time, needing to adapt to an emerging psychosocial model (Jasnoski & Schwartz, 1985) of medical treatment.

The aim of this study is twofold. It firstly contextualises the role of the psychologist in a developing health psychology and medical environment. It then examines if a particular, informational support programme for parents of children with cystic fibrosis may be successful in achieving its objectives of empowering parents and reducing at least some of their distress.

The shortcomings of psychological involvement alongside general medicine, as well as the historical structural barriers inherent in the dominance of the medical model (Parsons, 1970; Karabus 1994) is discussed. Attention is also drawn to the role of collaborative training (Gallo & Coyne, 2001; Kainz, 2002; Waters, 2001) as a facilitating force in the promotion of greater multidisciplinary co-operation.

In the context of a serious illness such as cystic fibrosis, the disturbances in normal family life is noted. Since the usual patterns of parent-child attachment (Bowlby, 1969) are affected by an anticipated death of the child before the parent, the concept of chronic sorrow (Olshansky, 1962) is also mentioned. Consequently, in this strained domestic environment, difficulties in measuring parental functioning are discussed.

A pilot study, in the form of a needs analysis on a small group of parents, precedes the main research, directed at a group of parents of pre-school children who had been diagnosed with cystic fibrosis. In the main research, an informational support package is provided to parents and aspects of their psychological functioning is measured on the General Health Questionnaire (Goldberg, 1978), Beck Depression Inventory (Beck & Steer, 1987), State-Trait Anxiety Inventory (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1970) and Brief Symptom Inventory (Derogatis, 1993).

Bivariate analysis, multivariate analysis and nonparametric comparisons were made to determine the effect of the informational support programme on aspects of the psychological functioning of parents. The results were mixed, with parents in the experimental group showing lower levels of depression, but not anxiety, after use of the support programme. While depression and anxiety ordinarily coexist (Lader, 1994; Stavrakaki & Vargo, 1986), it is speculated that the different nature of anxiety experienced by parents, entrusted with a demanding daily medical treatment regime, may account for these results. Positive results on the General Health Questionnaire, a measure which assesses stress responses in the health domain, are also reported.

In an environment where the United Kingdom Department of Health (2001) is promoting the concept of the expert patient, knowledge and empowerment may not be enough. Placing the research in this study in context, it is argued that innovation and cost-containment will contribute towards both opportunities and stresses for the psychologist working in a biopsychosocial model incorporating multidisciplinary teams. Shaw and Baker (2004) ask "Expert patient – dream or nightmare?" while Strawbridge (2002) remarks on the pitfalls of what she calls, the emergence of 'McDonaldization or fast food therapy' in psychology, in which we find ourselves doing 'McJobs'.

This study positions itself in the midst of the new concepts and demands of multidisciplinary service delivery and finds that its objectives are compromised by pressures of time, money and health care policy.

OPSOMMING

Hierdie tesis fokus op die betreding van die sielkundige op die terrein van die gesondheidsielkunde en die toepassing van sielkundige vaardighede in 'n multidissiplinêre konteks met spesifieke verwysing na sistiese fibrose. Moderne voorsiening vir gesondheidsorg word beïnvloed deur die gevolge van verbeterde mediese behandeling sowel as 'n wegbreek van die model van mediese dominansie. Die konsep van ouerlike bemagtiging (Melnik, Feinstein, Moldenhouer, & Small, 2001) word aanbeveel in 'n era van biomediese reduksionisme (Campbell, 1994).

Die druk om innoverend te wees in 'n klimaat van koste-inperking, dryf gesondheidsorg tot nuwe vorms van dienslewering sodat sielkundiges al hoe meer aanvaar word in die algemene hospitaalomgewing, maar terselfdertyd moet daar by 'n groeiende psigososiale model (Jasnoski & Schwartz, 1985) ten opsigte van mediese behandeling aangepas word.

Die mikpunt van hierdie studie is tweeledig. Dit kontekstualiseer eerstens die rol van die sielkundige in 'n ontwikkelende gesondheidsielkunde en mediese omgewing. Dit ondersoek dan die sukses al dan nie van 'n spesifieke inligting-ondersteuningsprogram wat die ouers van kinders met sistiese fibrose wil bemagtig of minstens hul nood gedeeltelik wil verlig.

Die tekortkominge van sielkundige betrokkenheid by die algemene mediese praktyk, sowel as die historiese strukturele versperrings inherent aan die dominansie van die mediese model (Parsons, 1970; Karabus 1994), word bespreek. Aandag word ook geskenk aan die rol van kollaboratiewe opleiding (Gallo & Coyne, 2001; Kainz, 2002; Waters, 2001) as 'n fasiliterende krag in die bevordering van groter multidissiplinêre samewerking.

In die konteks van 'n ernstige siekte soos sistiese fibrose, word versteuringe in 'n normale gesin bestudeer. Omdat die normale patroon van ouer-kind binding (Bowlby, 1969) beïnvloed word deur die verwagte dood van 'n kind voor dié van die ouer, word die konsep van kroniese smart (Olshansky, 1962) ook genoem. Gevolglik word die struikelblokke in die beoordeling van die ouerlike funksies in hierdie gespanne huishoudelike omgewing bespreek.

‘n Loodsstudie in die vorm van ‘n behoefte-analise op ‘n klein groep ouers gaan die hoofnavorsing vooraf en is gerig op ‘n groep ouers van voorskoolse kinders wat met sistiese vibrose gediagnoseer is. In die hoofnavorsing word die ouers van ‘n inligtingsondersteunings-pakket voorsien en aspekte van hul sielkundige funksionering word gemeet op die Algemene Gesondheidsvraelys (Goldberg, 1978), Beck Depression Inventory (Beck & Steer, 1987), State-Trait Anxiety Inventory (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1970) en Brief Symptom Inventory (Derogatis, 1993).

Bivariate analise, meerveranderlike analise en nie-parametriese vergelykings word gemaak om die effek van die inligtingsondersteunings-pakket op die sielkundige funksionering van ouers te bepaal. Die resultate is gemeng, met ouers in die eksperimentele groep wat laer depressievlakke, maar nie angstigheidsvlakke nie, ná afloop van die ondersteuningsprogram toon. Terwyl depressie en angs gewoonlik saam voorkom (Lader, 1994; Stavrakaki & Vargo, 1986), word bespiegel dat die verskillende vlakke van angs by ouers, verantwoordelik vir veeleisende daaglikse mediese behandeling, die oorsaak mag wees van hierdie bevinding. Positiewe uitslae op die Algemene Gesondheidsvraelys, ‘n meeting wat stres-reaksies in die gesondheidsveld assesseer, word ook gerapporteer.

In ‘n omgewing waar die *United Kingdom Department of Health* (2001) die konsep van die ekspert-pasiënt promoveer, mag kennis en bemagtiging moontlik nie genoeg wees nie. Om die navorsing in hierdie studie in konteks te plaas, word daar geredeneer dat innovering en koste-inperking sal bydra tot beide geleenthede en stres vir die sielkundige wat in ‘n bio-psigososiale model wat multidissiplinêre spanne insluit, werk. Shaw en Baker (2004) vra “Expert patient – dream or nightmare?” terwyl Strawbridge (2002) op slaggate wys wat sy die verskynsel van ‘McDonaldization or fast food therapy’ noem; sielkunde waarin ons onself in ‘McJobs’ bevind.

Hierdie studie is geplaas te midde van ‘n nuwe konsep met verwagtinge met betrekking tot multidissiplinêre dienslewering en daar word bevind dat die doelwitte gekompromiteer word weens tydsdruk, gebrek aan geld en gesondheidsorg-beleid.

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CHAPTER 1

INTRODUCTION AND PURPOSE OF THIS STUDY

1.1 INTRODUCTION

In an age of sophisticated medical procedures, treatments for life-threatening illnesses have improved. Improved life expectancy of terminally ill patients has shifted the emphasis from coping with death to coping with uncertain survival (Van Dongen-Melman & Sanders-Woudstra, 1986).

According to Campbell (1994), medical sophistication has also created the possibility of overspecialisation and crisis. In this regard he writes:

The Chinese character for crisis includes two symbols: one that stands for danger and the other for opportunity. The current health care system with its emphasis on biomedical reductionism, overspecialization, high technology, and high costs is in a state of crisis. This crisis offers many new opportunities for family professionals to become involved in the health care field. (p. 147).

A broader biopsychological perspective in long-term care is now necessary, O'Boyle (1997) points out, because it is becoming a focus of policy making in health. Assessing the effects of health technologies, the Department of Health of the United Kingdom (1992) proposed that outcome assessments should go beyond traditional indicators of survival and symptoms to include measures of quality of life, the experiences of patients and their carers, as well as consideration of cost.

In a UK Department of Health (2002) statement about the National Service Framework, the Health Minister stated that the health care system would have to deliver a user-centred,

interdisciplinary system, with rapid referral, information and support for carers and families, including help for people with long term conditions, their partners, parents and carers and, most significantly, the development of the concept of the expert patient.

Traditionally, medical treatment of life-threatening illnesses was based on decisions within a particular speciality, rarely with any meaningful interdisciplinary interaction (Karabus, 1994).

However, during the past 30 years, researchers within the field of psychology (Drotar, 1981; Havermans & Eiser, 1993; Michael & Copeland, 1987) have begun to highlight the need for psychologists to play an integral role within a multi-disciplinary team which is involved in the health care delivery system. Involvement, it was argued, would help with problems such as disagreements and misunderstanding about treatment (Mulhern, Crisco & Camitta, 1981), behavioural problems in adolescents (Magen, 1990), improved communication and participation in treatment decisions (Maguire, Brooke, Tait, Thomas & Sellwood, 1983; Maguire, 1985).

More recently, the importance of psychological processes in the experience of health and illness is being increasingly recognised (Marks et al., 1998).

Formal psychological services, however, have usually been provided within a clinical context, with most recipients of treatment falling into one or other category of the psychiatrically ill. Some patients were able to avail themselves of private treatment, while others received treatment after admission to a psychiatric hospital.

The emerging field of health psychology, on the other hand, does not presuppose psychiatric illness. It is more focussed on psychological and behavioural processes in health, illness and health care (Johnston, 1994). Furthermore, health psychologists are beginning to contribute to improved understanding of why people present with symptoms, how they adhere to clinical advice, and the extent to which they become distressed by their condition (Johnston, 1997).

Similarly, Wardle (2000) points out that health psychologists have begun to address problems of major public health importance, working in Departments of Epidemiology,

Public Health or Population Sciences. She goes on to suggest that, with new emphases emerging, it might be timely to coin the name 'public health psychology' for this new domain of employment.

Her latter remark may, however, have the unintended consequence of suggesting that such a specialism might become the dominant one in the delivery of health psychology, which is unfortunate. Lenihan and Iliffe (2000) write, in this regard, that it is the expectation of counselling psychologists, who are already working in primary care groups in the community, to rise to the challenge of, *inter alia*, addressing health problems in a specific community and embracing the complementary use of epidemiological and clinical skills.

Moreover, Lenihan and Iliffe (2000) point out that community-orientated primary care services, pioneered by Stanley Kark in South Africa in the 1940's and developed in Israel in the 1960's (Geiger, 1993), require co-ordination across a range of social and health agencies and an interdisciplinary perspective on health.

Therefore, it would seem more productive to seek common ground for the involvement of all applied psychologists relevant to the field of health psychology rather than seek a new title for this domain. A broader discussion of this topic follows in Chapter 2.

Chronic illnesses, Taylor (1995) states, has helped spawn the field of health psychology because these are diseases in which psychological and social factors are implicated and because they affect family functioning, where parents play a role in medical treatment compliance under sustained duress. Health psychologists, she writes, concern themselves with how people become ill and how they respond to illness, researching and providing interventions for psychosocial problems that illness may create.

Saxby and Svanberg (1998) have reported unambiguously that, over the previous decade, a solid body of evidence has emerged which clearly shows the benefit of health psychological services. These include primary prevention, life style adaptations, anticipatory side effects of medication, preparatory information about anticipated procedures, the post-operative period and the provision of cognitive coping strategies for reducing the perception of pain.

The emergence of health psychologists has, therefore, created scope for broader involvement of psychologists in the context of general medicine, with the prospect of novel or additional, innovative psychological interventions (Elander & Midence, 1997).

It would appear that innovation is being accompanied by pressure on members of a multi-disciplinary team to deliver cost-effective, evidence-based approaches (Walsh, 2003) but she goes on to point out that, while evidence of effectiveness is not necessarily disputed, the definition of 'effectiveness' is often not formulated satisfactorily. An example is given. An outcome measure of reducing waiting lists for patients may be thought to indicate effectiveness, but the same outcome occurs if lists are shortened due to other factors, such as clients dropping out of therapy, committing suicide or seeking care elsewhere.

With regard to evidence-based interventions, Corrie (2003) remarks that the concept of evidence is neither straightforward nor simplistic, stressing important questions, *inter alia*: What skills do we need to innovate successfully and what skills are needed for effective and ethical therapeutic decision-making?

Innovation is also being influenced by what Strawbridge (2002) refers to as 'McDonaldisation' or 'Fast-food therapy'. This development, she argues, has contributed to a tendency to promote short-term work, including manualised and computer treatments to the exclusion of more flexible and creative approaches.

There appears to be an emerging paradox. Innovation does not, necessarily, imply creativity. It suggests, rather, what Strawbridge is calling 'McJobs', characterized by efficiency, calculability, predictability, the use of non-human technologies and rationalised systems.

1.2 CONSEQUENCES OF IMPROVED MEDICAL TREATMENT

Drotar (1981) observed that improvements in treatment have succeeded in prolonging the lives of patients with several chronic conditions, such as cancer, cystic fibrosis, myelodysplasia and renal failure. Similarly, life expectancy for cystic fibrosis is increasing

medical and psychological treatment, but a common feature is prolonged life, requiring long-term management.

Meadows, McKee and Kazak (1989) observed that as many as two-thirds of patients who are diagnosed with cancer before their 16th birthday will reach early adulthood, free of the disease. With increased survival rates and periods of recovery, parents inevitably play a role in treatment and support. Interestingly, Campbell (1994) notes that it is only recently that the medical profession has begun to recognise families as primary caregivers and that chronic illnesses create enormous burdens on family members. The severity of illness can exert a powerful stress on the family unit (Foss & Tenholder, 1993).

Because management extends over many years, Magen (1990) notes that behavioural problems can interfere with disease control and non-compliance of treatment, posing difficulties for both young patient and parent. Where a condition is incurable, O'Boyle (1997) states, the primary goal is to ensure the best quality of life for the patient.

1.3 THE ROLE OF PARENTS IN LONG-TERM CARE

1.3.1 The central role of parents

While it is obvious that parents play a pivotal role in caring for their children under relatively normal circumstances, the nature of this role changes dramatically when the child is diagnosed as seriously ill, particularly in infancy.

Therapy regimes require active co-operation from the child and parents for several hours each day and, while most children do not feel sick, they need to be convinced to adhere to therapy (Goldbeck & Babka, 2001). The parents are, therefore, central in the aspects of persuasion and influence to treatment adherence.

Their role may be positively facilitated by psychologists, Elander and Midence (1997) suggest, through problem-focussed, cognitive or administrative interventions, each of which have their advantages. However, parental involvement, in whatever form, seems to uniformly imply the guardianship model, proposed by Eiser (1996). The parental role is

characterised in this model by their 'gatekeeper' or 'monitoring' function, where parents overview and check the decisions and actions of medical staff.

In the context of chronic illness, their role is also obviously characterised by a process of emotional and adjustment problems. While involved in monitoring the long-term care of their children, they need adequate information to facilitate their ability to care and for their emotional stability (Chesler & Barbarin, 1984), and for the development of realistic parental attitudes (Taylor, 1995).

While Bradford (1997) states that the factors which best facilitate successful adjustment remain poorly understood, Timko, Stovel, Moos and Miller (1992) argue that their adjustment may be helped if they are free of depression and have a sense of mastery over the child's illness.

Timko et al (1992) would not have known it but their phrase "mastery over the child 's illness" was ahead of its time, because, a decade later, the UK Department of Health's Expert Patient Programme (2001), was launched as a strategy to equip patients and their families with knowledge, promoting self-management of illnesses as a progressive approach to disease management in the new century.

1.3.2 Cystic Fibrosis

With the combination of increased survival rates, the pressures of economics and medical ethics, more people are now being treated in the community, placing greater responsibility on the family to care for its members at home (Altschuler, 1999). Cystic fibrosis is a good example of an illness which requires long-term care within the home. It involves regular, daily treatment, mostly overseen by parents.

Cystic fibrosis is the most common autosomal recessive disorder of childhood Caucasian populations, affecting one in every 2500-3000 live births (De Braekeleer et al., 2001). It is a disease which affects the functioning of the lungs and digestive system, caused by an autosomal recessive gene inherited from each parent. Genes, being the basic units of heredity, have the function to instruct cells to make particular proteins with life-sustaining roles. If the inherited pairs of genes from the parent are altered, this is referred to as

mutation. A mutation causes the body to make defective proteins or no protein at all, leading to a loss of some essential biological function and, hence, disease.

Cystic fibrosis is among the most common lethal genetic disease in children (Hamer & Parker, 1996). The disease manifests predominantly through abnormal secretions from exocrine glands, resulting in pulmonary lesions and other tissue deterioration, for which there is no cure.

In medical terms, cystic fibrosis is manifestly a disease of the exocrine organs (Wine, 1997; 1999). The respiratory, digestive and reproductive tracts rely extensively on exocrine secretions. The disease is characterized by abnormalities in electrolytes and macromolecule secretions of the exocrine glands, which causes pulmonary obstructions, infections and digestive disorders, such as pancreatic insufficiency (De Braekeleer et al., 2001).

In patients with cystic fibrosis, the surfaces of the lungs are gradually destroyed by bacteria. Therefore, a major treatment focus is to assist the patient's breathing by reducing the mucous blockages in the airways. In the lungs, the mucus produced in them is also abnormally thick, causing blockages, infection and, ultimately, damage to the lungs.

In the intestines, the linings secrete insufficient fluid and they become susceptible to blockage from inadequately hydrated stools. Additionally, stools contain excessive fat because of a loss of pancreatic enzymes.

Enzymes, produced in the pancreas, and intended to reach the intestines, are blocked with a sticky mucous. Blocked enzymes build up in the pancreas, causing inflammation, cysts and fibrosis. To help the patient, a well-balanced, high calorie diet, low in fat and high in protein, as well as pancreatic enzymes to assist digestion, are prescribed. Additionally, enemas and mucolytic medications are used to overcome intestinal obstructions.

According to Wine (1997; 1999), additional symptoms include blockages of the vas deference, in males, dehydrated cervical mucous, in females, and greatly elevated concentration of salt in sweat. There is a degree of variability in other symptoms such as focal biliary cirrhosis and an unusually small gallbladder.

The clinical features of the condition, the prognosis, and the intensive nature of medical intervention for cystic fibrosis are a source of considerable stress for both patients and their families (Lask, 1994).

Since cystic fibrosis cannot be cured or prevented, it remains fatal (De Baekeler, et al. 2001) but life expectancy is increasing (Conway, 1996; Wallis, 2003) and therefore one may readily agree that supportive psychological intervention is required (Taylor, 1995) to ensure the best quality of life for the patient (O'Boyle, 1997). The median life expectancy has increased from 8 years to 30 years during the past three decades (Goldbeck & Babka, 2001).

1.4 INFORMATIONAL INPUT

The first major study on the psychological aspects of cystic fibrosis (Turk, 1964) found that psychosocial stresses significantly affected relationships and communication within the family. Solnit and Green (1959) also reported that parental reactions to life-threatening illness have long-term psychologically deleterious effects which include disturbances in both psychosocial development and parent-child relationships.

Later studies confirmed a variety of difficulties for parents, including communication problems and fears about death (Kulczycki, Robinson & Berg, 1969), depression, guilt and denial (Tropauer, Franz & Dilgard, 1970), patient dependency (Lampo, Dab & Malfroot (1990), inadequate knowledge and nonadherence to prescribed medical treatment (Koocher, McGrath & Gudas, 1990; Michaud, Frappier & Pless, 1991).

The majority of complaints about health care are about communication problems (Kinderman, Feather & McDowell, 1996). At the same time, doctors and staff tend to underestimate the level of patients' need for information (Bradford, 1991; Eiser, Havermans, Parkyn, & MacNinch, 1994). While parents are willing to devolve decision-making to professionals, they are not willing to relinquish their right to consultation and information (Eiser, 1996).

If parents are to be involved in long-term care of their children, they need adequate information about medical decisions (Kinderman et al., 1996) and for their emotional stability (Chesler & Barbarin, 1984; Timko et al., 1992). Dunn (1995) observes that, to overcome uncertainty and misconceptions about chronic illness, a far greater part of health care consists of education than for other conditions. A central aspect of alleviating distress, therefore, involves the appropriate management of information (Kinderman et al., 1996).

There are many forms of informational programmes devised by psychologists. They range from pain management group meetings to self-help information packages. While one may readily agree with Corney (1991) that the provision of information can contribute towards a lessening of uncertainty and distress, psychologists would appear to be uniquely placed to play a meaningful role. This is so because they would have been trained to be sensitive to patient problems and emotions. In this regard, Maguire (quoted in Corney, 1991) reiterates that the provision of information is not always straightforward, requiring the professional to engage with the patient in a sensitive manner, exploring what is being understood and what is appropriate.

1.5 PURPOSE OF THIS STUDY

Historically, psychological research has been dominated by studies measuring adverse effects, producing inconsistent and often contradictory results (Bradford, 1997). Diseases also have very different consequences because of their survival rates (Elander & Midence, 1997).

However, the value of information specific to an illness and its management appears to be very important (Bradford, 1997). Feather, Kinderman and McDowell (1995) have confirmed that parents of hospitalised children attach significantly greater importance to the receipt of clinical information than did staff, while Fallowfield, Baum and Maguire (1987) state that, since anxiety is provoked by uncertainty and unrealistic fears, there are benefits from being well-informed.

Wereszczak, Miles and Hoditch-Davis (quoted in Melnyk, Feinstein, Moldenhouer & Small, 2001), point out that uncertainty regarding a child's condition and lifespan is a

major stressor, but distress could be reduced by providing information about the illness (Corney, 1996; Hymovitch & Baker, 1985, Kinderman et al., 1996).

The literature therefore suggests that it is necessary to establish aspects of psychological functioning of a particular population of parents whose children have been diagnosed with a specific illness and to devise appropriate informational programmes to alleviate distress.

Therefore, for cystic fibrosis, two important research opportunities exist. The first question is: What difficulties are parents experiencing? The second question is: Does an informational support programme alleviate some of these difficulties and improve at least some aspects of their psychological functioning? The goal of this study is to attempt to answer these questions. Answers to them would allow a comparative analysis with other interventions in health psychology studies.

However, it is also important to place the task of answering these questions in context because the opportunity to do so is in a climate where a variety of changes are occurring, including shifts in government policy, cost-containment and the integration of psychologists in biopsychosocial models of health care delivery, with all the attendant tensions and expectations of delivering alternative, innovative and brief interventions.

1.6 SUMMARY

The shift from coping with death to uncertain survival (Van Dongen-Melman & Sanders-Woudstra, 1986) has produced an opportunity for psychologists to participate in multi-disciplinary support of families in distress (Havermans & Eiser, 1993; Karabus, 1994; Saxby & Svanberg, 1998).

Alleviation of parental distress involves the appropriate management of information (Chesler & Barbarin, 1984; Kinderman, et al., 1996; Timko et al., 1992).

An opportunity, therefore, exists for an evaluation of parental needs and distress about chronic illness such as cystic fibrosis and to assess if an informational support programme contributes to improvement of at least some aspects of psychological functioning.

1.7 FOLLOWING CHAPTERS

Chapter 2 will present an overview of the emergence of health psychology in several medical specialisms, such as cardiology, oncology, surgery and chronic illness. and its applications within the context of general medicine. This will include a discussion on the role of the psychologist as part of a multi-disciplinary team.

Chapter 3 will present a discussion on the difficulties experienced in the quest to provide multidisciplinary support for patients, including the structural barriers inherent in service provision dominated by medicine. Reference will be made to parental problems in this context and the provision of psychological support.

Chapter 4 will report the results of a pilot study, in the form of a needs analysis, with parents of children with cystic fibrosis.

Chapter 5 will describe the compilation of an appropriate informational support programme, within the context of an emerging biopsychosocial model, for parents of children with cystic fibrosis. Justification for the implementation of a parent empowerment support programme within such a model will be given.

Chapter 6 will describe the objectives and method of research, including the design and psychometric measures used during the study. Hypotheses to be tested and the psychometric instruments used will be described. Mention will also be made of the necessity to engage with the participants in a sensitive and considerate manner.

Chapter 7 will present the results of the study, providing univariate descriptive statistics, bivariate analyses and multivariate analyses. Cell mean plots will also be depicted to illustrate where positive results of the intervention were found.

Finally, Chapter 8 will provide a critique of the results of this study, its shortcomings and suggestions on how research of this nature may be improved. Mention will also be made of the difficulties of integrating psychologists in multidisciplinary teams in an evolving biopsychosocial service framework, where innovation and efficiency are key factors.

CHAPTER 2

THE EMERGENCE OF HEALTH PSYCHOLOGY AND ITS APPLICATION WITHIN THE CONTEXT OF GENERAL MEDICINE

2.1 INTRODUCTION

This chapter will, firstly, define the field of health psychology and then provide an overview of the emergence of health psychology in general, with special reference to developments in the medical context.

Areas in which health psychology have been most visible will be described, followed by arguments on how multidisciplinary teams may improve the management of chronic illness. Examples will also be given of the integration of psychologists in multidisciplinary teams in the area of general medicine. It is argued that it is necessary to do so because health care service is changing in a climate of cost constraints and innovation (Martin 1990) and because psychologists in different specialities are being called upon by medicine to become involved in teams (Clay 1999; Rabasca, 1999).

Moreover, the evolution of psychological services alongside medicine cannot be seen in isolation from sociological forces because, as Martin (1990) pointed out, training is now more related to more general societal, political and educational trends, influencing the profession to be multifaceted and eclectic. There are increasing pressures towards eclectic time-limited therapies contemplated by Fuhriman, Paul and Burlingame (1986) and now being evidenced in psychological services (Strawbridge, 2002).

Also, there no longer seems to be a case to be argued for an elevated status of the historical caricature of clinical psychology alongside psychiatry, nor for one specialism within psychology to claim a dominant position in the general medical context. However, it is acknowledged that there continues to be vigorous debate about this and, therefore, a discussion regarding these issues follows.

2.2 DEFINITION OF HEALTH PSYCHOLOGY

Maddux, Roberts, Sledden and Wright (quoted in Taylor, 1995), describe health psychology as the study of all psychological aspects of health and illness across one's life span. Taylor (1995) adds that, in practice, health psychologists are mostly concerned with the psychological aspects of the prevention and treatment of illness.

The most cited definition of health psychology is from Matarazzo (1980), who states that it is:

... the aggregate of the specific educational, scientific and professional contributions of the discipline of psychology to the promotion and maintenance of health, the prevention and treatment of illness, the identification of etiologic and diagnostic correlates of health and illness and related dysfunctions, and the analysis and improvement of the health care system and health policy. (p. 815).

McDermott (2001) is critical of this definition for being over-inclusive. He goes on to argue that there is the danger of health psychology being subsumed by clinical psychology through collusion, saying that the intent may be to enjoy the status associated with the mistaken identity of their occupational relatives.

McDermott (2001) suggests, further, that if health psychology emphasizes illness prevention and health promotion (rather than have a remedial or rehabilitative emphasis), it would thrive as a sub-discipline of psychology as a whole. The implication here is that it would enjoy the positive involvement of counselling, educational and other applied psychologists as opposed to being subsumed as a sub-speciality within clinical psychology.

As health psychologists have become aware of the relationship of theory, research and practice, their work has been extended to understand the meaning of illness (DiMatteo, 1991). Conflicting views on how chronically ill patients perceive themselves and their suffering (Charmaz, 1983; Cuthbert, 1999) are amongst the reasons for professional training in the management of patients whose illness leaves them feeling vulnerable, excluded or disempowered (Altschuler, 1999).

Health psychology is an expanding area of psychology in the United Kingdom, across Europe, in Australia, New Zealand and the USA (Ogden, 2000).

In Europe, a Task Force on Health Psychology was established by the European Federation of Psychologists' Association in 1992 to define the nature and scope of health psychology, to specify training needs, and to implement programmes to satisfy these needs (Marks et al., 1998). In its final report, it acknowledged similarities and synergy between health psychology, clinical psychology, psychotherapy and other applied psychological fields, but differentiated health psychology from the other fields as follows:

- Clinical psychology is primarily concerned with assessing, predicting, preventing and alleviating cognitive, emotional and behavioural problems
- Psychotherapy is primarily concerned with treatment of psychologically influenced disorders by psychological means
- Health psychology is focussed on physical health, illness, and healthcare, while recognizing that mental and physical health are highly interrelated.

It will be argued here that arguments about differentiations are not helpful. The scope of other applied psychological fields, such as educational and counselling psychology, may include many of the above aspects. However, as Bor and du Plessis (1997) remark with regard to the pragmatics of counselling psychology research in health care settings, there is a need for counselling psychologists to describe to their professional colleagues what they do in their practice.

A way forward, they argue, is for counselling psychologists to demonstrate their worth by becoming more involved in service-related research and publication. However, they remind one of deterrents to such endeavour, in that it is sometimes viewed as potentially intrusive to the counselling relationship to conduct research while simultaneously developing a therapeutic relationship. Additionally, they say, collaboration with other colleagues may be minimal.

Returning, however, to the fields of health and clinical psychology, it may be necessary to add a comment on differentiation by indicating where health psychology provides its input

because clinical psychology has historically provided contributions mostly in psychiatric settings and private practice, with its primary focus on the treatment of mental illness as opposed to the promotion of psychological health. While this may have been historically true, McDermott (2001) recently remarks that there is recurrent evidence from job advertisements in the United Kingdom of an attempt by clinical psychology (whether deliberate or not) to reinvent itself and appropriate the banner of 'health psychology'.

In contrast to this view, Golden (2001) states that it is unfortunate that attempts to define a field should be at the expense of others (for example, clinical versus health psychology). She adopts a more positive stance, saying that collaboration is a two-way street and that research is informed and enriched through collaboration with professionals from other fields.

Indeed, psychologists attempting to promote the value of their work alongside general medicine, e.g. counselling psychologists working in primary care, may be productively informed from their colleagues in psychiatric settings. The importance of providing psychosocial interventions alongside medical treatment of severe mental illness is widely acknowledged (Burbach, 1999). It is in this area, say Mari and Steiner (quoted in Burbach, 1999) that there is now convincing research evidence of the efficacy of family interventions for mental illness. Additionally, the association between physical and psychiatric disorder in patients attending general practice has been well documented (Kiseley & Goldberg, 1997).

Therefore, outside of a psychiatric setting, there is sufficient motivation for health psychology to address the psychological consequences of serious physical problems. To this end, health psychology has contributed interventions based on research to enhance health care in areas targeted by government policy (Abraham, 1999). These areas are likely to be in general medical environments that target the general population (e.g. dietary change), adherence behaviours amongst patients (e.g. self-care following surgery), as well as changes to provide more effective treatment and advice.

Other areas are also likely to be in community settings (e.g. accident prevention) and in schools (e.g. sexual health education).

None of these areas of professional involvement necessarily imply mental illness characteristic of psychiatric settings but they do cater for potential psychological sequelae in the context of general medicine or within the community. At least, the work of health psychologists in these contexts do not presuppose mental illness for the necessity of their work.

Oldenburg and Ffrench (1997) also point out that, whereas most psychologists have been trained to focus primarily on the individual or small groups, health psychology is distinguished from most other fields by the expectation that research and work will contribute to improving not only the health of individuals, but also, health outcomes at a population level.

Furthermore, Bryne (1999) notes, in the field of training, the influence of health psychologists is broadening because they are providing courses to other health professionals in general medicine, physiotherapy, dentistry, occupational therapy and nursing.

Finally, in the context of chronic illnesses, where young patients are dependent on their parents and where ongoing support is most often provided in the home, Wass and Corr (1984) suggests that the work of the psychologist should include attention to parental emotions, understanding of the diagnosis and nature of the disease and the provision of any programmes, organizations and community resources, which may be available in that area.

With the combination of increased survival rates, the pressures of economics and medical ethics, more people are now being treated in the community, placing greater responsibility on the family to care for its members at home (Altschuler, 1999).

2.3 HISTORICAL PERSPECTIVE

2.3.1 Early literature

In an early literature review of mental health interventions with medically ill children, Johnson (1979) observed that, while physical illness had long been recognized as having a

major psychological impact on the child, there had nevertheless been little controlled research on the subject.

Drotar (1981) observed that a growing number of paediatric psychologists were now working with chronically ill children's families, investing their energies in chronic illness-related research to develop appropriate psychosocial support programmes.

At about the same time, Lubin, Nathan and Matarazzo (quoted in Tefft & Simeonsson, 1979) noted that there had been a relatively steady rate of increase in the involvement of psychologists in health care settings during the preceding ten years. According to Tefft and Simeonsson (1979), professional change had become visible in three distinct areas. These are described as the creation of new interdisciplinary roles, the development of training opportunities, and the publication of topical research in both psychological and medical journals.

The appearance of research in medical journals was a notable step towards contributions in general medicine. Beyond paediatrics, however, the developing role of the health psychologist within the medical environment has been most visible in areas which Saxby and Svanberg (1998) refer to as 'important areas of physical healthcare': cardiology, oncology and surgery.

While one may be critical of why his focus is limited to these areas only, they nevertheless make a useful contribution to the argument for the inclusion of psychologists in the medical environment.

The emergence of health psychology in these areas of medical treatment will, therefore, be discussed, to illustrate how psychologists have begun to integrate their contributions in a multidisciplinary context. This will be followed by a section on chronic illness, which is more specific to this study.

2.3.2 Cardiology

Weinberg (1994) observed that, during the past several decades, concepts of lifestyle in the genesis and treatment of coronary disease has gained prominence. This observation may

perhaps be stated too simply because lifestyle does not occur in isolation from a changing environment (Golden, 2001). An ever-changing environment brings with it a complexity of stressors, requiring imaginative psychological interventions.

It will be pointed out in this section that psychologists will inevitably find themselves working across various specialties. They will also, according to van Elderen (1994), work at different phases of treatment, namely the acute phase, the sub-acute phase in the nursing ward, and upon discharge from hospital. She enlarges on this by describing the type of work involved, i.e. psychological assessment, psychological treatment (crisis intervention, cognitive restructuring, relaxation training and counselling) and indirect patient care. This may include multidisciplinary consultation with a view to promoting an integrated approach, helping with the realisation of treatment objectives.

Such objectives imply a different approach because, as Ewart and Fitzgerald (1994) state, the established clinical methods for psychiatric patients are ill-suited to cardiac patients. Applied psychologists, they propose, should embrace a social action theory of health behaviour change, promoting well-being and altering behavioural risk factors.

Interest in coronary disease has been popular for a variety of reasons. Coronary heart disease is the leading cause of death in adulthood in most industrialised nations (Smith & Gallo, 1994). Clinical health psychology in this area is also stimulating because it encompasses a broad range of psychological specialties, including neuropsychology, paediatric psychology and difficulties relating to the process of ageing (Gardner & Worwood, 1997).

Additionally, while there is a greatly improved survival rate following acute myocardial infarction, survivors face problems such as psychological reactions to the unexpected and frightening onset of an attack, with curtailment of social, occupational and recreational activities (Ewart & Fitzgerald, 1994), which medical care systems are poorly prepared to treat (Ben-Sira & Eliezar, 1990; Fontana, Kerns, Rosenberg & Colonese, 1989).

Hamlet, Massey, Anson, Sathananthan and Sweetnam (1999), in their article on the prevalence of depression after myocardial infarction, argue that the treatment plan must include a psychosocial component. In their view, health professionals must start to regard

myocardial infarction not just as a physical illness but also a psychosocial one, requiring an expansion of the diagnostic and therapeutic process to reflect this.

However, it needs to be noted that their view is not new. Mead, Bower and Gask (1997) had already pointed out that practice nurses are involved in the emotional care with a variety of patient groups, although this is not always acknowledged as mental health work. Elwood (1998) states further that the role of the practice nurse already includes screening, recognition, assessment, education and management of chronic disease – all areas where depression is identified and treated by the practice nurse.

These recent developments are a welcome departure from what occurred in previous decades. While multidisciplinary cooperation, involving health psychologists, would appear to be an obvious advance towards agreement about better and more comprehensive health care, early attempts have been hindered by the authority of physicians and their reluctance to define problems in psychosocial terms (Tefft & Simeonsson, 1979). In a study of medical practitioners talking with patients suffering from terminal illness, Maguire (1985) refers to 'distancing tactics' used by doctors to prevent them getting close to their patients' psychological suffering. These tactics, he points out, discourage patients from disclosing their psychological concerns and they are, therefore, a serious barrier to effective psychological care.

Historically, physicians have had difficulties with incorporating sufficient care and warmth in the management of life-threatening illness owing to the nature of standard medical school training, which placed little emphasis on the need for personal supportive relationships (Chesler & Barbarin, 1984). Consequently, in later practice, physicians' typical neutrality was seen to clash with parents' and patients' affective needs and concerns (Meadow, 1968).

In the Netherlands, psychologists have sought proposals, through a series of reports of the Rehabilitation Commission of the Netherlands Heart Foundation, during the period 1966 to 1990 (van Elderen, 1994), to find a framework for discussions about 'norms regarding the contribution of psychologists' to assist in treatment of cardiac patients. Nevertheless, Hamlet et al. (1999) point out that there remains no generally accepted guidelines for the management of depression following acute myocardial infarction.

Of considerable significance, however, to the profession of psychology and its potential role within a multidisciplinary team, is the evidence that depression after acute myocardial infarction is up to four times more prevalent than depressive disorder in the general population (Hamlet et al., 1999). Also, coronary heart disease has a greater impact on functional status and sense of well-being than the nine other most common medical conditions (Stewart et al., 1989).

The work of clinical health psychologists has, therefore, probably been most visible for these reasons and for the search for evidence-based guidelines for the treatment of depression in both hospitals and community environments following acute myocardial infarction.

On a more positive note, however, Saxby and Svanberg (1998) report more broadly that, over the last decade, a solid body of evidence has emerged which clearly shows the potential benefit of clinical psychology services in physical healthcare. In their review of the literature, they reported positive effects of psychological intervention, not only in cardiology, but also in oncology and surgery - areas of medical intervention which are more well-known and which require the input of several professions.

One may perhaps add here that, while Saxby and Svanberg (1998) argue from a clinical perspective, it is equally important for counselling psychologists working in health care to be involved in service-related research and healthcare (Bor & du Plessis, 1997). In fields which have previously been seen as disparate, Lloyd-Bennett and Melvin (2002) point out the benefits of joint working practices between educational and clinical psychologists.

2.3.3 Oncology

While cancer is one of the most feared diseases, resulting in clinically significant adjustment disorders (Derogatis, 1993) and psychological distress (Farberm, 1984), studies show that oncologists frequently do not recognize these disturbances (Ford, 1994; Hardman, 1989).

According to Holland (2002), the formal beginnings of psycho-oncology date to the mid-1970's. Northouse & Northouse (1987) state that, over a 20 year period, prior to 1987, there have been over 200 articles in the psychosocial oncology literature on the problems of patient-physician communication. In an annual report of a community-based social work agency serving cancer patients and their families in New York, Blum and Blum (1991) reports that 25 per cent of the callers identified patient-physician communication as their primary concern.

More recently, McGuire (1999) reports that, in the USA, after a previous decade of inconsistent funding in cancer-related behavioural research, the two streams of psychological progress and medical acceptance of the role which psychological research can play, are flowing together. He goes on to cite areas of involvement:

- Through psycho-neuroimmunology, psychologists have explored the connection between how stress and anxiety can impact on the immune system
- Psychologists have designed sophisticated cancer education campaigns
- Decisions about undergoing genetic testing for cancer can psychologically affect individuals and their families
- Psychological support, during and after medical treatment enhances quality of life

Moreover, Rabasca (1999) remarks that physicians in the USA are becoming receptive to the use of psychological techniques, such as the use of relaxation tapes and the overcoming of fear, when preparing for surgery and about taking medication. Pain management is an integral part of overcoming post-operative distress, both from a psychological and medical perspective.

While the problems of communication and lack of support for the involvement of psychologists in comprehensive management may have persisted for some time, Bundy (1997) reports more recently that there are a small number of programmes in the United Kingdom that now have a dedicated psychologist as part of the multidisciplinary team. Examples of these advances will be described in the section on chronic illness at the end of this chapter.

Therefore, there appears to be progress from the early example, over two decades ago, of overcoming shortcomings in the management of oncology patients provided by Gordon et al (1980). They had developed a psychosocial intervention programme which involved educating the patient how to live with the disease effectively, with information on the medical system and the patient's own medical condition. It was found to improve their adjustment, a decline of negative affect (anxiety and hostility), a more realistic outlook on life and more active use of time. Now, two decades later, family interventions in paediatric oncology are common (Clay, 1999), influenced to a large extent by a shift of the burden of care from hospitals to patients' own homes.

Holland (2002), reporting on the history of psycho-oncology, remarks that it has become a sub-speciality in its own right, with a research agenda which has evolved with applications at all points on the cancer continuum. He mentions behavioural research in changing lifestyles to reduce cancer risk, studies of behaviours and attitudes to ensure early detection, studies of psychological issues related to genetic risk and testing, symptom control during treatment, management of psychological sequelae in cancer survivors, as well as the management of the psychological aspects of palliative and end-of-life care.

However, one ought to observe that, while such development in the psycho-oncology field may be considered impressive and necessary, it is not necessary sufficient in the context of holistic care. Multidisciplinary collaboration is one thing. An integrated, psychosocial approach, embracing the spiritual needs of the patient is another. Therefore one may readily agree with Otis-Green, Sherman, Perez and Baird (2002) that optimal patient management requires a psychosocial-spiritual model to become the new standard in comprehensive cancer care.

The point is made here because the health psychologist is well-placed, in contrast to the narrower medical health care system with its evolving specialisms and emphasis on biomedical reductionism (Campbell, 1994), to innovate and develop newer models of care, whether through influence in a multidisciplinary team, through action research or through teaching.

2.3.4 Surgery

Early studies have reported that a poorly informed patient is likely to be an anxious patient (Brewin, 1977; Gerle, Lindin & Sandblom, 1960). Since patients often feel inhibited about seeking information from a medical team, they invest much of their time in worry (Fallowfield, et al., 1987). If stress is related to recovery from surgery, Ogden (2000) states that information could be an important way of reducing this stress.

The majority of surgical patients experience moderate to high levels of anxiety (Graham & Conley, 1971; Wolfer & Davis, 1970), before and after operations (Johnson, 1980; Wilson-Barnett, 1979), even when their illness is rated less serious than medical patients (Volicier, 1997).

While these early studies demonstrated the types of interventions to improve psychological functioning, later research has attempted refinements. Ridgeway and Mathews (1982) noted that evidence had begun to emerge that patients who had been prepared for surgery with information about procedures, effects and anticipated recovery, had a better post-surgical recovery on one or more indices of recovery. They reported that cognitive coping strategies were associated with the best outcomes.

A study by Stuber, Nader, Yasuda, Pynoos and Cohen (1991) on children after bone marrow transplantation suggested that their symptoms are similar to those seen in children traumatized by violence. They suggested the use of post-traumatic stress as a model in understanding these symptoms and that this model may be applicable to other children exposed to both serious illness and intensive medical intervention.

A study to investigate anxiety of children awaiting oral surgery demonstrated that the use of a puppet model presenting accurate procedural information, a videotape of a child actor giving procedural information, alternatively a commercial film of a child actor giving procedural information, all reduced anxiety and distress compared to a control group receiving information preparation from hospital staff (Peterson, Schultheis, Ridley-Johnson, Miller & Tracy, 1984).

A study to investigate the timing of pre-operative intervention with cholecystectomy patients, comparing groups receiving preparation two weeks before surgery and one day before surgery, showed no significant differences on measures of post-operative anxiety, pain, mood, number of analgesics, or length of stay, although a trend in favour of late preparation was reported (Mavrias, 1990).

There has also been confirmation of the effectiveness of didactic material to reduce anxiety in patients awaiting a medical procedure (Marteau, Kidd & Walker, 1993).

2.3.5 Chronic Illness

Taylor (1995) states that health psychology is one of the most important developments within the field of psychology in the last 50 years. She argues that chronic illnesses have spawned the field of health psychology because these are diseases in which psychological factors are implicated as causes.

The number of families coping with chronicity, while endeavouring to meet the normal conditions of living, is increasing with every advance in medical science (London & Smith, 1982). Although Bradford (1997) notes that epidemiological studies have shown a variation of between 6% and 30% of children having a chronic illness because of differences of opinion on classification, it is nevertheless clear that families have to cope with incurable conditions and their implications for the dependent child's development and life expectancy.

While children with chronic medical conditions are at risk for mental health problems, the paucity of psychological services they receive have, in the past, been affected by barriers contributed by families, medical staff and mental health providers (Sabbeth & Stein, 1990).

While a central aspect of family involvement in treatment involves appropriate management of information exchange between parents and medical staff (Kinderman et al., 1996), a survey of the Consumers Association in the United Kingdom (1993) revealed that the majority of complaints about health care in the United Kingdom reflect dissatisfaction with communication. Staff tend to underestimate the level of patients' need

for information (Bradford, 1991). Parents of hospitalised children attach greater significance to the receipt of clinical information than do staff (Feather et al., 1995).

Families are becoming the primary caretakers for patients with chronic illness (Campbell, 1994) and psychologists have been invited to think, with families, about the sources of stress, their strengths and their way of coping (Brazier, 1996).

Johnston (1997) argues that, within the context of chronic disease, health psychologists are now making a difference to treatment by contributing to scientific endeavour, by describing phenomena, developing measurement techniques, finding predictive relationships, contributing theoretical insights and creating effective therapeutic interventions.

Chronic illness, where childhood dependency on parents is a factor, invites the development of innovative strategies to deal with the impact of long-term adaptation.

In a study (N=101) on illness adjustment among patients with diverse chronic medical conditions, Bombardier, D'Amico and Jordan (1990) concluded that adaptation to chronic illness may be affected by psychological factors, especially how patients appraise and cope with their illness. Obviously, the young child is highly dependent on the influence of parents in such appraisal and coping. People with chronic illnesses are often reluctant to adopt self-care behaviours (Baker & Stern, 1993).

However, while Sherbourne, Meredith, Rogers and Ware (1992) found that stressful life events impacted differentially on health-related quality of life, younger patients were especially vulnerable, reinforcing the need to deal with psychosocial problems among patients with chronic disease.

Estimating that between 10% and 20% of adolescents have a chronic disease, Buhlmann (1992) states that chronic disease is not a strictly defined term because it includes a large number of illnesses, ranging from physical illnesses to mental impairment. He notes that, while there may be no specific psychopathology, the type of impairment, its impact on family life and other factors will interact with psychosocial maturation, involving parents and requiring counselling to address problems which arise.

In a grounded theory study of how families define and manage a child's chronic illness, Breitmayer, Gallo, Knafl and Zoeller (1992) found that parents indicated a significantly greater risk for social competence difficulties among the chronically ill children compared with the normative sample. Care of the chronically ill patient confined to the home carries with it a serious social and psychological burden (Puig, Hernandez-Monsalve & Gervas, 1992), ranging from helping their children with sexual maturation (Selekman & McIlvain-Simpson, 1991) to overcoming difficulties with taking medication (Babbitt, Parrish, Brierley & Kohr, 1991).

2.4 PSYCHOLOGISTS IN MULTIDISCIPLINARY TEAMS

The recent incorporation of psychologists within multidisciplinary medical teams as opposed to the previous ad hoc services from outside the hospital, or from a different departmental base, suggests a shift towards the recognition that holistic intervention would help overcome the shortcomings of fragmented services.

Interestingly, the term 'holism' was originally coined by a South African philosopher and statesman, Jan Smuts, to designate the tendency in nature to produce wholes from the ordered grouping of unit structures (Karabus, 1994; Smuts, 1926).

An alternative view of a comprehensive service delivery is provided by Elander and Midence (1997), who refer to such interventions as a social approach, which involves the family or community with the affected child, integrating medical, psychological and community-based services.

The report by Bundy (1997) that there are now a small number of programmes in the United Kingdom that have a dedicated psychologist as part of the multidisciplinary team is encouraging evidence of the acceptance of the concept.

The Chichester Health Authority, West Sussex, introduced a children's palliative care team, consisting of a consultant community paediatrician, a social worker, nurses and a clinical psychologist (Wallace & Jackson, 1995). Interestingly, this example provides even

broader support by involving other professionals such as a hospice consultant, pain specialist, dietician, paediatric pharmacist and chaplain, when considered necessary.

Another, more recent, example of progress by psychologists in a different area of medical treatment is evident in Manchester. As a result of psychological screening for victims of stroke, Nothard and Kitching (1999) report that the Mental Health Services of Salford have budgeted to fund a permanent psychologist to assist the rehabilitation team. Their argument for the inclusion of psychological input was strengthened by the view that life-threatening events increase the risk of stroke, which is consistent with what is known about the relationship between severe events and other physical illness (House, Dennis, Mogridge, Hawton, & Warlow, 1990).

As an alternative to fragmented services, Sabbath and Stein (1990) described such a service as an integrated approach, providing families with tangible evidence that psychological and support services are an essential part of comprehensive care, while Wysocki (1993) suggests that health and behavioural benefits could be refined further through interventions which improve parent-adolescent communication skills.

The imperative for a holistic approach has been most succinctly argued by Karabus (1994), when he reminds one that the child is not his disease and that, instead of concentrating only on an illness, the child should be seen as an individual personality in a family looking for help. The development of holistic treatment has been effected through multidisciplinary management, he says, through the inclusion of physicians and other professions allied to medicine, adding that the paternalistic era of medical infallibility is long gone, with family members and child involved in decision-making. Thereby they are in fact members of the treatment team.

Now, a decade later, a report of a joint working party of the Royal College of Physicians and the Royal College of Psychiatrists in the UK (2003) unambiguously state that, in general hospital practice, where physical and psychological co-morbidity is treated, specialist mental health management is best delivered by a service which should include a nurse, psychologist, social worker and psychiatrist. This endorsement of the role of a psychologist in a multidisciplinary team from a joint working party of such status, is likely to facilitate greater awareness and acceptance of the contribution which psychologists are able to make.

2.5 SUMMARY

This chapter has attempted to define the field of health psychology and to provide an overview of how research and interventions have begun in the context of physical medicine. While earlier research in cardiology, oncology and surgery has been highlighted, attention was drawn to the more recent involvement of psychologists in chronic illness.

Areas in which health psychology have been most visible have been described (Saxby & Svanberg, 1998), followed by a discussion of the problems of chronic illness where families are involved.

Finally, an overview was provided of how contributions have moved from within the discipline of psychology towards inclusion, as full partners, within multidisciplinary teams (Bundy, 1997; Nothard & Kitching, 1999; Sabbath & Stein, 1990).

In the following chapter, attention will first be given to structural barriers which have hindered or prevented psychological involvement within multidisciplinary teams. The historical dominance of medicine will be discussed and how the emergence of psychosocial care became necessary in the context of longer survival rates. Theoretical consideration will also be given to the impact on parenting where it is anticipated that the death of a child will precede that of the parents.

A literature review will also indicate how early attempts were made to establish parents' needs and the shortcomings of these attempts, including the problems of measuring parental functioning.

CHAPTER 3

LITERATURE REVIEW OF THE PROVISION OF PSYCHOSOCIAL SUPPORT AND RESEARCH ON PARENTAL PROBLEMS

3.1 INTRODUCTION

This chapter will refer, in the first instance, to historical barriers to multidisciplinary involvement in the care of families experiencing chronic illness, followed by the emergence of psychological care alongside general medicine.

Before the emergence of health psychology and the concept of inclusion in multidisciplinary teams in general medicine, the medical model was characterized by medical dominance (Parsons, 1978). Medical practitioners were preoccupied with disease and it was their definition of what constituted health care provision that prevailed (Bury, 1997).

This chapter will discuss structural barriers that prevented multidisciplinary support, followed by a critical review of the first early attempts, within a medical context, to recognize parental issues in the management of children with a specific illness, cystic fibrosis.

Improvements in medical treatment with an increased life expectancy and longer treatment, requiring a shift towards an acceptance of multidisciplinary support, will be described.

Finally, ongoing difficulties in research methodology, particularly with parents anticipating their child's inevitable death, will be discussed. Reference will also be made to the sensitive engagement of psychologists in this context.

3.2 STRUCTURAL BARRIERS TO MULTIDISCIPLINARY SUPPORT

3.2.1 Introduction

Structural barriers in the context of an illness, which requires support from several disciplines, requires careful consideration. Unlike acute illnesses which may require a more narrowly focussed treatment regime, a hallmark of cystic fibrosis is the nature of the burden that is placed on parents for the child's care, which involves a complex, physically demanding daily treatment (Drotar, 1992; Matthews & Drotar, 1984; Ievers & Drotar, 1996). This requires constant medical input, including physiotherapy.

This burden, accompanied by the knowledge that there is no cure and that cystic fibrosis is a long-term terminal illness (Bouma & Schweitzer, 1990; Canam, 1986), requiring continuous medical treatment, identifies parents as a distinctive group in terms of emotional distress (Drotar, 1992; Matthews & Drotar, 1984). These factors require very special professional consideration.

3.2.2 Historical overview

The historical dominance of medicine, accompanied by the influence of its structures and institutions, have had a major role to play in the medical model of care, to the relative exclusion of the psychosocial alternative, which will be discussed below.

Therefore, in the critical review of existing literature, which follows, it is necessary to bear in mind that research in the psychosocial field has been compromised not only by the need to be cautious about intrusion into sensitive families' lives but by other factors as well. These include less than adequate research methodology and historical barriers to patient access owing to the dominant role of medicine, particularly physicians, in the management and 'protection' of 'their' patients. In this regard, Karabus (1994) describes this background as antagonistic interdisciplinary rivalry and reliance on individual decision making (usually by a consultant).

Reference is made here to the situation in the 1970's, 1980's and 1990's to indicate a shift away from the dominant role of medicine and to illustrate the paradigm shift towards a biopsychosocial model.

Nearly three decades ago, Menninger (1976) had criticized an ethos in which there was a striking inability of physicians (including psychiatrists) to practice holistic medicine that integrates knowledge of the body, the mind, and the environment.

At that time, Enos and Sultan (1977) had explained that the health care settings had strong medical traditions, involving entrenched social, economic and political relationships.

Tefft and Simeonsson (1979) also observed that psychosocial aspects of health care did not readily lend themselves to the prevailing medical paradigm in which the individual doctor-patient relationship was paramount. They go on to propose that this paradigm was a major reason why medical conditions involving a significant psychosocial component (such as oncology and cystic fibrosis) have historically received little interest or attention from most health care providers.

Pointing out that this was not exclusively a criticism of the medical professions, Meyerowitz and Wyatt (1977) state that psychologists too had done little to break down the psychological, social, and cultural barriers between large health care settings and the communities they serve. The lack of contributions from psychologists in the 1970's within the institutions of general medicine reinforced the notion that health care was the sole responsibility of an elite group of medical experts rather than a cooperative effort between various professional staff, generally, and patients (Tefft & Simeonsson, 1979).

It would be wrong, therefore, to lay the blame for the maintenance of the dominant medical model solely at the door of medicine.

Naylor and Mattson (1973) had also pointed out that, even where physicians might have considered the benefits of overcoming difficulties, they would often be reluctant to define problems in psychosocial terms, fearing psychological labels or focus on family problems, in which they were ill-prepared to intervene.

In this context, parents were faced with fragmented services in which medical services were dominant, to the relative exclusion of the support which other professions may have been able to provide. Families of children with chronic illnesses have, therefore, been managed largely by medical specialists, without the potential benefits of integrated, multidisciplinary teams.

Additionally, the dominance of medical specialists in management had persisted when studies of doctor-patient communication confirmed dissatisfaction with medical consultations (Ley, 1988).

However, examining trends from a sociological perspective, Bury (1997) observes that there was a shift, towards the end of the 1980's, when professional-patient relationships began to operate in what he describes as a contractual model, in which doctors and patients began to expect different patterns of behaviour and, more importantly, outlook, from each other. He goes on to identify several sources of change, which had implications for changing relationships and the fostering of a contractual model.

These include changes in illness patterns (especially the growing importance of chronic illness), the decline of medical authority (brought about by the dissemination of medical information), the influence of social movements, the growth of legal, managerial and consumer challenges to medicine and increasing evaluation of health care (linked to notions of accountability).

One of the changes in illness patterns which Bury (1997) mentions, in his critique, is the role of palliative care that is presently required over long periods of time rather than for those facing imminent death. This requires a multi-disciplinary approach to the alleviation of suffering at any point in the disease trajectory (O'Boyle, 1997). Chronic childhood problems, therefore, require skilled intervention involving both medical and psychological approaches (Bradford, 1997).

It will also mean that future research projects, on how this will be best achieved, will take into account the political agendas of specific groups and their active involvement in research design (Bury, 1997).

Political agendas have progressed to include the restructuring of health care institutions and the re-definition of these institutions, described by Bury (1994) as 'providers' or 'producers' and patients as 'consumers' in the United Kingdom. This has contributed to the emergence of a 'contractual' or 'consumerist' relationship between health care professionals and patients as 'equal partners' (Bury, 1997).

Notwithstanding the anticipated changes, more visible change will occur when integration of psychologists and physicians at the training level is developed (Gallo & Coyne, 2000). This may be easier said than done when one notes the research by Leipzig et al (2002) which demonstrates that medical students, although positive about multidisciplinary approaches, were less so than nurses or social workers. While these differences occur, Minore and Boone (2002) describe multidisciplinary teams collaborating on a practical level even with paraprofessionals in Canada and they argue for an extension of the information on multidisciplinary practice in health science education programmes to promote this development.

Indeed, Patterson (2001) points out that requests for collaborative training are being made from many settings (e.g. health service organizations) and that mental health specialists are being re-trained to work in primary care. More pertinently, Patterson (2001) suggests that physicians also need re-training to effectively work in a collaborative setting and that they ought to be interested in psychosocial treatments.

In their work on barriers and enhancements to physician-psychologist collaboration, Kainz (2002) points out that one of the difficulties for physicians during training is that they receive inadequate information on psychosocial interventions. In this regard, Patterson (2001) remarks that, while requests for collaborative training are being made from different sources and, while physicians might need retraining, they must firstly have an interest:

For collaborative care to work, physicians must have some interest in the non-biomedical aspects of their patients' lives. They must have some curiosity about psychosocial treatments and be able to recognize clinical problems such as somatization, depression, and anxiety when they conduct patient interviews. (p. 53).

The need for real change is suggested in an editorial by Gallo and Coyne (2000) in the *Journal of the American Medical Association*:

Merely placing mental health personnel into primary health care settings may be too simple a solution ... Team work is needed ... Real change may be more likely by learning to integrate the training experiences of physicians with mental health specialists and the training of mental health specialists with primary care physicians (p. 1571).

Moreover, Kainz (2002) states, most physicians currently believe that patients resist being referred to psychologists. On a practical level, she recommends that psychologists who practice in a medical setting should appreciate that they are visitors to another culture and they need to make an effort to build collaborative relationships.

In an insightful commentary on collaborative care, Waters (2001) reminds one of some issues, at a deeper level, which have hindered the progress of multidisciplinary teams. These include attempts to alter the doctor-patient dyad, which is the basic, historical paradigm of medical care. Furthermore, he argues that collaborative work addresses medicine's 'dirty secret', namely that, while medical care is divided more or less equally between the technical sick-cure needs of the patient and the complex psychosocial needs, training and financial resources are heavily biased in favour of institutionalised medicine.

More pertinently, however, Waters (2001) remarks that collaborative care inherently makes medical care a matter of education as well as service. He concludes that medicine is at a critical point, with physicians wrestling with the question of merely remaining 'fixers' or if they will embrace the broader notion of healing; helping patients within a multidisciplinary treatment regime to get better in body, mind and/or spirit.

3.2.3 Emergence of Psychosocial Care

Whereas Bury (1997) had provided a useful sociological perspective to explain shifts in institutions and patient management, Lubin, Nathan, & Matarazzo (1978) observed that, during the previous decade, the involvement of psychologists in health care settings had

begun to increase steadily. They mention several reasons for this progress, namely, the creation of new interdisciplinary roles, the development of training opportunities, and the publication of topical research in both psychological and medical journals.

The greater visibility of articles referred to by Lubin et al. (1978) was accompanied by an awareness of the need for multidisciplinary teams in paediatrics. Credit is given by Burchenal (1975; 1976) to paediatric oncologists for the first demonstration of the value of multidisciplinary management of patients. Burchenal (1975) also proposed that the multidisciplinary model should be used in the treatment of other diseases.

It is also necessary to contextualise a review of the literature by noting that parents have been burdened not only by daily medical treatment but also by psychological sequelae, such as emotional distress (Drotar, 1992; Matthews & Drotar, 1984) and coping with the knowledge of the terminal nature of the illness (Bouma & Schweitzer, 1990; Canam, 1986). Melnyk et al (2001) point out that, for such parents, their experience of stressors is usually multiple and ongoing. Cohen (quoted in Melnyk et al., 2001), as well as Wereszczak, Miles and Holditch-Davis (quoted in Melnyk et al., 2001) state that it is the uncertainty of the child's condition and his or her potential outcome which contributes to the situation as a major stressor.

One ordinarily expects that, when knowing that an illness is terminal and, at the same time, being uncertain of its duration, will have profound effects on parental emotions, since a degree of control is diminished. Kidel (1988) eloquently puts it as follows:

Illness (and death), however, are manifestations of the unpredictable, the dark forces which form an integral part of life, and cannot easily be brought under human control. Diseases sometimes vanish as mysteriously as they appear; others linger recalcitrantly, unaffected by our efforts to heal. There is, therefore, something very deeply unsettling about becoming ill, for we are forced into a conscious or semi-conscious awareness of the very uncertainty of our being, a sense that our life is essentially beyond our control. Illness involves an often critical confrontation between our self-determined stance in life and the unpredictable autonomy of Nature. (p. 7)

Melnyk et al (2001) conclude that, while chronic illness is a stressful experience for parents, with potentially long-lasting, negative outcomes, the empowerment of parents to function more effectively ought to contribute to improved outcomes.

3.2.4 Parenting and attachment

Distress for parents of children with cystic fibrosis occurs early in the child's life. This has implications for the relationship between the parent and child. It is during a period when mother-infant interactions, according to Bowlby (1969), contribute towards the development in the young child of an emotional attachment during a critical developmental phase. Central to his theory is the phenomenon of species-specific behaviours in infants that are effective in eliciting parental proximity and protection. Van Ijzendoorn, Goldberg, Kroonenberg and Frenkel (1992) write, in this regard, that, while attachment theorists have argued that parental behaviour plays a more powerful role than infant behaviour in shaping the quality of attachment, there are, in normal groups, some studies that support this assertion (Belsky, Rovine & Taylor, 1984) while others contradict it (Lewis & Feiring, 1989).

Nevertheless, the infant's relationship with a parent is widely recognized as an important influence on subsequent development, particularly with regard to vulnerability or resistance to psychopathology (Goldberg, Gotowiec & Simmons, 1995).

However, whereas attachment theory is described to explain the significance of mother-child interaction during normal development, the diagnosis of a life-threatening illness, according to Bradford (1997), is similar to bereavement for parents, producing grief reactions, followed by stages of shock and disbelief, denial, anger, adaptation and adjustment (Raphael, 1984). In this regard, Eiser (1996) argues that the bereavement process begins as the child is diagnosed, with the onset of a future which is uncertain, requiring family lifestyle changes and the emotional demands of treatment on the family.

Therefore, it will be argued here that this invites consideration that the interactions between parent and child will be different, resulting in a disturbance of normal patterns of attachment. In this regard, Murray (quoted in McKenry & Price, 1994), points out that,

when the sequence of death differs from societal order, problems occur. The death of child is contrary to expected developmental progression.

Bradford (1997), therefore, suggests a more appropriate model, in which parents suffer from 'chronic sorrow' (Olshansky, 1962), which is characterized by periods of coping, punctuated by periods of mourning. The term 'chronic sorrow' appears to be particularly descriptive since it highlights emotional reactions on the part of the parent which, in closeness to the young child, has the potential of influencing the early experiences of emotion. As Campbell (1994) reminds one, the family is the primary social context in which health promotion and disease prevention takes place. He goes on to say that parents' health-related behaviours influence how children adopt health-related behaviours and that family support is an important determinant of an individual's ability to change an unhealthy tendency.

Klass and Marwit (quoted in McKenry, 1994) are critical of attachment and psychoanalytic models, arguing that they are inadequate, since both parents are experiencing anticipatory grief, and are grieving with their own 'unique timetables'. They argue that an underlying emotion of survivor guilt occurs.

If parents perceive their children as unusually vulnerable, Cappelli, McGrath, MacDonald, Katsanis and Lascelles (1989) remind one that parental overprotection has often been clinically associated with the psychological maladjustment of children with a chronic disease. In a study comparing parents with cystic fibrosis children of school going age with parents of a control group, they did not find significant differences of care and overprotection on the part of parents in the two groups. Admitting to limitations of study because of a small sample size (28 mothers, 19 fathers) and that results may be an artifact of this small sample size, they nevertheless point out relevant aspects of interaction between parents and their children, namely care and overprotection.

What Cappelli et al (1989) were able to confirm, using the Parental Bonding Instrument (Parker, 1983; Parker, Tupling & Brown, 1979), was that both parents within the cystic fibrosis group reported similar degrees of care and overprotection. However, within the control group, consisting of parents with healthy children, mothers scored higher on care, while fathers scored higher on overprotection. They speculate on their findings by saying

that this could be because parents of healthy children apply the more traditional roles of parenting, whereas, because of the demands of chronic disease on the family, mothers and fathers often share the responsibility of care. This is an interesting speculation because it implies a shared degree of interaction between the child and both parents.

In this regard, Ievers and Drotar (1996) reiterate that research findings on parents of children with cystic fibrosis have had major limitations because of reliance on parental self-report measures and that the majority of these studies are limited to the maternal perspective. Indeed, this may account for different findings such as the study by Quittner, DiGirolamo, Michel and Eigen (1992). Using the Parenting Stress Index (Abidin, 1983), they found that, within families, mothers reported significantly higher levels of role strain than fathers (Hoteling's $T = 3.61$, $F(1,26) = 12.63$, $p < 0.001$).

Ievers and Drotar (1996) observe, further, that most studies do not easily translate into practical implications for day-to-day practice, adding that findings based on general, non-specific measures do not translate into practical application. However, most importantly, they state that, with the inclusion of data from fathers, one would gain a more well rounded picture of a family's adjustment.

Adjustment would appear to play a central role. In this regard, Bradford (1997) points out that there is a need to adjust to an illness that will affect the child for a lifetime, namely limitations and uncertainty of the child's future. Parents, as part of an ongoing adjustment, would be playing a central role with procedures, e.g. physiotherapy, feeding, and take into account disruption to normal family life.

Noting these issues, it facilitates an understanding of why parental problems were, and indeed remain, very difficult to research and why early attempts to gather data, described in the section which follows, have been inadequate.

3.3 LITERATURE REVIEW

It is necessary to consider the shortcomings of early research because these reports not only indicate inadequacies which occurred from a lack of multidisciplinary involvement

but also because health psychology was hampered by relative lack of access to a predominantly medical environment.

It is important to note, from the examples that follow, that interest in the plight of distressed families is not new. However, health psychology had not reached the degree of development required for sophisticated research, at least not from the vantage of contributions within a multidisciplinary framework.

The impact of cystic fibrosis on families had been the focus of numerous descriptive and empirical projects from the late 1960's (Ievers & Drotar, 1996). Most relied on clinical impressions or abbreviated projective techniques such as the Draw-A-Person or the House-Tree-Person Test, lacking the means to assess the validity of such impressions (Gayton & Friedman, 1973).

In their examination of the needs, concerns and coping ability of parents of children with cystic fibrosis, Hymovich and Baker (1985) observed that previous research reports had been primarily descriptive. They go on to point out that, while they had contributed to our understanding of the impact of chronic illness on families, the majority of studies had based their findings on interviews with one member of a family (usually the mother).

Hymovich and Baker (1985) also remark that researchers were beginning to develop assessment instruments, such as the CHIP – Coping Health Inventory for Parents (McCubbin, McCubbin, Cauble & Nevin, 1979) and the Impact-on-Family Scale (Stein & Riessman, 1980) to assess the impact of the condition on the family or the coping strategies of family members. Hymovich and Baker (1985) report the use of The Chronicity Impact and Coping Instrument: Parent Questionnaire (Hymovich, 1983) on parents (N=161) with which they were able to confirm the following concerns. Parents were most concerned about their child's future and wanting to make their child comfortable, identifying further that parents wanted information on their child's condition (73%), physical development (66%), emotional development (62%), diet and nutrition (57%), physical care (56%), social development (55%), intellectual development (52%), expected child development (53%), help with managing minor childhood illnesses (42%), dental needs (38%), help with managing behaviour (32%), play and recreation (31%), play and learning experiences (29%), sleep habits (24%) and genetic counselling (23%).

According to this study by Hymovich and Baker (1985), the coping strategies mentioned most often were asking a physician (92%), nurse (88%), other parents (63%), clergy (16%) and others, not specified (48%) for information.

Although this early study could be noted for its attempt to develop an assessment instrument and to improve research methodology, Hymovich and Baker (1985), to their credit, acknowledge the limitations of their findings. They point out that their findings could not be generalised because only a majority of patients calling at a particular Cystic Fibrosis Centre participated.

Other early studies had been criticized for emphasizing the pathology of mothers caring for their children, being largely anecdotal (Bradford 1997) and, according to Fielding (quoted in Bradford, 1997) with reliance on subjective evaluations and uncontrolled investigations, lacking therefore in methodology with which an experimental and control group may be properly compared.

In an early review of the literature, Gayton and Friedman (1973) reported that the first major study on the psychological aspects of cystic fibrosis was conducted by Turk (1964) in the USA. Gayton and Friedman (1973) state that he used self-administered questionnaires (not specified) which focussed on the psychosocial consequences of having a child with cystic fibrosis. This was completed by a small sample of 25 families. He concluded that psychosocial stresses prevented the participants from maintaining usual patterns of family relationships, with an impairment of communication between family members.

Gayton and Friedman (1973) also report that, in a smaller study of 11 families in Canada, Lawler, Nakielny and Wright (1966), using psychiatric interviews, observed that eight of the mothers were judged to be clinically depressed, and six parental diads revealed marital discord. Results were presented merely in a descriptive fashion.

During this same era, Kulczycki et al (1969) conducted interviews with parents to reveal problems that have persisted over the last thirty years. Parents indicated in their responses that they were experiencing feelings of helplessness, communication difficulties, and an inability to deal with their children's feelings and fears regarding the illness and the issue

of death. To help with the management of the illness, the authors concluded that a continuing care programme, which was sensitive to the psychosocial needs of the child, was necessary.

Further studies at this time found that parental needs were difficult to fulfil (McCollum & Gibson, 1970) and mothers' reactions were primarily feelings of depression and guilt, with a tendency to deny the severity of the child's medical condition (Tropauer, Franz & Dilgard, 1970).

While most of these early studies relied on clinical impressions, without an assessment of the validity of such impressions, Gayton and Friedman (1973) comment that they nevertheless revealed psychosocial consequences for families. They add that it seemed imperative that physicians concern themselves with the psychosocial aspects of cystic fibrosis.

It is apparent from these comments that emphasis had not yet been placed on appropriate research methodology, nor had psychological input (either as support or through appropriate research) been motivated in the context of an integrated, multidisciplinary team. Rather, it appeared to be driven by descriptive information obtained in a medical, psychiatric context.

It needs to be noted that these shortcomings were not exclusively a failure in the field of cystic fibrosis, since methodological inadequacies could also be found elsewhere, e.g. in oncology (Van Dongen-Melman & Sanders-Woudstra, 1986). In their literature review of the psychosocial aspects of childhood cancer, they concluded that methodological and theoretical shortcomings in research had frequently jeopardized studies through biased selection of children and families, incomplete descriptions of sample group and design, inappropriate use of design and of research instruments, and lack of theory.

Nevertheless, despite these shortcomings and fragmented efforts, Van Dongen-Melman and Sanders-Woudstra (1986) note that there had now been exploration of psychosocial issues in the context where a disease, once regarded as an acute, fatal illness, had become a chronic, life-threatening one.

While acknowledging these criticisms and observations, these studies nevertheless remained important for at least two important reasons. They revealed difficulties and inadequacies in the gathering of data. They also drew attention to the need for research on psychosocial problems of families facing life-threatening illnesses.

Therefore, these early studies highlighted a deserving area for improved psychological enquiry and support, in at least two chronic illnesses where long-term parental involvement was required.

3.4 RESEARCH METHODOLOGY ISSUES

3.4.1 Emerging problems

Two major problems appeared to be emerging simultaneously for researchers in the area of cystic fibrosis. One problem was the need to overcome shortcomings in research methodology. The other was the increasing needs of parents as they anticipated longer survival periods for their children.

These two problems presented researchers with an opportunity to address areas of great need.

Continuing from a medical perspective, Kollberg (1982) explored the sociomedical conditions of Swedish families with cystic fibrosis children, over a twelve year period. Using a central registry of all patients in the country, he noted that the median survival age had increased to 16,0 years by 1977 and that the number of patients had increased from 116 to 200. While this is an old study, it is mentioned here to illustrate the points that, two decades later, life expectancy has now almost doubled (Ievers & Drotar, 1996).

A shift in survival age towards adulthood, with an increase in the number of patients in the country, would appear sufficient justification for concern about the increasing implications for management, parental involvement and availability of health care, including psychosocial support.

Of particular significance in this study by Kollberg (1982), however, was the reconfirmation of the heavy burden placed on parents, with the following needs indicated by them:

- Intensive research on the basic defect and medical treatment
- The need to put pressure on politicians for better social welfare
- Medical personnel should be given more information and education about the disease

In a more recent review of research on parental functioning, Ievers and Drotar (1996) observed that advances in medical treatment continued to prolong life span, with the mean life expectancy increasing to 29 years. They go on to state that this increased life expectancy makes it essential that professionals explore ways to improve the quality of life of those affected by the disease.

While parents are closely involved in the ongoing and more prolonged treatment of their children, their involvement is influenced by several important considerations:

- Treatment involves a complex, physically strenuous daily treatment regimen (Drotar, 1992; Matthews & Drotar, 1984)
- They must cope with emotional distress as well as with the social demands, threats and barriers associated with the illness (Drotar, 1992)
- They must cope with the terminal nature of the illness, the limited life expectancy, and decisions on when and how much to disclose to their children (Bouma & Schweitzer, 1990; Canam (1986).

However, a shift in emphasis, to one of managing a chronic condition over a long period of time, anticipating inevitable death, makes much of the previous research on the impact of the illness on family functioning outdated (Ievers & Drotar, 1996).

Bradford (1997) also remarks that inconsistent reports concerning the psychosocial effects of chronic disease are often the consequence of researchers failing to put the child's illness in context.

At the same time, the intricate relationships, between physical and psychological factors in terminal illness, remains significantly under-researched and the mechanisms of human adaptation in progressive disease is little understood (O'Boyle, 1997).

3.4.2 Problems in measurement of parent functioning

In their review article on family and parental functioning in cystic fibrosis, Ievers and Drotar (1996) point out that, irrespective of the type of design used, studies have been limited by recurrent methodological problems, including the reliance on self-report (mostly by mothers as informants), a lack of clinical relevance (meaning that the abstract nature of measures do not easily translate into practical implications for day-to-day practice) and relatively small sample sizes and the use of single-site sampling.

While previous research may have been inadequate in design and outdated, one needs to acknowledge that lengthy or elaborate research with parents, who are already burdened with long-term terminal illness, is inappropriate. Any research of this nature needs to strike a balance, taking into account the sensitive area, limited access to participants, as well as being mindful of an appropriate intervention.

Interventions and evaluation of parent functioning have the potential of providing, clinically relevant indications of the influence on their children's functioning. However, as Ievers and Drotar (1996) point out, only five articles (Schroder, Casadaba & Davis, 1988; Stark, Brown, Tyc, Evans & Passero, 1990; Stark et al., 1993; Stark, Powers, Jelalian, Rape & Miller, 1994; Stark et al., 1996) on evaluations of interventions with parents of children with cystic fibrosis have been published since 1981.

When attempts have been made to focus on a particular aspect, such as familial factors in coping with adherence to prescribed medical regimes, Ricker et al (1998) also report that this has been studied to only a limited degree (Koocher et al., 1990).

A more recent overview of literature by Carew (2001) pertaining to the mental health of children with cystic fibrosis revealed that clinic-based studies have either adopted a broad perspective and studied chronic disorders as a whole or narrowed the focus to a single disorder. She also re-confirms that there have been relatively few studies focussing on

children's adjustment and cystic fibrosis and suggests further that emotional disturbances go undetected in conventional studies owing to the use of social adaptation measures to determine psychological functioning.

Carew (2001) makes two further conclusions that pertain to the motivation for this study, namely that the psychological effects of cystic fibrosis require further exploration, and that sensitivity to the distress of families is necessary.

Awareness of services and research has been facilitated by the growth of self-help groups, campaigning organizations, social movements and media attention, all of which have created a new environment for the conduct of research on chronic illness (Bury, 1997).

However, in this environment, awareness, interest by professionals and self-help groups have not necessarily contributed towards a reduction of uncertainty for parents. Although their remarks were made in a study of childhood leukaemia rather than of cystic fibrosis, Comaroff and Maguire (1981) pertinently points out that modern medical technology has helped reduce uncertainty for parents but, at the same time, they say, modern medicine has revealed more of what is not known. Maguire (quoted in Corney, 1991) remarks in this regard that it is often the period of uncertainty, of not knowing, which is the most difficult period to bear.

Bury (1997) remarks that the transformation of fatal diseases into chronic ones may create unintended consequences, which then have to be managed by both professionals and patients alike.

When Kollberg (1982) found in the Swedish study that life expectancy was improving, he also revealed the emergence of pressure for better social welfare and the need for information and education about cystic fibrosis. A few years later, Hymovich and Baker (1985) conducted a study in an American environment with the aim to sensitise health professionals about parental needs, concerns and coping strategies, and to provide guidelines for intervention that are specific to the expressed needs of parents.

Using the Chronicity Impact and Coping Instrument: Parent Questionnaire (Hymovich, 1981; 1983), Hymovitch and Baker (1985) concluded, in their study that there were no

significant differences noted between responses of mothers and fathers on their perceptions of concerns, needs and coping strategies, their greatest needs being information about their child's condition (73%), physical development (66%), emotional development (62%), and diet and nutrition (57%).

According to Mullins et al. (1991) and Thompson, Gustafson, Hamlett and Spock (1992), parents who use emotion-focussed strategies (such as avoidance, self-blame and wishful thinking) show greater degrees of distress than parents who engage in problem-focussed strategies (such as seeking social support, cognitive restructuring and seeking information).

Distress would appear to be potentially greater in the absence of social support and information, if one considers the following.

In studies by Quittner, DiGirolamo, Jacobsen and Eigen (1991) and Quittner, DiGirolamo, Michel and Eigen (1992) it was found that mothers experienced higher levels of role strain than fathers. However, mothers who received more support from their husbands, showed better adjustment (Nagy & Ungerer, 1990). These studies, according to Miller, Jelalian and Stark (1999), provide support for the 'stress-buffering effect' of social support on maternal adjustment.

Additionally, Quittner et al (1992) point out that, while mothers and fathers reported elevated levels of depressive symptomatology, mothers reported significantly greater symptomatology than fathers.

According to Maguire (quoted in Corney, 1991), distress can usually be reduced by providing information about the illness and its treatment. However, he goes on to caution that the provision of information is not always straightforward because it often needs to be provided in a sensitive manner after exploring what the individual already understands, wants to hear, and can cope with.

According to Ievers and Drotar (1996), practitioners should expect parents to be burdened, show signs of distress, require support from a comprehensive care team, including psychosocial intervention.

Therefore, the sensitive engagement of psychologists with distressed parents to ascertain their psychological functioning and needs, coupled to the provision of an appropriate psycho-educational support programme, would appear to be an appropriate contribution within multi-disciplinary health psychology.

3.5 SUMMARY

This chapter has referred to historical barriers, within a medical context, to effective multi-disciplinary support for families managing chronic illness. It discussed how psychologists were beginning to contribute in a context of medical dominance and antagonistic interdisciplinary rivalry (Karabus, 1994; Waters, 2001) and how shifts towards a multi-disciplinary model emerged (Bury, 1997; O'Boyle, 1997).

The central role of the parent in management of the child, with reference to attachment theory (Bowlby, 1969) and chronic sorrow (Olshansky, 1962) is relevant to a situation where the child's death is anticipated to be ahead of the parents.

This was followed by a review of the first attempts to research the psychosocial needs of parents and to address their broader needs. Attention was drawn to the fact that, while these early attempts were relatively unsophisticated and fragmented, they began to highlight deserving areas of further research.

Finally, inherent difficulties while working with families coping with terminal illness, and the unique problems associated with research in this area, was discussed.

In the chapter which follows, a pilot study, in the form of a needs analysis of parents with children who have been diagnosed with a serious illness, will be described. It was a preliminary exercise before the implementation of the main study.

CHAPTER 4

ASSESSMENT OF PARENTS' EVERYDAY NEEDS

4.1 INTRODUCTION

While the literature may provide a comprehensive indication of parents' needs during times of crisis, work within a defined area may be undertaken more elegantly if one is aided by specific information on their needs. Such information ought to be gathered in a systematic manner and then analysed to determine which needs are most important.

4.2 NEEDS ANALYSIS

A needs analysis constitutes the first phase of this study. While a logical first step is to establish from parents what their needs might be, this is possible on two levels:

- Their everyday unmet needs as they are perceived in a practical sense
- The degree to which the crisis has affected them emotionally

This exercise was also carried out with the intention to use it as a familiarisation process, objectives being to become comfortable with the population of subjects and to facilitate an appropriate demeanour in preparation for the more demanding main study. The needs analysis would also provide an opportunity to discover problems in the implementation of the main study not yet contemplated.

4.2.1 Method

A Needs Analysis was conducted by approaching parents and asking them to complete questionnaires which would identify their everyday practical needs and difficulties in psychological functioning.

4.2.2 Participants

The subjects for the Needs Analysis were 26 parents (13 male and 13 female) of children who were diagnosed with a life-threatening illness. They were on the list of a Social Worker of a hospital, whose task it was to co-ordinate services for these families in the area.

Parents consisted of two groups, one of parents whose children had been diagnosed with cystic fibrosis (N=14), the other of parents whose children had been diagnosed with cancer (N=10).

4.2.3 Measuring Instruments / Questionnaires

The measuring instruments or questionnaires used were intended to identify parents' perceived unmet service needs as well as their psychological functioning.

4.2.4 Perceived unmet service needs

Parents' everyday practical needs were determined by asking them to complete a Perceived Unmet Needs Scale (Appendix A).

This 22-item questionnaire had been developed by Duncan and O'Flynn (1994) of the Department of Health's pilot project for children with life-threatening illnesses in East Suffolk, a major objective of their project being to identify and recommend opportunities for improved service provision in the Department of Social Services.

Although this questionnaire identifies practical problems (such as financial and housing difficulties) it also assists in determining unmet needs that could be addressed through a form of psycho-educational support (e.g. informational requirements, advisory input or counselling needs).

4.2.5 Psychological functioning

Parents' problems with aspects of their psychological functioning were determined by asking them to complete the following psychometric questionnaires:

4.2.5.1 The State-Trait Anxiety Inventory

The State-Trait Anxiety Inventory, devised by Spielberger, Gorsuch, Lushene, Vagg and Jacob (1970), has been used extensively in research and clinical practice for measuring state and trait anxiety. In particular, it has also been used extensively to assess levels of anxiety during times of unavoidable real-life stressors such as medical treatment.

Regarding its internal consistency, Spielberger et al (1970) report that the overall median alpha coefficient for the state anxiety scale is 0.92. They report also, with regard to its validity, that it correlated 0.70 with the Cornell Medical Index, indicating that a large number of medical symptoms are associated with high scores on the scale.

The State-Trait Anxiety Inventory continues to be reported as a validated generic measure of anxiety (van der Bijl, de Weerd, Cikot, Steegers, & Braspenning, 2003; Sesti, 2000) and is used in diverse settings, including the impact of cancer on adolescents (Allen, Newman & Souhami, 1997), anxiety during teacher training (Konen & Horton, 2000), aerobic exercise and exercise intensity (Cox, Thomas & Davis, 2000), surgical significance of therapeutic touch (Ramnarine-Singh, 1999) and effects of maternal anxiety on perception of fetal movements (Sjostrom, Thelin, Marsal & Valentin, 2003).

4.2.5.2 The General Health Questionnaire

The General Health Questionnaire, developed by Goldberg and Williams (1991), was designed as a screening test to detect psychiatric disorders in community settings, such as among primary care patients or among general medical outpatients.

This 30 item questionnaire identifies persons who are impeded in carrying out their normal "healthy" functions and who are in distress. According to its manual (Goldberg, 1978), it

identifies people who have a mixed affective neurosis with symptoms of both depression and anxiety together with patterns of physical symptom formation and, almost invariably, social dysfunction.

Split-half reliability studies by Chan (1985), Chan and Chan (1983), Goodchild and Duncan-Jones (1985) and Keyes (1984) show reliability coefficients between 0.82 and 0.93. Regarding its validity as an indication of psychiatric disorder, there is evidence from studies by Goldberg, Rickels, Downing and Hesbacher (1976), Harding (1976), Mann (1977) and Tarnopolsky, Hand, McLean, Roberts and Wiggins (1979) to demonstrate that it correlates highly with other clinical assessments such as the Clinical Interview Schedule of Goldberg, Cooper, Eastwood, Kedward and Shepherd (1970).

The use of the General Health Questionnaire has continued to be used throughout the world. Politi, Piccinelli and Wilkinson (1994) investigated its internal consistency, validity and factor structure in Italy and concluded that it is a reliable instrument, as indicated by a Cronbach alpha of 0.81. Similarly, in Iran, Montazeri et al (2003) concluded that the translated version is a reliable and valid instrument to measure minor psychological distress in young people and has a good factor structure.

In a summary of evidence for the use of screening tests in primary care settings in the USA, Johnstone and Goldberg (quoted in Pignone et al., 2002) report its continued use, as does Lewis (quoted in Pignone et al., 2002) in primary care settings in London. Tait, Hulse and Robertson (2002) reports that the General Health Questionnaire has been extensively used and validated with adults but their review article also identifies eight studies on its use with adolescents. A more recent investigation by Tait, French and Hulse (2003) concluded that the General Health Questionnaire is a valid index of psychological wellbeing when used on adolescents in Australia. In hospitals in the UK, Paice, Rutter, Wetherell, Winder and McManus (2002) used the General Health Questionnaire to identify psychological morbidity of pre-registration house doctors, while in Canada, Nickell et al (2004) used it to determine the psychological effects of a virus on hospital staff.

4.3 PROCEDURE

Parents were interviewed by appointment in their own homes, at their convenience. Each interview was done consistently by the researcher. The purpose of the needs analysis was explained, after which each parent was asked to complete three questionnaires.

One of the questionnaires, the General Health Questionnaire, was followed by a semi-structured interview, in which more detail on their responses was sought. The researcher referred to their responses on the General Health Questionnaire where clarification was necessary. This was done with the objective of checking that a contemplated support programme, to be used in the main study, would address their identified needs.

4.4 RESULTS

Of the 14 parents of children with cystic fibrosis, 11 completed the questionnaires. The three parents who did not were either not available at the time of the arranged interview or did not return their questionnaires.

Of the 12 parents of children with cancer, seven completed the questionnaires. The five parents who did not were either not available at the time of the arranged interview or did not return their questionnaires.

The results of the Needs Analysis are summarized in two sub-sections below:

4.4.1 Everyday practical needs

For the purposes of this study, attention is paid only to the everyday practical needs of parents whose children have cystic fibrosis, since the focus during phase two of the research programme was intended to be on this group.

The six most frequently reported needs of a practical nature, in which psychological input could be incorporated within a support programme for parents of cystic fibrosis children, are indicated in Table 4.1 below. The findings for parents of children with cancer are indicated alongside for comparison.

Parents of children with cystic fibrosis rated information, services, advice on their children's condition, and help with teaching positive skills, in that order. The sample of parents who completed the questionnaire was small (N=11) but their needs appear to be similar to those reported in the literature.

Table 4.1

Most Frequent Needs of Parents as Reflected on the Unmet Service Needs Questionnaire

	Percentage of Parents	
	Cystic Fibrosis	Cancer
- Information on services	55%	29%
- Emergency services for times of difficulty	55%	57%
- Advice on the child's condition	36%	43%
- Help with teaching the child positive skills	36%	14%
- Help with coming to terms with the child's condition	27%	29%
- Chance to discuss child's progress / development regularly	27%	43%

4.4.2 Psychological functioning

Parents' responses on the General Health Questionnaire confirmed that the majority were impeded in their normal functioning.

Scored for "caseness", and adopting a score of 5 as the cut-off recommended by Spielberger et al (1970), Table 4.2 below gives an indication of the extent of poor functioning amongst these parents.

Table 4.2

Identification of Parents as Risk Cases as Determined by the General Health Questionnaire

	Percentage of Parents	
	Cystic Fibrosis	Cancer
Percentage of parents as risk cases	63.6%	75%

Parents' responses on the State-Trait Anxiety Inventory were scored quantitatively to examine differences between the two sub-groups (cystic fibrosis and cancer). Parents of cystic fibrosis children (Mean=39.81; SD=9.9) scored lower than parents of cancer children (Mean=51.86; SD=11.81) on trait anxiety ($F=160.88$; $df=1,16$; $p<0.01$). The null hypothesis of no difference between the means has to be rejected.

Similarly, with the analysis of variance of raw state anxiety scores, the difference between the means of parents of children with cystic fibrosis (Mean=38.72; SD=14.87) and those whose children have cancer (Mean=49.28; SD=20.06) was investigated. Differences were statistically significant ($F=58.1$; $df=1,16$; $p<0.01$).

Thus, the data revealed, firstly, that parents of children with cystic fibrosis experience significantly less anxiety than parents whose children have cancer. This finding is true for both state and trait anxiety.

4.5 DISCUSSION

The results from the needs analysis re-confirm findings in the literature that parents of seriously ill children have special needs which could be addressed through appropriate psychological intervention, one form being an informational support package.

The responses to the General Health Questionnaire confirmed a large number of cases.

The pilot study indicated that parents' problems appear to be predominantly informational needs and symptoms indicative of psychological difficulties.

One may also speculate that parents of children with cancer experience more elevated levels of anxiety, probably due to greater clarity about the expected length of life remaining for the child. In the case of cystic fibrosis, while death is inevitable, there is greater hope of an increasing lifespan, possibly moderating anxiety associated with the immediacy of a terminal illness.

From this confirmation, it would seem appropriate to investigate if a support programme, ideally with strong informational and a counselling component, might address the parents' needs and, through this process, alter their symptoms of anxiety and depression.

With this objective in mind, Phase 2 of the research was intended to determine the efficacy of an informational support programme, consisting uniformly of printed material and a counselling programme (in question and answer format) on audio cassette developed by paediatricians and other professional people concerned with the treatment of cystic fibrosis.

This support package was offered to a population of parents of children with cystic fibrosis, for whom the package was specifically designed by the Cystic Fibrosis Trust in London. Parents were assessed to determine if the support package had an impact on certain aspects of their psychological functioning.

CHAPTER 5

THE COMPILATION OF AN APPROPRIATE INFORMATIONAL SUPPORT PROGRAMME FOR PARENTS OF CHILDREN WITH CYSTIC FIBROSIS

5.1 INTRODUCTION

Chapter 4 has described how the needs of parents, experiencing problems with the management of their terminally ill children, have been reconfirmed in a small-scale needs analysis.

This chapter will describe how an integrated and comprehensive informational support programme for parents of children diagnosed with cystic fibrosis, and based on their confirmed needs, was compiled. It will do so by describing how it was influenced by an awareness of the paradigm shift from strictly biomedical models towards a synchronous model for health described by Jasnoskie and Schwartz (1985).

Mention will be made of research projects by Connolly (1993) and While (1999) which reveal the support required by parents. The support package devised for this study will then be described.

5.2 THEORETICAL CONSIDERATIONS

5.2.1 Introduction

Theoretical considerations are necessary because the compilation of the informational support programme, the use of it by parents, the involvement of the psychologist in research and support within medical departments, invites the demonstration of a biopsychosocial approach. It incorporates the consequences of a medical diagnosis, including identified needs, aspects of psychological functioning and the effects of an appropriate informational support programme.

5.2.2 The biopsychosocial model

The biopsychosocial model of health and illness (Engel, 1980) represents an attempt to integrate the strictly medical aspects of disease (e.g. viruses and bacterias) with its psychological and social implications (e.g. behaviour, beliefs and coping). Interventions in the field of health psychology therefore take into account the biological aspects of illness but also require that the patient and supporting family take some of the responsibility for treatment (Ogden, 2000).

If one agrees with Gilbert (2002) that the biopsychosocial approach is holistic but also more than that, it is because there is the temptation to confuse the biopsychosocial approach with psychiatry's use of the biomedical model (Kiesler, 1999; Meehl, 1995). This confusion is understandable against the history of the association of clinical psychology and psychiatry.

However, the biopsychosocial context of this study goes beyond the 'medical dominance' inherent in a biomedical model to expand conceptual boundaries, thereby promoting, what Jarnoski and Schwartz (1985) describe as, a paradigm which applies general systems theory to a biopsychosocial structure depicting spheres of influence upon human functioning. It is no longer considered sufficient to provide biomedical care without appropriate attention to the psychological and social impact of a condition and its treatment (Sabbeth & Stein, 1990).

The manner in which psycho-educational forms of support have been influenced, may be understood by what Jarnoskie and Schwartz (1985) described as a synchronous model for health. In such a synchronous model, there has been a convergence of the fields of science, medicine and psychology, thereby promoting a more sophisticated understanding of the influences affecting human experience and behaviour.

In their articulation of this model, Jarnoskie and Schwartz (1985) mention that, to help to understand the tendency towards an integrated health delivery system, one should note that science, medicine and psychology have revealed the merging of separate fields into new disciplines. Psycho-neuroimmunology and biochemistry are given as examples.

Similarly, the paradigm shift, towards the synchronous model, increases explanatory and intervention power by stimulating new thought and research across conceptual boundaries rather than solely within particular disciplines. Therefore, it could be argued that the provision of a health service within a synchronous context may be researched innovatively

by integrating medical aspects (for example, patients' understanding of diagnosis and treatment) with psychological aspects (for example, anxiety about efficacy).

Since this study incorporates research within a service delivery context, these aspects are central in the demonstration of the practical application of the shift.

Two further aspects of the synchronous model (Jasnoskie & Schwartz, 1985) are particularly relevant for contextualising an informational support programme for terminally ill patients, who, by necessity, require ongoing medical support .

The first aspect is that the biopsychosocial model subsumes rather than discards the biomedical model as it combines forces with psychology.

The second aspect is that health research and service delivery are beginning to evidence the paradigm shift to the synchronous model. This shift is clearly evident in the management of cystic fibrosis because, while some treatment may initially occur in a medical setting, parents are now retaining a central role in the domestic setting, helping their child cope with procedures, providing physiotherapy and administering medication (Bradford, 1997).

A criticism of such observations, however, is the omission of emphasising the positive. What appears to be missing from these observations of models and paradigm shifts is an opportunity to more strongly bring to the fore the more positive aspects of parental and psychological involvement in a new model. It is one thing to argue against the disadvantages of the medical model, and its reductionist emphasis, in favour of the a biopsychosocial model, which improves our understanding and management of illness. It is another thing, however, to simply do so convincingly without extending the argument to highlight how, in focussing on the person as a whole rather than the illness, the strengths of key players may make a difference. In this regard, Rappaport (1977) proposed the difference model, which embraces a psychology of strengths rather than weaknesses. Its main contribution is that it improves on the biopsychosocial model, an essentially deficit model of illness with its focus on what is wrong with the person, to a model which takes that into account but also what is positive. In other words, what human aspects make a difference?

It is proposed, therefore, that a shift in emphasis from what is wrong with the person to the utilisation of a person's strengths would contribute towards an illness management culture which is not only integrative and progressive but also more positive. Therefore,

the pronounced role of the parent, in a service delivery culture which embraces positive, enabling elements, would appear to be the way forward.

5.2.3 Contextualizing parental involvement in the biopsychosocial model

Parental co-operation in this central role may be influenced, according to Bury (1997) by new forms of information helping them restore a sense of control over treatment. He notes, furthermore, that medical sociologists perceive a relative displacement of the doctor from the central position in health care towards a more pluralistic structure and outlook. In this new context, he argues, patients are becoming the “experts” in the treatment of illness.

Noting earlier observations in this regard by Coyne (1996) and Hutchfield (1999), one is inclined to readily agree with the observation made by Down (2004) that parents have found themselves in an evolution from relative non-participation in the care of the child, to involvement, to partnership with professionals and, in modern times, to the concept of family centred care.

It could be argued that, just as the patient is experiencing a paradigm shift in the manner of health care delivery, the psychologist, also, is working in an environment where this shift is facilitating a collaborative and integral role in the management of an illness. This is being encouraged because of several issues. One is that studies of doctor-patient communication confirm that parental dissatisfaction with medical consultations increases the stresses associated with looking after an ill child (Bradford, 1997). Rabasca (1999) remarks that, because physicians do not always have a good understanding of the gap between what they are saying and what the patient understands, more oncologists are calling in psychologists to improve patient treatment. McGuire (1999) remarks, in this regard, that psychologists are being welcomed as part of the team in the field of oncology, assisting family members to cope with stress, while Clay (1999) argues that interventions help ease family members' stress by including them in patient care.

From the perspective of the patient, Bury (1997) remarks that medical knowledge is being disseminated in an increasing variety of forms, with medical doctors no longer able to maintain their historically privileged control over it. He goes on to point out that, while this has facilitated the accrual of knowledge and alternatives, the patient then might experience a vacuum of ‘who to turn to’ if the traditional doctor-patient relationship is changing.

While the patient remains central, the flow of information on illness, Bury (1997) states, is becoming increasingly available from a variety of sources, including investigatory journalists, campaigners, academics, sociologists, economists and health care managers. Therefore, the dominance of medical knowledge from a purely medical source has been waning (Bury & Gabe, 1994).

For patients with cystic fibrosis, it is important to point out that while improved survival has been attributed to earlier diagnosis, multidisciplinary care and more effective treatment (Abbott & Gee, 1998), treatment adherence remains an important factor in the management of the disease. Information on treatment adherence would, therefore, be important.

While Abbott and Gee (1998) argue that there is no consistent, single reason or set of predictor variables to explain why patients engage in adherent or non-adherent behaviours, Koocher et al (1990) identified three non-adherent types on the basis of the patients' knowledge and beliefs:

- Inadequate knowledge (i.e. a lack of understanding of cystic fibrosis)
- Psychosocial resistance (a struggle for control, peer pressure, difficult domestic circumstances, denial and depression)
- Educated non-adherence (The term 'educated non-adherence' refers to situations where patients decide not to comply with treatment after considering negative aspects such as time involved or side effects)

Therefore, one may readily agree with Bradford (1997) that chronic childhood illnesses require skilled interventions involving both medical and psychological approaches. The biopsychosocial approach is inherently interactional, offering a way out of the disease-focussed and person-focussed polarities (Gilbert, 2002). Integrated approaches provide families with tangible evidence that psychological services are an essential part of the package of care (Sabbeth & Stein, 1990), with psychologists taking their rightful place at the forefront of developing biopsychosocial models of intervention (Gilbert, 2002).

5.3 EXAMPLES OF RESEARCH PROJECTS

In their review of contemporary psychosocial issues in cystic fibrosis, with specific reference to treatment adherence and quality of life, Abbott and Gee (1998) make several important observations relevant to this study. In particular, they point out that, while adherence to treatment is important to the successful management of the disease, there has been a paucity of direct evaluation. These authors also argue that poor experimental designs, using data collected in atypical situations, from medical records alone, or on perceptions of physicians, or insensitive scoring systems, have contributed towards unsatisfactory conclusions.

Research projects in the National Health Service of the United Kingdom are conducted to inform multidisciplinary teams of patients' needs but, owing to lack of time and funding, do not allow the methodological rigour usually associated with scientific enquiry. Nevertheless, two examples of local research projects are mentioned in support of the need for further enquiry.

In a research project to establish a palliative care team for the care of children with life-threatening illnesses and their families, Connolly (1993) reports that the perception of greatest need of all interviewed families was for respite care, half of them requiring it at home. More importantly, the project reported that eighty per cent wanted contact with a community carer to overcome coping problems and to meet their need for emotional help and supportive presence. To overcome these difficulties, the project introduced regular contact by a community carer and a psychologist, specifically to provide emotional support and bereavement counselling.

Connolly (1993) reports further that, when school nurses were asked to identify areas of concern through a questionnaire, responses confirmed the following main areas:

- Information concerning children's diagnoses and care came mainly from parents rather than from their general practitioners or the hospital
- School nurses were of the opinion that there is insufficient communication between all professionals concerned in a child's care
- There is a lack of emotional support and help for children, siblings, parents and school nurses

One of the conclusions drawn from the project was that an improvement in support for children and their parents could be met through the planned team, including the introduction to the team of a psychologist who would be directly available to the families.

In a research project on bereaved parents' views of caring for a child with a life-limiting incurable disorder, While (1999) established that the most common health problems of parents were stress and anxiety. Their findings confirmed the need for information at diagnosis and during subsequent treatment. Nearly half of the sample of 44 families felt that the diagnosis of the child's disorder could have been imparted in a better way. Alarmingly, a third of the sample waited seven months or more for a diagnosis. In the absence of adequate support, parents most frequently sought the help from voluntary organizations for emotional support and information.

While these research projects may be criticized for lacking in rigorous research methodology, they nevertheless reflect awareness of the problems associated with the management of an illness.

A Neurological Clinical Research Unit at McMaster University, Canada, on the other hand, was able to complete a comprehensive study on parents (Baine, Rosenbaum & King, 1995), to confirm that parents of children with chronic illnesses are at significantly increased risk to experience mental health problems. They examined parents of children with diabetes mellitus, and parents of children with cystic fibrosis, to whom they had access through a regional university-affiliated hospital. A significant agreement between the two groups of parents was found on their rankings of several components of care (Spearman rank coefficient $r = 0.92$, $p < 0.001$). The components of care ranked most highly by both groups of parents were diagnosis, treatment, education / information, continuity / consistency, accessible and available care, evaluation of chronic illness and parental involvement.

An American study by Nolan, Desmond, Herlich and Hardy (1986), pointing out that patients rely heavily on parents for information about cystic fibrosis, concluded that one third of both patients and parents sought more information about the disease and its implications

5.4 CONSIDERATIONS FOR THE PROJECT ON CYSTIC FIBROSIS

Appropriate psychological intervention can take many forms. In this study, the format of the intervention was influenced by the following factors:

- The appropriateness of psycho-educational programmes where medical conditions are a central focus (Cummings & Cummings, 1997), described below
- The large geographical area in which the target group was spread
- The lack of a formal budget to support new, innovative strategies to reach parents
- The climate of cost-containment already prevailing in the National Health Service, which requires the search for innovative cost-effective health care delivery

According to Cummings & Cummings (1997), there had been, in the last 20 years, and especially during the last decade, a rapid emergence of psycho-educational programmes that enhance treatment with related information and behavioural techniques directed at life-style changes. For example, cardiac rehabilitation may be enhanced by guides on the benefits of medication and appropriate exercise.

Time-limited models, which incorporate features of medical information and behavioural adaptations have their foundations in what Ivey and Authier (1978) describe as the psycho-educator model. This model aims to facilitate competence in moving from a medical model, concerned with illness, diagnosis, prescription, therapy and cure, to an educational model, with its focus on goal setting, skill teaching and goal achievement.

While parents of children with a chronic illness may require more specific medical information to achieve the learning objectives which Ivey and Authier (1978) originally envisaged for the development of interviewing skills, their goals are nevertheless based on some of the essential propositions. These are a lessening of the complexity of the treatment process through focussing on single skills, the use of models (video, audio or printed), demonstrating the skills the parents are to learn and the teaching of skills in a wide area of diverse theoretical and practical frameworks.

The psycho-educational model of intervention implies the empowerment of knowledge or skills in a proactive way. The benefits of such proactive support for families, Davis (1993)

argues, include fewer psychological and social difficulties, with parents being able to cope independently, fewer demands on frontline services such as general practice, and a reduced need for hospital admission.

The concept of psycho-education in programme format has the potential of overcoming the difficulties of traditional models of communication, which Ogden (2000) characterizes as the transfer of knowledge from expert to layperson, with a diminished role for the patient.

The cognitive hypothesis model of compliance (Ley, 1988), however, stresses that compliance may be facilitated by patient satisfaction with understanding information and recalling information.

However, a criticism could be made here that compliance is a contradiction in a context where parents are empowered. If the locus of control is shifted to parents through enabling techniques, then the traditional view of medical practitioner as an expert who advises the compliant patient needs to be replaced with a different model (Ogden, 2000). Therefore, is it more appropriate to speak of a model of adherence (Stanton, 1987). This emphasizes that it is enhanced parental knowledge that results in adherence as a consequence of their locus of control. Instead of being instructed, they become empowered and therefore exercise an informed choice.

Therefore, it could be argued that a user-friendly informational support programme should contain the following components. It should attempt to overcome the problem of primary effect (remembering only the first things being told and ignoring others), explain the benefits of adherence to prescribed treatment, simplify the information to avoid confusion, use repetition to aide memory, and be specific about outcome.

With this in mind, all of these aids to effective information were included in the support programme, which will be described in section 5.6.1.

The role of improved information becomes particularly important, according to Moos and Schaefer (1984), when there is an experience of unclear or ambiguous information, where

decisions frequently have to be made quickly, or where there is uncertainty about causality and outcome.

An informational support programme, with a view to improving compliance with medical treatment, is especially important in cystic fibrosis, because regular, daily treatment is required to facilitate breathing and eating.

Moreover, since positive family functioning is an important mediating variable in affecting psycho-social adjustment in children with cystic fibrosis (de Wet, 1984), then materials which can encourage positive involvement in their child's well-being ought to contribute towards healthier psychological functioning.

Ley's (1988) work on consultations had demonstrated that much of what patients are told is forgotten, and this, in turn influences compliance with treatment (Button, 1998).

Furthermore, medical advice without proper understanding of the cause of the illness, the correct location of the relevant organ or the processes involved in the treatment, is likely to affect compliance with this advice (Ogden, 2000).

Treatment compliance is considered essential to well-being and research suggests that information may be an effective means of improving compliance (Ogden, 2000).

It is interesting to note that parents' informational needs appear to have remained the same for nearly three decades. Burton (1975) reported that, while most parents are helped by paediatricians in understanding cystic fibrosis at the diagnostic stage, written material, such as books and pamphlets, were also necessary. She goes on to say that parents frequently commented that pamphlets were the only optimistic source of information and gave hope and encouragement in their task of treating the child.

De Braekeleer et al (2001) observes that information about levels of knowledge on cystic fibrosis in patients and their parents is discrepant. However, as reported earlier in this chapter, a study by Baine et al (1995) asked 80 parents of children with diabetes mellitus and 45 parents of children with cystic fibrosis to identify which components of care-giving were most valued. They reported significant agreement (Spearman rank coefficient $r =$

0.92, $p < 0.05$) between the two groups on the need for diagnosis, treatment, information, accessible care and parental involvement.

Providing printed information in booklet format, accompanied by an audio cassette, would therefore appear to be an appropriate way of helping the parent with home management.

While Burton (1975) makes the assertion that active participation in the child's treatment mobilises parental hope and diminishes feelings of guilt and shame fostered by the diagnosis, greater clarity on psychological functioning would be an improvement in understanding their plight.

This study is intended to develop and apply an appropriate intervention and to determine, through psychometric assessment, if such help has altered parents' psychological functioning.

5.5 COMPONENTS OF THE INFORMATIONAL SUPPORT PACKAGE

It is noted that informational support programmes devised by psychologists vary greatly in their focus and duration. Two examples are mentioned here to illustrate the point.

In what they described as a preventive, psycho-educational approach to increase perceived social support (Brand, Lakey & Berman, 1995) devised a 13-week programme, while a brief psycho-educational programme for cancer patients and family members in a large group format (Cunningham, Edmonds & Williams, 1999) consists of a 4-session programme.

Also, it is necessary to mention that there has been much confusion (Martin, 1990) surrounding the notion of "psychological skills training" and, as in many areas of psychological intervention, unless clarification is provided, the aims of an intervention may be misunderstood. To the extent that this study assists families to achieve improved psychological functioning, it is an empowering intervention consistent with enabling, i.e. the following aspects are important:

- Empowerment-orientated interventions, which ameliorate problems, allow participants to develop knowledge and skills. They engage professions as collaborators instead of authoritative experts.
- While there is a diversity in the literature on the precise meaning of empowerment, one may deduce a central theme of participants achieving an important stake in their well-being through active participation.

This clarification is necessary because, while there is a growing need for creative psychological services within a context of cost constraints, Martin (1990) points out that innovative interventions, to this end, can be multifaceted, eclectic, and consequently difficult to characterize with great precision. Therefore, the informational support programme in this study should not be confused with the more contentious “psychological skills training” he refers to in the context of equipping students, clients and others with psychological skills which emulate the attributes of the psychologist. It needs also to be differentiated from what Ivey and Authier (1978) and Ivey, Ivey and Simek-Downing (1987) describe as modelling skills.

Having clarified these issues to obviate the confusion which Martin (1990) describes, three examples follow to illustrate the use of innovative psycho-education programmes in a medical context.

In their thematic model of a psychosocial intervention for patients with soft tissue sarcoma, Payne, Lundberg, Brennan and Holland (1997), included medical information, coping and problem solving skills and the coordination of guest speakers, where appropriate.

In their brief psycho-educational programme for cancer patients, Cunningham et al (1999) utilised a combination of large group classes, and a workbook and audio tapes for home practice.

Hosaka (1996) used five one-hour sessions of psycho-education, psychological support, relaxation training and guided imagery described in manual format to assure uniformity for all participants in his study with breast cancer patients.

One may be critical of the brief nature of these interventions because they reflect what Strawbridge (2002) refers to as 'McDonaldisation' or 'fast food therapy' in psychology, meeting a particular urgency. However, this would be a narrow view because they ought to be acknowledged more positively for their contributions in a context where efficiency and time-limitations are real considerations and where the medical setting demands it.

5.6 PRACTICAL CONSIDERATIONS

The selection of the components of the informational support package for parents in this study of cystic fibrosis was influenced by several important practical considerations. The most important was that it had to contain accurate and reliable information in a manner acceptable to its users.

To this end, the researcher sought the assistance of the Cystic Fibrosis Trust in, Bromley, London to provide such material.

A meeting was arranged with the Trust in London to explain the intentions of the research and to obtain the required information. It was found that there was a wide range of material available. This material, while available on a request basis for parents and their children, had never been disseminated in a systematic way or in an integrated format. Nor had their impact ever been comprehensively researched.

From a variety of their materials, the researcher and the information officer of the Trust selected those items which were specific with regard to parents' information needs and which contributed towards overcoming the problems highlighted by Ley (1988), described previously in section 5.4.

On this basis, a selection of pamphlets, booklets and a counselling audio cassette in question and answer format, was made. This provided information on the nature and treatment of cystic fibrosis. All of these materials were medically correct and updated by the Director of Research of the Cystic Fibrosis Trust. Together, they provided a comprehensive informational, resource and counselling package.

A copy of the materials used is available for reference.

5.6.1 Summary of Materials Used

The following is a summary of the materials used in the support package. It describes both the written material and audio cassette.

5.6.1.1 Pamphlets

The informational pamphlets in the support package consisted of the following subject matter:

5.6.1.1.1 Help for people with cystic fibrosis and their families

This 6-page pamphlet introduces the family to the support service and contains information on practical, emotional and financial support.

It explains how a diagnosis can arouse shock in the patient and parents and, therefore, requires attention with regard to the management of social life. It includes practical advice on where to find emotional support and financial guidance.

It also explains that cystic fibrosis is likely to affect the extended family rather than the patient only. It mentions that many of the difficulties will lead to anxiety.

5.6.1.1.2 Cystic Fibrosis: The Facts

This 6-page pamphlet explains, briefly, what cystic fibrosis is and its genetic origins.

It also provides reassurance that, whereas babies were expected to live for only a few months, forty years ago, life expectancy is improving for most patients, into adolescence and even adulthood.

It furthermore explains how a combination of physiotherapy, regular exercise, medication and high-energy foods can help control the symptoms of cystic fibrosis.

Mention is made of new drugs that are being tested and of experiments with gene therapy that are being conducted with a view to improved treatment.

5.6.1.2 Booklets

The informational booklets in the support programme consisted of subject matter in four areas, as detailed below:

5.6.1.2.1 Finding out about cystic fibrosis

This 32-page booklet explains cystic fibrosis in some detail and gives an overview of how it affects the child's body. It removes ambiguity about survival by providing facts regarding advances in medical treatment.

It also provides, in user-friendly format, a section on the psychological impact the disease has on parents, with particular reference to disbelief, anger, guilt, bewilderment and strained relationships. It recommends a positive approach to the illness, encouraging parents to ask questions about medical treatment and to ask for support, advice and reassurance from professional staff.

A section on diagnosis, the effects of cystic fibrosis on the digestive system, the role of enzymes and related issues about feeding, is also provided.

The booklet also reinforces the necessity of regular physiotherapy and provides a useful list of 12 symptoms that indicate a visit to the doctor.

5.6.1.2.2 Genetics, carrier tests and tests during pregnancy

This 16-page booklet explains genes and genetic diseases, the detection of cystic fibrosis genes, carrier testing and prenatal diagnosis.

It includes a section on the different types of inheritance of chromosomes, with reassurance that no one is to blame for genetic diseases.

While acknowledging that the booklet cannot replace specialist genetic counselling, it will help in the process of facilitating appropriate questions when visiting the doctor or a genetic clinic.

The prospect of advances in gene therapy is also described, with an explanation of how clinical trials first have to be conducted before such treatment may be considered.

5.6.1.2.3 The physical treatment of cystic fibrosis

This 36-page booklet provides information on the lungs, the importance of physiotherapy, the application of techniques to treat young children, and the importance of medication, exercise and posture.

The section on the lungs describes its structure and function, how cystic fibrosis affects the lungs, why chest physiotherapy is important and how the procedure should be carried out.

This is followed by sections on physiotherapy techniques and other important aspects of chest care, such as inhaled medication, exercise, posture and chest mobility.

5.6.1.2.4 Eating well with cystic fibrosis

This 21-page booklet provides guidelines on the usefulness of high protein and high calorie foods, appropriate fruit and vegetables, guidelines for special dietary supplements, the role of vitamin supplements, salt and when to see a dietician.

A particularly innovative section of this booklet is devoted to the provision of several detailed recipes for meals and drinks.

5.6.1.3 Cassette

The additional counselling component, in question and answer format, consisted of an audio cassette entitled 'Finding Out About Cystic Fibrosis - a guide for parents of newly diagnosed children' and it contained contributions from consultant paediatricians, a dietician, physiotherapist and nurse, described below.

It was designed as an innovative form of counselling programme, featuring a question and answer format, with the questioner playing the role of a parent, asking typical questions which a concerned parent might ask.

A transcript of the programme is provided in Appendix B.

A summary of the contents is provided in Section 5.6.1.3.1 below.

5.6.1.3.1 Information from Consultant Paediatricians

This provides basic information and answers typical questions. Underlying issues of despair and shock are acknowledged, with reassurance that parents in this state cannot be expected to remember everything. Therefore, the programme is a useful means of revising information.

Questions on life expectancy are also answered, with mention that this is increasing to age 40, and that new developments in the treatment of cystic fibrosis are emerging. There is also reassurance that modern treatments are contributing to longer life expectancy.

This is followed by a section on how genetic endowment affects the problems of breathing and digestion. Cystic fibrosis is a genetic disease, with a large number of carriers, involving a single gene that controls the rate at which water and salt cross the surface of the lungs. The paediatrician dispels the role of blame on the part of the parents.

There is also an explanation about the degrees of severity of the illness, adding that some children can function better than what is usually predicted.

5.6.1.3.2 Information from Dietician, Physiotherapist and Nurse

Information in this section is focussed on the management of diet to allow strong breathing muscles, explaining that there is a direct link between well-nourished children and the ability to fight infections.

An explanation is given on pancreatic enzyme supplements and the reasons for the use of vitamin supplements.

Advice is given on how to manage rebellious children who present with food refusal. Information is also given on how high calorie supplements can help the child gain weight, with the benefit of having better developed chests.

There is an explanation on how physiotherapy assists with the expulsion of mucous from the chest, and the required frequency of treatment. Also covered are the following main principles of physiotherapy:

- The positioning of the child
- The patting of the child
- The gentle shaking of the child

A following section focuses on drug therapy, including the use of antibiotics to fight chest infections.

A further section pays attention to emotional issues which result from uncertainty, with an explanation that emotional support can be provided by nurses who are trained to manage parents who have children diagnosed with cystic fibrosis. There is a reminder that such nurses provide a link between the family and the Doctor, discussing the type of care needed.

Also mentioned is the role of a Health Visitor, who can be called on to provide support and to arrange inclusion in a parent support group.

An example of the entire support package is available from the researcher.

5.7 OTHER PRACTICAL CONSIDERATIONS

It is to be noted that some practical considerations influenced the delivery of a support package because of the geographical area being covered. A lengthier intervention,

consisting possibly of more contacts, was not feasible, firstly, by the long travelling distances involved. Families were dispersed over a large area of East Anglia, England.

Apart from this, each visit required at least an hour, and it was difficult to arrange visits when both parents were available simultaneously. Use of time was also constrained by the limitations imposed on the researcher by hospital management for research of this nature. Most costs, nationally and internationally, were borne by the researcher since the project was not financially supported by the employer.

For these reasons, a reasonably compact informational support package, and a limited number of five contacts per family, was possible.

Further time-related difficulties arose from the tedious nature of the hospital bureaucracy, resulting in long delays with regard to communication and subsequent arrangements. This will be referred to again in a critical discussion at the end of the study.

With the forms of psycho-educational support programmes described earlier in this chapter, this study examined if it contributed to an alleviation of certain psychological symptoms according to the hypotheses described in Chapter 6, which follows.

5.8 SUMMARY

This chapter considered how a paradigm shift towards an integrated health delivery system created opportunities for psychologists to become involved in providing support for parents of children with cystic fibrosis. Consideration was given to the argument that, since parents of children with chronic illness are at significantly increased risk to experience mental health problems (Baine et al, 1995), health service delivery might contribute to the development or prevention of their emotional burdens.

Consideration was also given to parental needs identified in studies by Connolly (1993) and While, Cornish and Citrone (1996), and how psycho-educational approaches, described by Brand, Lakey and Berman (1995), Cunningham, et al (1999), Hosaka (1996) and Payne, et al (1997) might be utilised.

It was argued that the plight of parents might be eased through a comprehensive informational support package, combining the essential components of accurate and appropriate information, relevant to the management of their children. Hypotheses concerning the effects of its use were formulated.

Justification for the provision of an empowering informational support programme was supported by reference to the benefits of biopsychological approach and government policy of patient empowerment (Kennedy, Gately & Rogers; 2004; O'Boyle, 1997; Shaw & Baker, 2004; UK Department of Health, 2001).

Chapter 6 will describe the preliminary steps taken to initiate contact with parents, the design of the main study, the participants and psychometric measurement of parents' functioning.

CHAPTER 6

METHOD

6.1 INTRODUCTION

This section will describe the formulation of the hypotheses, design of the study, preliminary steps, the design of the study and psychometric instruments used. Practical considerations in the implementation of the study are also mentioned.

It has been argued that the value of information specific to an illness and its management is important (Bradford, 1997; Corney, 1996; Feather, et al., 1995) and that without it, uncertainty and unrealistic fears provoke anxiety (Fallowfield et al., 1987). Uncertainty regarding a child's lifespan is a major stressor (Melnik et al., 2001; Wereszczak, Miles, & Holditch-Davis, 1997).

In a health care delivery system that is increasingly cost-conscious and where psychologists are being integrated into multi-disciplinary teams, opportunities arise to explore if parental distress may be alleviated through brief and appropriate informational support. On a theoretical level, informational support ought to contribute towards empowerment. The benefits of empowerment, according to Perkins and Zimmerman (1995) include the amelioration of problems, opportunities for participants to acquire knowledge and skills and involve professionals as collaborators rather than authoritative experts.

Answers to whether or not informational support in this study contribute meaningfully to the empowerment of parents would also shed some light on the extent to which it contributes towards the modern concept of the expert patient (Kennedy et al., 2004; Shaw & Baker, 2004). It ought to be mentioned, however, that this latter term (expert patient) was not contemplated at the time of the commencement of the study.

The expert patient concept is a National Health Service initiative to provide empowering self-management skills for people with long-term chronic conditions and is now being promoted as an opportunity for patients to make a tangible impact on their disease and quality of life (UK Department of Health, 2002).

6.2 HYPOTHESES

In the formulation of the hypotheses, the following observations were made with regard to parental distress and their needs.

Depression often coexists with anxiety. Therefore, patients suffering from depression usually also experience symptoms of anxiety (Lader, 1994; Stavrakaki & Vargo, 1986).

Uncertainty regarding a child's condition and lifespan is a major stressor (Melnyk, et al., 2001; Wereszczak et al., 1997) and distress could be reduced by providing information about the illness (Corney, 1996; Hymovitch & Baker, 1985; Kinderman et al., 1996). It is, therefore, hypothesized that the informational support programme will bring about an improvement in aspects of psychological functioning in parents.

The following hypotheses were, therefore, investigated in this study:

6.2.1 The main hypothesis was that an informational support programme on cystic fibrosis will bring about a significant decrease in their experience of psychological distress.

6.2.2 The following, secondary hypothesis was that an informational support programme on cystic fibrosis for parents will bring about a significant decrease in their symptoms of depression.

6.2.2.1 The second, secondary hypothesis was that an informational support programme on cystic fibrosis for parents will bring about a significant decrease in their symptoms of anxiety.

6.2.2.2 A third, secondary hypothesis was that an informational support programme on cystic fibrosis for parents will bring about a significant decrease in distress (or “caseness”) which may be preventing normal or ‘healthy’ functioning (Goldberg & Williams, 1991) within the community.

6.2.2.3 A fourth, secondary hypothesis was that an informational support programme on cystic fibrosis for parents will bring about a significant decrease in psychological symptom status of individuals in the community who, in the nomenclature of Derogatis (1993), are not currently patients. Particular reference is made to the Global Severity Index, which is the most sensitive single indicator of respondents’ distress levels (Derogatis, 1993).

The third and fourth secondary hypotheses were formulated in order to be informed on the impact of the informational support programme as measured with instruments intended for use on participants within the community.

The value of testing these hypotheses would not only be to determine if certain aspects of psychological functioning of parents might be improved. It would also contribute towards being informed if the informational support programme made a positive contribution towards the goal of empowering within a context of biopsychological health care, which is becoming a focus of policy making in health (O’Boyle, 1997). Policy-making is relevant, it should be noted, because it is a construct that is not isolated from the larger social and political environment and, as Perkins and Zimmerman (1995) point out, it connects mental health to mutual health and the objective to create a responsive community.

Moreover, it later transpired that the format of the intervention is consistent with the new approach to chronic disease management, promoted by the UK Department of Health (2001).

6.3 PARTICIPANTS

Participants were 44 literate parents (22 couples) living in a defined area of East Anglia, United Kingdom, in the counties of Cambridgeshire, Norfolk and Suffolk, identified on the hospital data base as being parents of pre-school children. They were identified by the chief medical officer in charge of medical records.

The demographic data available for parents assigned to the experimental and control groups are shown in Table 6.1 and demographic data relating to their children are shown in Table 6.2 below.

It would appear from this data that the participants in the experimental and control groups appear to be evenly matched in terms of couples married or living together, mean ages, their children's mean ages, mean number of children in the household and mean age of children at the time of diagnosis.

6.1 *Demographic Data Available for Participants*

Group	Married couples	Unmarried couples	Fathers mean age years	Mothers mean age years	Duration of marriage or living together years
Experimental	9	3	32.48	29.75	7.0
Control	8	2	30.66	27.70	7.3

Table 6.2 *Demographic Data Available for Children of Participants*

Group	Number of Couples	Mean number of Children in family	Mean age years	Mean age at time of diagnosis months
Experimental	12	1.83	3.12	3.75
Control	10	1.70	2.51	1.88

6.4 DESIGN

After initial contact by the paediatrician by telephone, parents received five further visits from the researcher, in accordance with the design shown in Table 6.3 below. Greater detail of what transpired is provided after the table.

It is mentioned that, for ethical reasons, it was decided not to exclude any families from the possible benefits of the informational support package. Therefore, the support package was also provided to the control group at the end of the fifth contact.

Table 6.3

Design of the Experimental Intervention Study

VISIT NUMBER	CONTROL GROUP	EXPERIMENTAL GROUP
	Preliminary contact by Paediatrician by telephone	Preliminary contact by Paediatrician by telephone
1	Home Visit to establish contact and request par- ticipation	Home Visit to establish contact and request par- ticipation
2	Explanation of study and offer of help	Explanation of study and offer of help
3	Administration of questionnaires	Administration of questionnaires
4	No support package	Support package and guidance on its use
5	Administration of questionnaires and provision of support programme	Administration of questionnaires, de-briefing and check on use of support programme
6	De-briefing and check on use of support programme	

6.5 PRACTICAL CONSIDERATIONS

The size of the group of parents was determined by two major practical considerations. The parents were living over a wide area of East Anglia, requiring lengthy travel of between 20 miles and 300 miles for each visit. Preference was given to personal contact over mailed requests owing to the already limited support being received and the parents' burdensome existence.

The other practical consideration was to limit participation to those parents whose children were still at pre-school age (below 6 years) and at least one year old. This decision was guided by two considerations. On the one hand, the researcher wanted to reduce the impact of possible intervening variables. The stressors of the commencement of formal schooling may have created additional burdens for the family. On the other hand, a sub-group of families, where the shock of the diagnosis was relatively recent, i.e. for those under one year, were also not included.

A further precaution was also taken. Parents (N=2), whose child was considered to be at risk of imminent death by the consultant paediatrician, were excluded from the study. This was to protect the parents (one family) from additional burdens during their time of crisis.

Also, the researcher took into account the experience gained from the pilot study, which revealed parents' hostility towards an unsatisfactory support system. While not initially anticipated at that time, the degree of hostility served as a useful indication that the main study ought to be conducted in a cautious and considerate manner, allowing the participants an opportunity to evaluate a more helpful approach. Therefore, as a strategy, initial contact, to request participation and to explain the study, was divided into two visits. This was designed to make the process as comfortable as possible, to ease participation and to give parents an opportunity to become familiar with the researcher.

6.6 SIZE OF GROUPS

There were two groups of participants: parents who formed the control group (n=20; ten fathers and ten mothers) and parents who formed the experimental group (n=24; twelve fathers and 12 mothers).

6.7 MEASURES

The following psychometric instruments were selected owing to their acceptable psychometric properties (described below) and their ability to test the hypotheses in an objective manner.

Because depression often coexists with anxiety, and patients suffering from depression usually also experience symptoms of anxiety (Lader, 1994; Stavrakaki & Vargo, 1986), it was decided to use instruments which measure levels of both symptoms in its subscales, as well as instruments which measure each of the symptoms separately.

6.7.1 State-Trait Anxiety Inventory

The State-Trait Anxiety Inventory, a self-report instrument developed by Spielberger et al (1970), has been used extensively in research and clinical practice for measuring state and trait anxiety.

Scores on the State-Anxiety scale were used in this research because, according to Spielberger et al (1970), it has been found to be a sensitive indicator of changes in transitory anxiety experienced in counselling, psychotherapy and behaviour-modification programmes. In particular, it has also been used extensively to assess levels of anxiety during times of unavoidable real-life stressors such as medical treatment.

Information on its internal consistency and validity has already been provided in Chapter 4. It was also reported that it continues to be used as a validated generic measure of anxiety in diverse settings (Allen et al., 1997; Cox et al., 2000; Konen & Horton; Lui & Wu, 1999; Ramnarine-Singh, 1999; Sesti, 2000; Sjostrom et al., 2003; van der Bijl et al., 2003).

Sesti (2000) states that the State-Trait Anxiety Inventory has been used in over 8,000 studies in medicine, dentistry, education, psychology and other social science studies.

6.7.2 The Beck Depression Inventory

The Beck Depression Inventory (Beck and Steer, 1987) is a 21-item instrument which assesses the severity of depression.

According to Beck and Steer (1987), it is one of the most widely accepted clinical instruments for the assessment of depression and its psychometric status is high. According to Rippere (1994), the Beck Depression Inventory covers areas associated with depressive cognitions, feelings and behaviours, and provides information about mood, pessimism, sense of failure, lack of satisfaction, guilt, sense of punishment, self-hate, self-accusation, self-punitive wishes, crying spells, irritability, social withdrawal, decisiveness and body image, amongst others.

The psychometric status of the Beck Depression Inventory is high. Reliability studies have shown a high degree of internal consistency (Beck & Steer, 1987), in that all item scores correlate highly with the total score, and high split-half reliability has been found (Rippere, 1994). Test-retest reliability has been studied and is regarded as satisfactory with correlations ranging from 0.48 to 0.90 (Beck & Steer, 1987). Validation studies have confirmed the psychometric utility of the inventory. It has consistently been found to correlate highly with clinicians' ratings of depression (Williams, 1992).

The Beck Depression Inventory has continued to be used in a variety of research settings, as diverse as an investigation into mood disturbances in cigarette smokers (Patten, Gillin, & Golshan, 2001), changes in depression in older adults (Penninx, Deeg, & van Eijk, 2000) and the effectiveness of St John's Wort in major depression (Shelton, Keller, & Geldenberg, 2001). Furthermore, Melnyk et al (2001), in their sampling of valid and reliable instruments used to measure parental coping, report that the Beck Depression Inventory is used worldwide with multiple populations, including parents of children with acute and chronic illness conditions.

6.7.3 Brief Symptom Inventory

The Brief Symptom Inventory, a self-report instrument, is described in its manual as most useful in clinical and research settings where time is a major limiting variable (Derogatis, 1993). It is a 53-item inventory designed to reflect psychological symptom patterns.

The primary symptom dimensions are:

- Somatization (SOM)
- Obsessive-Compulsive (O-C)
- Interpersonal Sensitivity (I-S)
- Depression (DEP)
- Anxiety (ANX)
- Hostility (HOS)
- Phobic Anxiety (PHOB)
- Paranoid Ideation (PAR)
- Psychoticism (PSY)

In addition, the Brief Symptom Inventory can be scored to reflect three global indices which, according to Derogatis, Yevzeroff and Wittelsberger (1975) and Wood (1986), reflect distinct aspects of psychological disorder.

The global indices are:

- Global Severity Index (GSI)
- Positive Symptom Total (PST)
- Positive Symptom Distress Index (PSDI)

Nunnally (1970), and Aroian and Patsdaughter (1989) report a high degree of internal consistency and test-retest reliability.

Additionally, impressive convergent validity for the Brief Symptom Index with the MMPI has been reported by Derogatis, Rickels and Rock (1976).

The Brief Symptom Inventory's reliability as an instrument for measuring psychological distress has recently been confirmed by Kellet, Beail, Newman and Frankish (2003), while

Gilbar and Ben-Zur (2002) established Israeli norms, reporting high internal reliabilities for its scales and total score and validated it as a measure of distress.

The Brief Symptom Inventory continues to be used in a variety of research settings, such as alcoholic children and their parents (Benda, 1991), coping with breast cancer (Ben-Zur, Gilbar, & Lev, 2001) investigations of psychiatric symptoms of clients seeking treatment for drug dependence (Marsden, Gossop, Stewart, Rolfe and Farrell, 2000), cocaine dependence (Shearer, Wodak, van Beek, Mattick, & Lewis, 2003), and the relationship of parenting stress to adjustment among mothers in prison (Houck & Loper, 2002).

6.7.4 General Health Questionnaire

The General Health Questionnaire, a self-report instrument developed by Goldberg (1978), was designed as a screening test to detect psychiatric disorders among respondents in the community settings, such as primary care or among general medical outpatients, thereby assessing stress responses in the health domain.

This 30-item questionnaire identifies persons who are impeded in carrying out their normal "healthy" functions and who are in distress. According to its manual (Goldberg, 1978), it will identify people who have a mixed affective neurosis with symptoms of both depression and anxiety together with patterns of physical symptom formation and almost invariable social dysfunction.

Information on its reliability and validity has already been provided in Chapter 4. It was also reported that it continues to be used throughout the world in diverse settings, including caring for patients with cystic fibrosis (Carr, Roseingrave, & Fitzgerald, 1996) and primary care (Nickell, et al., 2004; Paice et al., 2002; Pignone et al., 2002; Tait et al, 2002, Tait et al, 2003) .

6.8 PROCEDURE

The research was preceded by obtaining formal permission from the ethics committee of the hospital to commence the study (Appendix E). The paediatric department of a regional hospital was then informed of this step and asked to identify, from their list of patients, the

names and addresses of all parents whose children were between the ages of one and six years and who were being treated for cystic fibrosis.

Since these parents would have had an established relationship with the consultant paediatrician providing treatment, the first contact was via this practitioner by telephone. He explained to each parent that their needs were being researched and that a psychologist was prepared to visit them, at their convenience, to discuss it further and to request the completion of questionnaires. This was also a necessary first step owing to the fact that the researcher, being attached to the Department of Psychology of the hospital, had no control over access or selection of parents within a different department. Services to these families were provided by the Department of Paediatrics, and access to the parents was at the discretion of the paediatrician holding the responsibility for their well-being.

Parents were contacted by telephone to arrange a first meeting, in their homes, at their convenience. Because of the extensive travel involved, appointments were arranged so that both parents were seen at the same time (where this did not materialize, which was often the case, the meeting was postponed until another suitable date for the parents).

The first home visit was made by the researcher to establish face-to-face contact and request participation. At this first meeting, parents' formal consent to participate was obtained, using a Consent Form (Appendix C) and Information Sheet (Appendix D), in accordance with the directive of the ethics committee of the hospital. Given the sensitivity of the research area, this first meeting also served as an opportunity for parents to familiarise themselves with the researcher. All parents agreed to participate.

At the second meeting, a fuller explanation of the components of a support package was given. Components of the support package (information and counselling programme on cassette) were explained. Parents were also asked if they would be willing to complete four questionnaires. A convenient time was then arranged for the third home visit.

It is pointed out that, because of the sensitive area of research and the burden of care experienced by the families, initial contact by the researcher was spread over two home visits before the administration of questionnaires. This was also done to facilitate comfort

and familiarisation with the researcher, who adopted a relaxed, unhurried demeanour, being mindful of the prevailing anxieties within the homes.

The third home visit was made by the researcher to administer questionnaires.

At the third visit, the questionnaires were completed. The researcher remained in attendance during their completion to ensure that they were being completed correctly and to answer any questions.

Parent couples then randomly assigned to either an Experimental or Control Group, by an Assistant Psychologist, using a Table of Random Numbers (Kerlinger, 1973).

Within a few days, the support package was delivered to the parents who formed the experimental group. It was explained to them, verbally, and in written form, how to use the support package. Guidance was given on how to systematically work through the material. The written form of explanation was provided uniformly with the support package. By providing a uniform intervention in the form of the support package, consistency was a goal to help reduce the impact of possible intervening variables. The parents were then requested to work through the material over the following four week period.

Visits to parents forming both the experimental and control groups took place after about a month, at which time they were asked to complete four questionnaires (the same as those done at their first visit). Additional information was provided, where requested.

For ethical reasons, it was decided not to exclude any families from the possible benefits of the informational support package. Therefore, the support package was also provided to the control group at the end of the fifth contact. The control group received their support package and guidance on its use after the completion of their second set of questionnaires.

A follow-up meeting was arranged for parents of both groups a few weeks later to de-brief them on participation and to ensure that they knew who to contact for their remaining concerns (general practitioner, consultant paediatrician, nurse, Cystic Fibrosis Trust and other support structures).

All the questionnaires were then checked to see if they had been completed fully. This proved to be the case.

A letter of thanks to all participants was also subsequently sent, advising them that their participation in the study would contribute towards an improved understanding of their needs and difficulties.

6.9 SUMMARY

This chapter described the method employed for the selection of the participants, the design of the study and the allocation of participants to either an experimental group or a control group.

Practical considerations of accessing the participating parents, over several counties in East Anglia, were also mentioned. A reason was given for excluding a couple whose child was considered to be at risk of imminent death.

Reasons were given for using reliable, valid, and well-known instruments, the results from which reasonable conclusions could be drawn.

The procedure explained how parents were contacted, visited in their homes, questionnaires administered and informational support package delivered.

The results obtained from the questionnaires completed by the participants will be discussed in Chapter 7, which follows.

CHAPTER 7

RESULTS

7.1 INTRODUCTION

This chapter will report the results of the study in the following order:

Firstly, an overview of the analysis is provided. A descriptive, univariate analysis was conducted on the separate variables.

Secondly, a bivariate analysis of pretest and posttest scores of the experimental and control groups was conducted.

Thirdly, a multivariate analysis of pretest and posttest scores for all variables was conducted.

Finally, a between-groups comparison, using non-parametric statistics, was made.

Tables will be shown in each instance.

This will be followed by a section, depicting cell mean plots where significant differences were confirmed, for both the experimental and control groups.

7.2 UNIVARIATE DESCRIPTIVE STATISTICS

Descriptive statistics (means and standard deviations) are shown in Table 7.1 for each variable, for pretest and posttest scores for the experimental group.

Table 7.1 reveals that the means have decreased on posttest scores of the Beck Depression Inventory, General Health Questionnaire and the Global Severity Index of the experimental group, compared to their pre-test scores, indicative of improvements in aspects of psychological functioning. Standard Deviations have increased on the Beck Depression Inventory, the State-Trait Anxiety Inventory and Global Severity Index of the

Brief Symptom Inventory. Larger standard deviations suggest greater variability in effect of the intervention on the participants.

Table 7.1

Descriptive Statistics of the Different Scales for the Experimental Group Pretest- and Post-test (n=24)

	Pretest		Posttest	
	Mean	SD	Mean	SD
Beck Depression Inventory	14.17	4.64	10.38	5.78
State-Trait Anxiety Inventory	35.13	10.89	35.33	14.13
General Health Questionnaire	26.17	10.89	22.04	10.28
<i>Brief Symptom Inventory</i>				
<i>Subscales</i>				
Somatization	54.17	11.81	51.42	10.93
Obsessive- Compulsive	63.29	8.62	55.21	12.11
Interpersonal Sensitivity	57.50	9.74	53.38	10.87
Depression	57.25	11.48	54.63	10.42
Anxiety	58.92	10.76	53.29	12.81
Hostility	61.29	9.88	58.38	11.31
Phobic Anxiety	54.58	8.83	53.79	11.00
Paranoid Ideation	59.08	11.18	57.00	11.30
Psychoticism	55.79	10.32	53.92	10.54
<i>Global Indices</i>				
Global Severity Index	59.54	10.30	55.54	14.96
(Positive Symptom Total)	59.13	9.07	53.80	20.00
(Positive Symptom Distress Index)	59.13	6.95	53.79	14.66

Descriptive statistics (means and standard deviations) are shown in Table 7.2 for each variable, for the pretest and posttest scores of the control group.

Table 7.2 reveals that the means on the Beck Depression Inventory, State-Trait Anxiety Inventory, General Health Questionnaire and Global severity Index of the Brief Symptom Inventory for the control group are also slightly lower on posttest scores, compared to pretest scores. Standard deviations are somewhat lower on the Beck Depression Inventory

and General Health Questionnaire but only slightly lower on the posttest scores of the State-Trait Anxiety Inventory.

Table 7.2

Descriptive Statistics of the Different Scales for the Control Group Pretest and Posttest (n=20)

	Pre-test		Post-test	
	Mean	SD	Mean	SD
Beck Depression Inventory	13.95	7.02	12.20	5.47
Stait-Trait Anxiety Inventory	38.05	14.33	34.30	13.95
General Health Questionnaire	28.20	13.17	27.65	10.98
Brief Symptom Inventory				
<i>Subscales</i>				
Somatization	53.80	11.25	52.15	10.93
Obsessive-Compulsive	59.85	13.43	57.95	12.81
Interpersonal Sensitivity	57.20	10.92	53.35	10.37
Depression	54.90	9.99	53.20	9.83
Anxiety	57.80	11.65	53.35	13.16
Hostility	59.65	10.04	56.25	11.61
Phobic Anxiety	53.20	9.63	48.80	6.44
Paranoid Ideation	58.10	10.48	53.75	8.81
Psychoticism	54.65	9.53	53.75	9.23
<i>Global Indices</i>				
Global Severity Index	58.30	11.79	55.25	12.04
(Positive Symptom Total)	57.00	10.86	53.55	12.21
(Positive Symptom Distress Index)	56.50	8.87	54.65	11.24

7.3 BIVARIATE ANALYSIS

A bivariate analysis was carried out to establish the degree of covariation between the separate variables. This was conducted for the whole group (N=44).

The correlation matrix is shown in Table 7.3. It confirms that the various tests are highly correlated with each other. Only six pairs of variables are not significantly correlated, these being:

Beck Depression Inventory and the phobic subscale of the Brief Symptom Inventory

Beck Depression Inventory and the psychoticism subscale of the Brief Symptom Inventory

General Health Questionnaire and the phobic subscale of the Positive Symptom Distress Index of the Brief Symptom Inventory

The phobic subscale of the Brief Symptom Inventory and the Positive Symptom Distress Index of the Brief Symptom Inventory

The paranoia subscale of the Brief Symptom Inventory and the Positive Symptom Distress Index of the Brief Symptom Inventory

The hostility subscale of the Brief Symptom Inventory and the phobic subscale of the Brief Symptom Inventory

Table 7.3

Spearman Correlation Coefficient Results between the Different Pretest Scales for both Experimental and Control Groups (N=44)

	BDI	STAI	GHQ	SOM	O-C	I-S	DEP	ANX	HOST	PHOB	PAR	PSY	GSI	PSDI	PST
BDI	1.00														
STAI	0.43**	1.00													
GHQ	0.48**	0.55**	1.00												
SOM	0.49**	0.39**	0.37*	1.00											
O-C	0.39**	0.68**	0.64**	0.45**	1.00										
I-S	0.41**	0.58**	0.59**	0.44**	0.77**	1.00									
DEP	0.43**	0.61**	0.78**	0.42**	0.65**	0.71**	1.00								
ANX	0.54**	0.47**	0.55**	0.42**	0.60**	0.62**	0.57**	1.00							
HOST	0.44**	0.47**	0.61**	0.36*	0.67**	0.60**	0.59**	0.55**	1.00						
PHOB	0.19	0.42**	0.17	0.38*	0.46**	0.34*	0.38*	0.31*	0.23	1.00					
PAR	0.38*	0.60**	0.47**	0.30*	0.64**	0.63**	0.69**	0.45**	0.50**	0.33*	1.00				
PSY	0.25	0.56**	0.58**	0.35*	0.73**	0.76**	0.71**	0.59**	0.63**	0.31*	0.59**	1.00			
GSI	0.50**	0.63**	0.67**	0.51**	0.84**	0.80**	0.73**	0.74**	0.80**	0.45**	0.71**	0.73**	1.00		
PSDI	0.36*	0.35*	0.54**	0.38*	0.73**	0.58**	0.46**	0.48**	0.61**	0.23	0.30	0.62**	0.62**	1.00	
PST	0.49**	0.68**	0.69**	0.57**	0.83**	0.83**	0.83**	0.74**	0.70**	0.49**	0.79**	0.81**	0.91**	0.51**	1.00

* p<0.05

** p<0.01

Note

BDI= Beck Depression Inventory; STAI= State-Trait Anxiety Inventory; GHQ= General Health Questionnaire; Brief Symptom Inventory Subscales: SOM= Somatization; O-C= Obsessive-Compulsive; I-S= Interpersonal Sensitivity; DEP= Depression; ANX= Anxiety; HOST= Hostility; PHOB= Phobic Anxiety; PAR= Paranoid; PSY= Psychoticism; GSI= Global Severity Index; PSDI= Positive Symptom Distress Index; PST= Positive Symptom Total

Having found a high level of inter-correlation for pretest variables when data for the experimental group and control group were analyzed together, it was then necessary to establish that this high level of covariation of the variables occurred in each of the groups separately.

Tables 7.4 and 7.5 show high levels of inter-correlation for most of the pretest variables but some differences between groups are evident.

None of the phobic subscale and somatization subscale of the Brief Symptom Inventory correlated significantly with any other scale in the experimental group, whereas they did in the control group.

In the control group, the Beck Depression Inventory was not significantly correlated with any other scale, with the exception of somatization subscale of the Brief Symptom Inventory.

However, most of the variables in both the experimental group and control group are significantly correlated. Therefore, this justifies the use of a MANOVA to evaluate differences in outcome variables between groups.

Table 7.4

Spearman Correlation Coefficient Results between the Different Pretest Scales for the Experimental Group (n=24)

	BDI	STAI	GHQ	SOM	O-C	I-S	DEP	ANX	HOST	PHOB	PAR	PSY	GSI	PSDI	PST
BDI	1.00														
STAI	0.41*	1.00													
GHQ	0.56**	0.40	1.00												
SOM	0.42*	0.17	0.22	1.00											
O-C	0.36	0.64**	0.48*	0.17	1.00										
I-S	0.46*	0.73**	0.63**	0.33	0.75**	1.00									
DEP	0.48*	0.54**	0.86**	0.18	0.53**	0.79**	1.00								
ANX	0.69**	0.40	0.53**	0.18	0.45*	0.49*	0.45*	1.00							
HOST	0.69**	0.57**	0.56**	0.23	0.69**	0.71**	0.61**	0.59**	1.00						
PHOB	-0.12	0.09	-0.10	0.00	0.21	0.12	0.13	-0.04	0.25	1.00					
PAR	0.30	0.53**	0.58**	-0.01	0.65**	0.76**	0.70**	0.40	0.57**	0.05	1.00				
PSY	0.29	0.58**	0.44*	0.06	0.67**	0.75**	0.67**	0.40	0.50*	0.15	0.71**	1.00			
GSI	0.61**	0.60**	0.60**	0.19	0.72**	0.81**	0.64**	0.63**	0.88**	0.20	0.75**	0.62**	1.00		
PSDI	0.41*	0.38	0.40	0.31	0.70**	0.50*	0.38	0.33	0.56**	0.07	0.42*	0.48*	0.52*	1.00	
PST	0.58**	0.67**	0.72**	0.26	0.77**	0.90**	0.82**	0.64**	0.79**	0.17	0.79**	0.80**	0.86**	0.44**	1.00

* $p < 0.05$

** $p < 0.01$

Note

BDI= Beck Depression Inventory; STAI= State-Trait Anxiety Inventory; GHQ= General Health Questionnaire; Brief Symptom Inventory Subscales: SOM= Somatization; O-C= Obsessive-Compulsive; I-S= Interpersonal Sensitivity; DEP= Depression; ANX= Anxiety; HOST= Hostility; PHOB= Phobic Anxiety; PAR= Paranoid; PSY= Psychoticism; GSI= Global Severity Index; PSDI= Positive Symptom Distress Index; PST= Positive Symptom Total

Table 7.5

Spearman Correlation Coefficient Results between the Different Pretest Scales for the Control Group (n=20)

	BDI	STAI	GHQ	SOM	O-C	I-S	DEP	ANX	HOST	PHOB	PAR	PSY	GSI	PSDI	PST
BDI	1.00														
STAI	0.38	1.00													
GHQ	0.33	0.72**	1.00												
SOM	0.48*	0.54*	0.49*	1.00											
O-C	0.41	0.70**	0.82**	0.70**	1.00										
I-S	0.35	0.44*	0.46*	0.55*	0.78**	1.00									
DEP	0.34	0.70**	0.77**	0.67**	0.79**	0.57**	1.00								
ANX	0.37	0.49*	0.57*	0.61**	0.72**	0.70**	0.65**	1.00							
HOST	0.19	0.35	0.70**	0.50*	0.67**	0.49**	0.66**	0.51*	1.00						
PHOB	0.42	0.70**	0.45*	0.70**	0.55*	0.49*	0.60**	0.47*	0.22	1.00					
PAR	0.40	0.66**	0.35	0.63**	0.59**	0.48*	0.69**	0.47*	0.43	0.62**	1.00				
PSY	0.18	0.52*	0.75**	0.65**	0.80**	0.70**	0.75**	0.79**	0.80**	0.45*	0.44	1.00			
GSI	0.44	0.68**	0.72**	0.80**	0.95**	0.81**	0.84**	0.74**	0.74**	0.61**	0.71**	0.85**	1.00		
PSDI	0.31	0.30	0.69**	0.50*	0.75**	0.60**	0.57**	0.66**	0.66**	0.31	0.15	0.74**	0.68**	1.00	
PST	0.42	0.73**	0.69**	0.81**	0.88**	0.73**	0.85**	0.74**	0.70**	0.66**	0.80**	0.84**	0.97**	0.56*	1.00

* p<0.05

** p<0.01

Note

BDI= Beck Depression Inventory; STAI= State-Trait Anxiety Inventory; GHQ= General Health Questionnaire; Brief Symptom Inventory Subscales: SOM= Somatization; O-C= Obsessive-Compulsive; I-S= Interpersonal Sensitivity; DEP= Depression; ANX= Anxiety; HOST= Hostility; PHOB= Phobic Anxiety; PAR= Paranoia; PSY= Psychoticism; GSI= Global Severity Index; PSDI= Positive Symptom Distress Index; PST= Positive Symptom Total

7.4 MULTIVARIATE ANALYSIS

A MANOVA (Howell, 2002) was used to test for differences between pretest and posttest scores for the experimental group and control group for the dependent variables (Beck Depression Inventory, State-Trait Anxiety Inventory, General Health Questionnaire and the Global Severity Index of the Brief Symptom Inventory).

A MANOVA (Howell, 2002) and the Hotellings T^2 Test (Johnson & Wichern, 2002) were used because of the small sample size and the number of highly correlated tests. It carries out multiple comparisons between groups, allowing for the effect of multicollinearity (George & Mallery, 2001).

Table 7.6 shows that, on the pretest scores, there is no statistical difference ($p=0.455$) between the groups, while there is a significant difference ($p=0.011$) between the groups for posttest scores.

Table 7.6

Multivariate Analysis of Variance of Experimental and Control Group scores on the Beck Depression Inventory, State-Trait Anxiety Inventory, General Health Questionnaire and the following Global Indices of the Brief Symptom Inventory: Global Severity Index, Positive Symptom Distress Index and Positive Symptom Total (N=44)

	Hotelling T^2	F	p
Pretest	0.552	1.031	0.455
Posttest	1.456	2.717	0.011

7.5 NONPARAMETRIC COMPARISON

To examine the differences between the groups, identified by the MANOVA (Howell, 2002), a non-parametric comparison was conducted, using the Kruskal-Wallis Test (Kerlinger & Lee, 2000). This is shown in Table 7.7.

It reveals that no statistically significant differences were found between the groups on any of the scales for either pretest or posttest measures.

In contrast to the Hotellings T test, the lack of significant difference found when each of the posttest variables was separately analysed (using Kruskal-Wallis), is explained by the small sample size and the large number of inter-correlated scales.

Table 7.7

Kruskal-Wallis Results of Mean Differences between the Experimental Group (n=24) and Control Group (n=20) Pretest and Posttest on the Different Scales

	Experimental & Control Groups			Experimental & Control Groups		
	Pretest			Posttest		
	Chi-Square	Df	p	Chi-Square	Df	p
Beck Depression Inventory	0.002	1	0.962	2.044	1	0.153
State-Trait Anxiety Inventory	0.134	1	0.714	0.152	1	0.697
General Health Questionnaire	0.170	1	0.680	2.616	1	0.106
Brief Symptom Inventory						
<i>Subscales</i>						
Somatization	0.004	1	0.953	0.154	1	0.695
Obsessive-Compulsive	0.392	1	0.531	0.407	1	0.523
Interpersonal Sensitivity	0.009	1	0.924	0.024	1	0.876
Depression	0.940	1	0.332	0.111	1	0.739
Anxiety	0.336	1	0.562	0.005	1	0.943
Hostility	0.028	1	0.868	0.413	1	0.520
Phobic Anxiety	0.558	1	0.455	1.793	1	0.181
Paranoid Ideation	0.080	1	0.777	1.013	1	0.314
Psychoticism	0.070	1	0.791	0.017	1	0.896
<i>Global Indices</i>						
Global Severity Index	0.191	1	0.662	0.074	1	0.786
Positive Symptom Total	0.702	1	0.402	0.102	1	0.750
Positive Symptom Distress Index	0.645	1	0.422	0.611	1	0.434

Since no significant difference was observed between the groups for any of the scales, using the Kruskal-Wallis Test, the significant differences found, when using MANOVA, may be better explained by differences within groups.

To test for within-groups differences, pretest and posttest, the Wilcoxon Signed Ranks Test (Howell, 2002) was used.

Table 7.8 shows the differences in ranks for pretest and posttest scores for the experimental group and control group.

Both groups showed improvement on posttest scores, when compared to pretest scores (Z scores). However, the difference between pretest scores and posttest scores in the experimental group were larger, with differences in two scales (Beck Depression Inventory and General Health Questionnaire), five subscales of the Brief Symptom Inventory (Obsessive-Compulsive, Interpersonal Sensitivity, Depression, Anxiety, and Hostility), and two Global Indices of the Brief Symptom Inventory (Positive Symptom Total and Positive Symptom Distress Index) reaching conventional levels of statistical significance ($p < 0.05$). For the control group, subscales of the Brief Symptom Inventory (Anxiety and Phobic Anxiety) and one Global Index of the Brief Symptom Inventory (Positive Symptom Total) are statistically significant ($p < 0.05$).

Table 7.8

Wilcoxon Signed Ranks Test Results for Mean Differences between Pretest and Post-test for the Experimental Group (n=24) and Control Group (n=20)

	Experimental Group		Control Group	
	Pre/Post		Pre/Post	
	Z	p	Z	p
Beck Depression Inventory	- 3.764	0.000**	- 1.830	0.067
State-Trait Anxiety Inventory	- 0.104	0.917	- 1.417	0.157
General Health Questionnaire	- 2.392	0.017*	- 0.153	0.879
Brief Symptom Inventory				
<i>Subscales</i>				
Somatization	- 1.423	0.155	- 0.734	0.463

Obsessive-Compulsive	- 3.217	0.001**	- 1.269	0.294
Interpersonal Sensitivity	- 2.615	0.009**	- 1.853	0.064
Depression	- 2.017	0.044*	- 1.050	0.294
Anxiety	- 2.560	0.010 *	- 2.495	0.013*
Hostility	- 1.984	0.047*	- 1.440	0.150
Phobic Anxiety	- 0.595	0.552	- 2.147	0.032*
Paranoid Ideation	- 1.330	0.184	- 1.790	0.073
Psychoticism	- 1.176	0.240	- 0.549	0.583
<i>Global Indices</i>				
Global Severity Index	- 1.625	0.104	- 1.945	0.052
(Positive Symptom Total)	- 2.120	0.034*	- 1.994	0.046*
(Positive Symptom Distress Index)	- 3.358	0.001**	- 1.210	0.226

* $p < 0.05$

** $p < 0.01$

7.6 CELL MEAN PLOTS FOR SIGNIFICANT DIFFERENCES FOR THE EXPERIMENTAL GROUP

Where significant differences have been found for the experimental group, these are depicted in cell mean plots derived from the following measures.

7.6.1 Beck Depression Inventory

Figure 7.1 shows a cell mean plot for the experimental group's pretest and posttest scores on the Beck Depression Inventory.

7.6.2 General Health Questionnaire

Figure 7.2 shows a cell mean plot for the experimental group's pretest and posttest scores on the General Health Questionnaire.

7.6.3 Brief Symptom Inventory

The following figures show cell mean plots for the experimental group's pretest and posttest scores on the Brief Symptom Inventory

7.6.3.1 Obsessive-compulsive subscale

Figure 7.3.1 shows a cell mean plot of the experimental group and control group pretest and posttest scores on the obsessive-compulsive subscale of the Brief Symptom Inventory.

7.6.3.2 Interpersonal sensitivity subscale

Figure 7.3.2 shows a cell mean plot of the experimental group and control group pretest and posttest scores on the interpersonal sensitivity subscale of the Brief Symptom Inventory.

7.6.3.3 Depression sub-scale

Figure 7.3.3 shows a cell mean plot of the experimental group and control group pretest and posttest scores on the depression subscale of the Brief Symptom Inventory.

7.6.3.4 Anxiety subscale

Figure 7.3.4 shows a cell mean plot of the experimental group and control group pretest and post-test scores on the anxiety subscale of the Brief Symptom Inventory.

7.6.3.5 Hostility subscale

Figure 7.3.5 shows a cell mean plot of the experimental group and control group pretest and posttest scores on the hostility subscale of the Brief Symptom Inventory.

7.7 CELL MEAN PLOTS FOR THE SIGNIFICANT DIFFERENCES FOR THE CONTROL GROUP

Where significant differences have been found for the control group, these are depicted in cell mean plots derived from the following measure.

7.7.1 Brief Symptom Inventory

The following figures show cell mean plots for the control group's pretest and posttest scores on the Brief Symptom Inventory.

7.7.1.1 Anxiety subscale

Figure 7.4.1 shows a cell mean plot of the experimental group and control group pretest and posttest scores on the anxiety subscale of the Brief Symptom Inventory.

7.7.1.2 Phobic anxiety subscale

Figure 7.4.2 shows a cell mean plot of the experimental group and control group pretest and posttest scores on the phobic anxiety subscale of the Brief Symptom Inventory.

7.7.1.3 Positive symptom total (one of the Global Indices)

Figure 7.4.3 shows a cell mean plot of the experimental group and control group pretest and posttest scores on the positive symptom total, one of the Global Indices of the Brief Symptom Inventory.

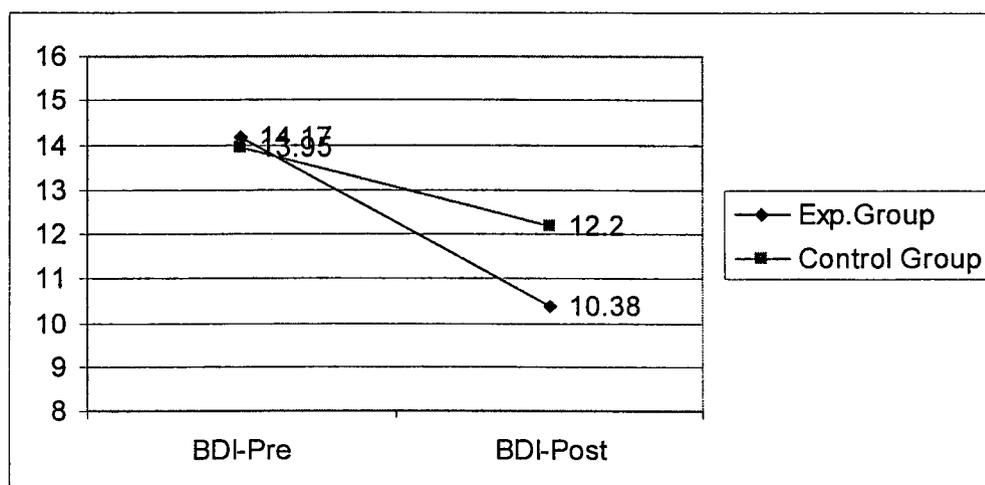


Figure 7.1 Cell mean plot of the experimental group and control group pretest and posttest scores on the Beck Depression Inventory.

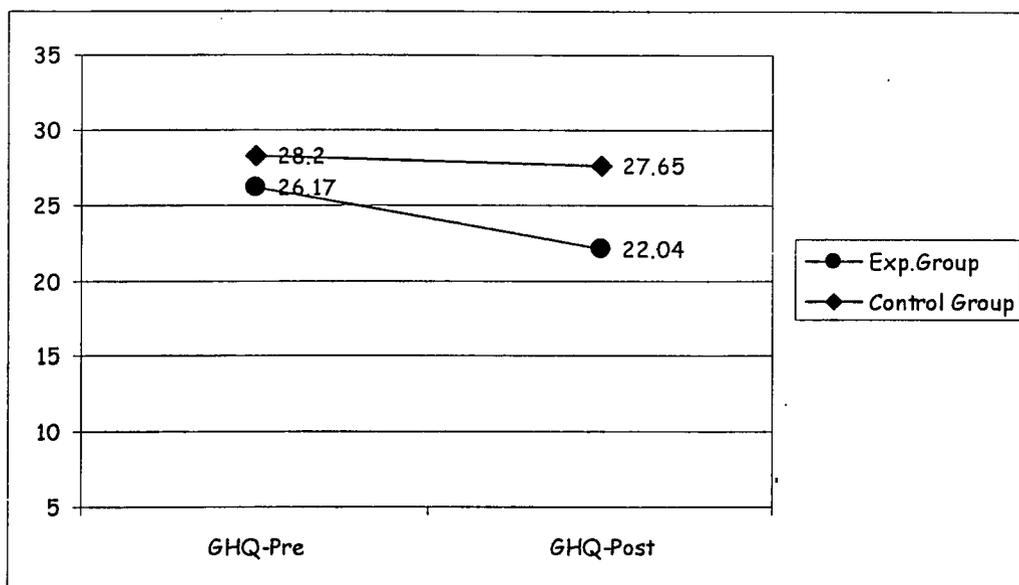


Figure 7.2 Cell mean plot of the experimental group and control group pretest and posttest scores on the General Health Questionnaire

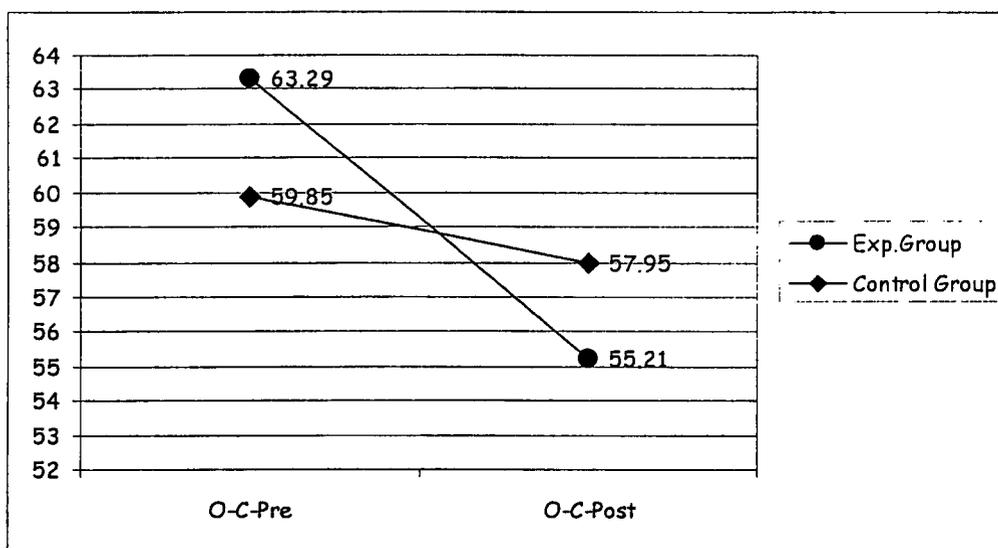


Figure 7.3.1 Cell mean plot of the experimental group and control group pretest and posttest scores on the obsessive-compulsive subscale of the Brief Symptom Inventory.

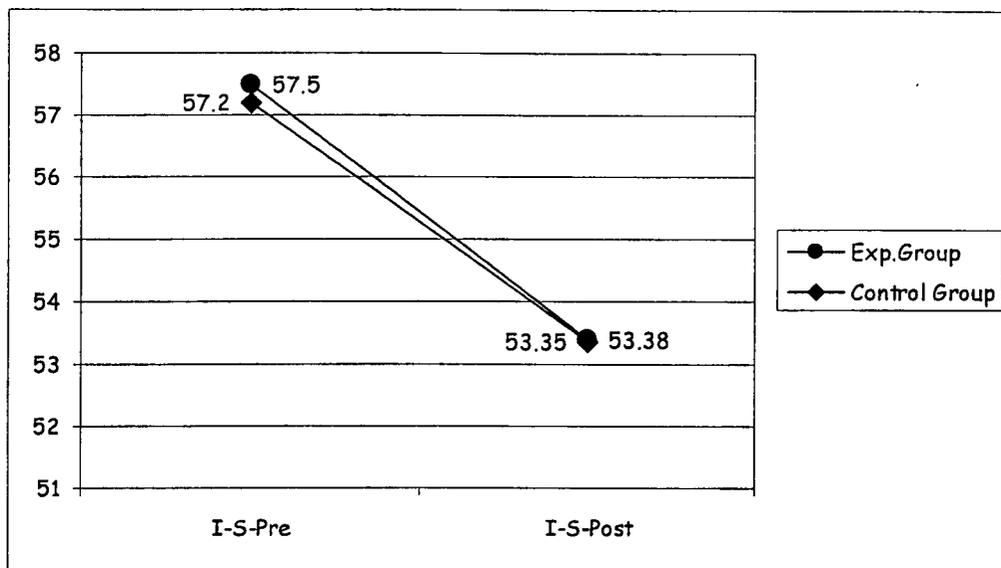


Figure 7.3.2 Cell mean plot of the experimental group and control group pretest and posttest scores on the interpersonal sensitivity subscale of the Brief Symptom Inventory .

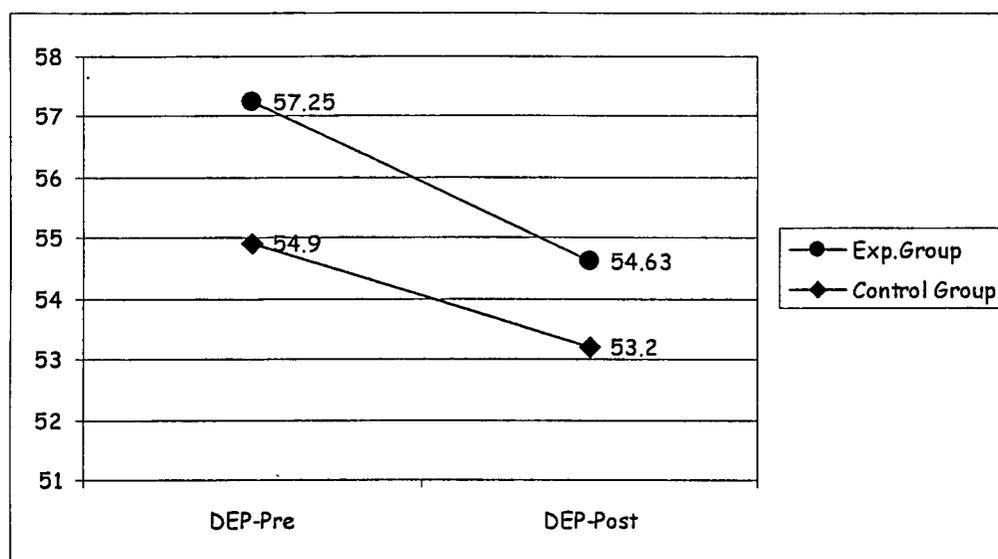


Figure 7.3.3 Cell mean plot of the experimental group and control group pretest and posttest scores on the depression subscale of the Brief Symptom Inventory.

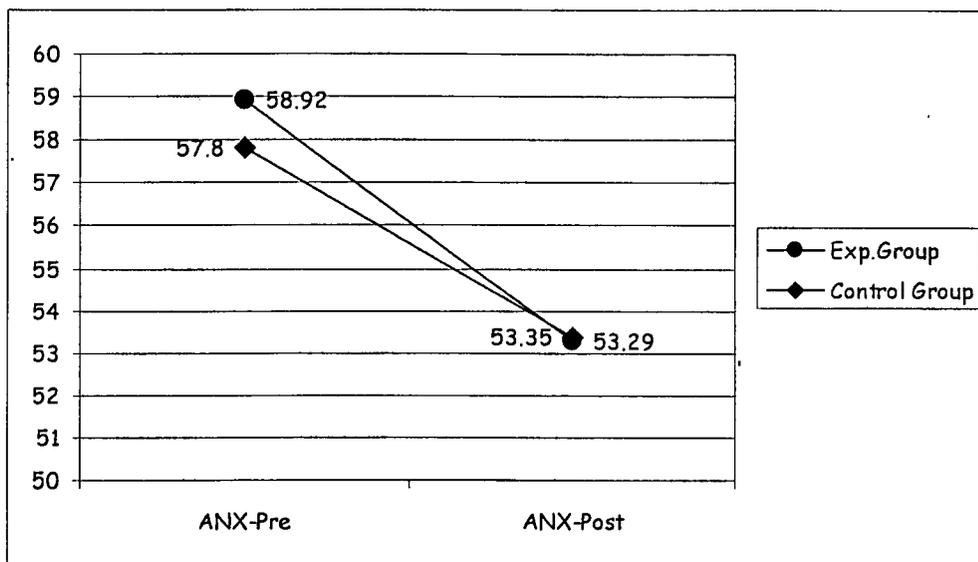


Figure 7.3.4 Cell mean plot of the experimental group and control group pretest and posttest scores on the anxiety subscale of the Brief Symptom Inventory.

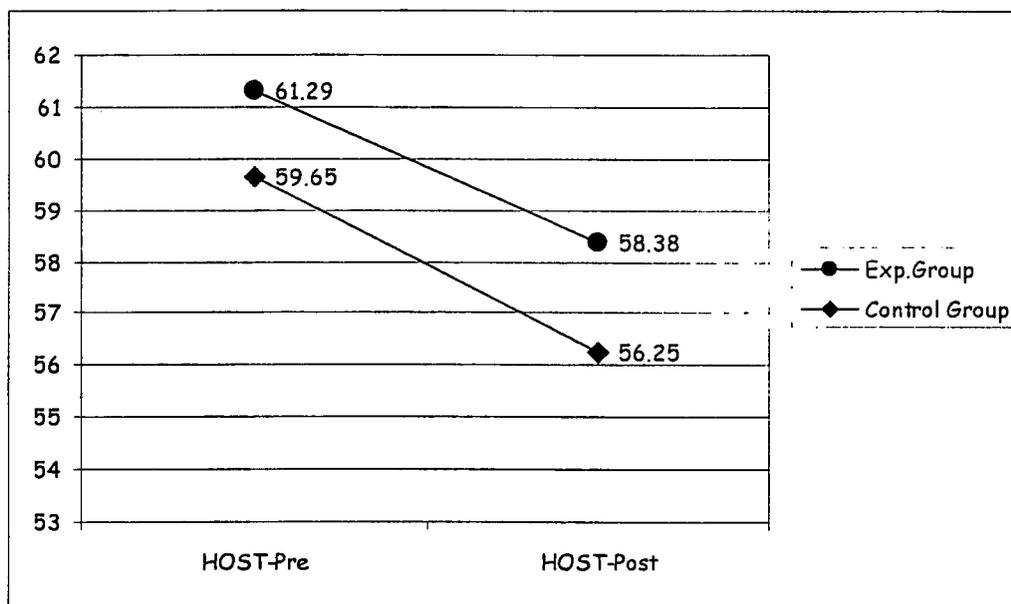


Figure 7.3.5 Cell mean plot of the experimental group and control group pretest and posttest scores on the hostility subscale of the Brief Symptom Inventory.

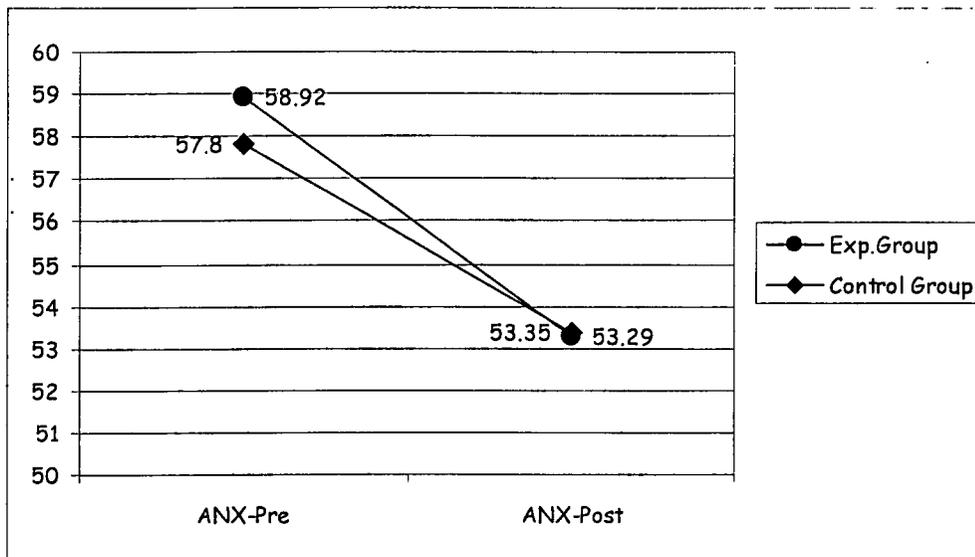


Figure 7.4.1 Cell mean plot of the experimental group and control group pretest and posttest scores on the anxiety subscale of the Brief Symptom Inventory.

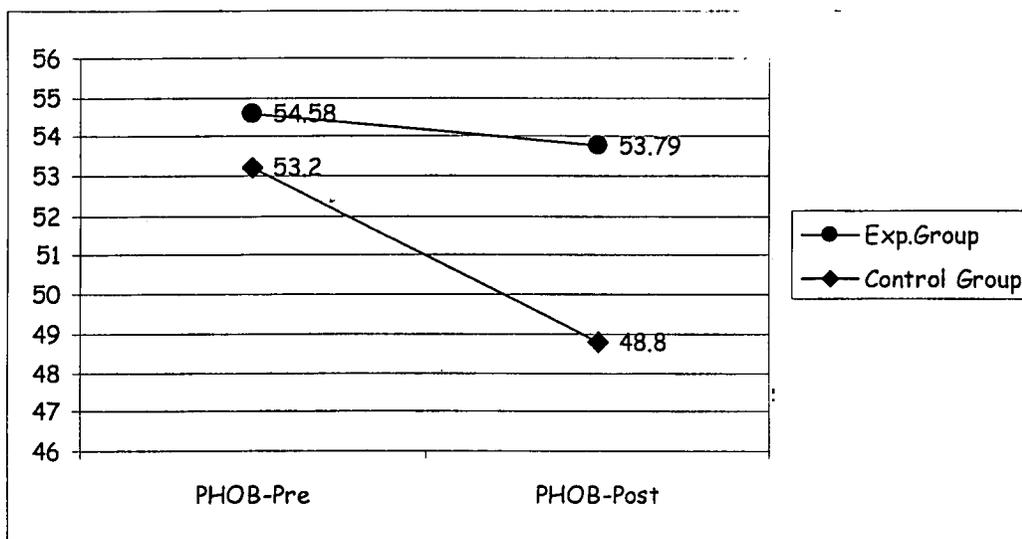


Figure 7.4.2 Cell mean plot for the experimental group and control group pretest and posttest scores on the phobic anxiety subscale of the Brief Symptom Inventory.

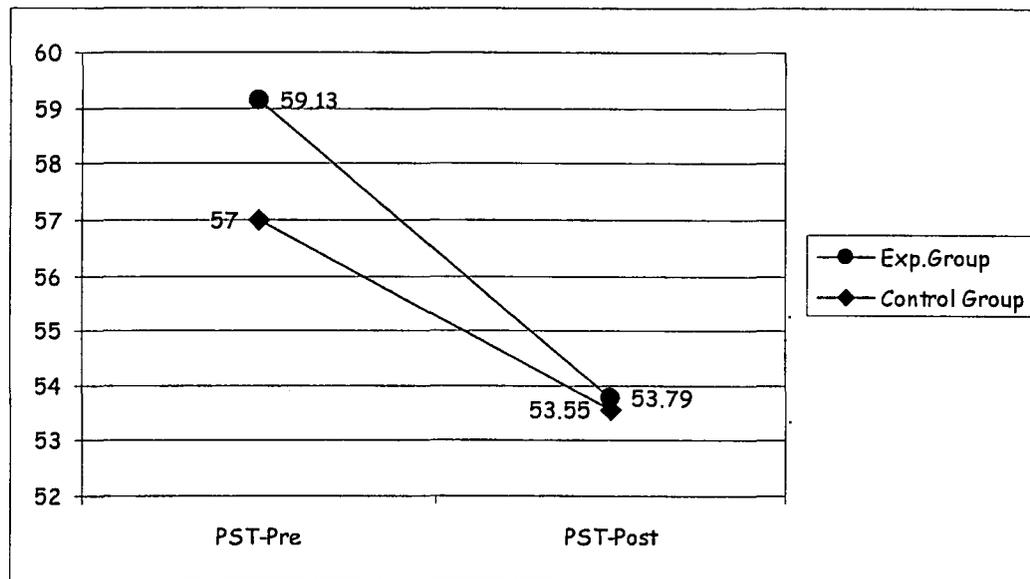


Figure 7.4.3 Cell mean plot for the experimental group and control group pretest and posttest scores on the positive symptom total subscale of the Brief Symptom Inventory.

7.8 SUMMARY

This chapter, firstly, provided an overview of the analysis of the results. A descriptive, univariate analysis was conducted on the separate variables.

Secondly, a bivariate analysis of pretest and posttest scores of the experimental and control groups was conducted.

This was followed by a multivariate analysis of pretest and posttest scores for all variables.

Finally, a between-groups comparison, using non-parametric statistics, was made.

Tables were shown in each instance.

This was followed by a section, depicting cell mean plots where significant differences were confirmed, for both the experimental and control groups.

CHAPTER 8

DISCUSSION OF RESULTS AND SUMMARY

8.1 INTRODUCTION

In this final chapter the research results obtained in this study are discussed. It will also consider limitations and shortcomings of the study in the context of a time limited and cost-conscious working environment.

Its limitations will be contextualised with reference to the emergence of psychologists who are applying their skills in a modern, biopsychosocial framework in a demanding, cost containment environment of health care delivery.

8.2 RESULTS

The results, according to each of the hypotheses, are as follows.

8.2.1 The main hypothesis was that an informational support programme on cystic fibrosis for parents will bring about a significant decrease in their experience of psychological distress.

Results show that the informational support programme brought about a significant decrease in depression for the experimental group, as measured on the Beck Depression Inventory ($p < 0.01$) and the depression subscale of the Brief Symptom Inventory ($p < 0.05$).

8.2.2 The first, secondary hypothesis was that the informational support programme on cystic fibrosis for parents will bring about a significant decrease in their symptoms of anxiety. There was no significant decrease in anxiety, measured on the State-Trait Anxiety Inventory, but there was a significant decrease in the anxiety subscale of the Brief Symptom Inventory ($p < 0.05$).

- 8.2.3 The second, secondary hypothesis, that an informational support programme on cystic fibrosis for parents will bring about a significant decrease in distress (or “caseness”) which may, in the nomenclature of Goldberg (1991), prevent normal or ‘healthy’ functioning within the community. Positive results were found on the General Health Questionnaire ($p < 0.05$), which indicates a decrease in “caseness”, an assessment of stress responses in the health domain (Goldberg, 1978).
- 8.2.4 The third, secondary hypothesis was that an informational support programme on cystic fibrosis for parents will bring about a significant decrease in psychological symptom status of parents who, in the nomenclature of Derogatis (1993), are not currently patients. Positive results were found on two global indices of the Brief Symptom Inventory, namely the Positive Symptom Total ($p < 0.05$) and the Positive Symptom Distress Index ($p < 0.01$) but not on the Global Severity Index which, according to Derogatis (1993), is the most sensitive single indicator of respondents’ distress levels (Derogatis, 1993).

The result on the Global Severity Index, being the most sensitive indicator of distress level (Derogatis, 1993), is consistent with the MANOVA finding of no significant overall improvement in parental functioning.

Some surprise results in the experimental group (see Table 7.8), not contemplated in the formulation of the original hypotheses, were found in three subscales of the Brief Symptom Inventory, namely, obsessive-compulsive ($p < 0.01$), interpersonal sensitivity ($p < 0.01$) and hostility ($p < 0.05$).

Similarly, some surprise results in the control group (see Table 7.8) were found on two subscales of the Brief Symptom Inventory, namely anxiety ($p < 0.05$) and phobic anxiety ($p < 0.05$). It is speculated that these, minor anomalous findings may have been due simply to parents’ participation in a process with the expectation of receiving help which was more than the usual, limited support provided by the health care situation. Mere contact from an interested party could have accounted for lessening of some anxiety.

However, these minor subscales consist of a small number of questions (typically five), and Derogatis (1993) advises the user that the Global Severity Index is the

most sensitive single indicator of the respondent's distress level. He goes on to point out that the primary symptom dimensions essentially provide, what he calls, "a broadbrush profile" of the patient's psychopathological status. This implies that more confident conclusions ought to be confined to one of the global indices, namely the Global Severity Index, on which no significant findings were evident for the control group.

While the surprise findings on some subscales do call for caution in interpretation, they nevertheless hint at a possible area for further study. Research of this kind might be improved with the inclusion of additional, more comprehensive measures of, for example, obsessive-compulsive tendencies or interpersonal sensitivity.

8.3 DISCUSSION

The main hypothesis, that the informational support programme on cystic fibrosis for parents will bring about a decrease in their psychological distress, needs to be interpreted in the light of mixed results. There were no statistically significant differences found between the groups on any of the scales for either pretest or posttest measures (see Table 7.7). However, some within groups differences, pretest and posttest, were found (see Table 7.8).

The results on the General Health Questionnaire (a measure of "caseness") indicates improvement for the experimental group but psychological distress manifests itself in several forms, two of which are depression and anxiety.

Although depression co-exists with anxiety (Lader, 1994; Stavrakaki & Vargo, 1986), this study revealed a significant decrease in levels of depression (measured on the Beck Depression Inventory and the depression subscale of the Brief Symptom Inventory) but not in anxiety (see Table 7.8) for the experimental group.

It is true that, in the control group, one subscale (anxiety) of the Brief Symptom Inventory also indicated lower levels. However, these minor subscales consist of a small number of questions (typically five). Derogatis (1993) advises the user that the Global Severity Index

is the most sensitive single indicator of the respondent's distress level. This implies that more confident conclusions ought to be confined to one of the global indices, namely the Global Severity Index, on which no significant findings were evident for the control group.

If one, therefore, adopts a cautious interpretation of the results by discarding the use of these two, minor subscales (the depression subscale of the Brief Symptom Inventory in the experimental group and the anxiety subscale of the Brief Symptom Inventory in the control group), one is left with the remaining finding (shown in Table 7.8 and depicted in Figure 7.1) that the participants in the experimental group had lower levels of depression after the intervention. This is contrary to the theory that depression and anxiety ordinarily coexist and invites consideration of a more elegant research design which may enquire why this is the case. One may speculate perhaps that the parents have felt less depressed after receiving help but remained anxious, not because of support, but in spite of it, owing to the anxieties routinely associated with the daily demands of a treatment regime which has severe consequences if neglected.

In the light of this, the theory that distress may be alleviated by providing information about the illness (Corney, 1996; Kinderman et al., 1996; Hymovitch & Baker, 1985) may be only partly true. The manner of information provision and the context in which such support is provided, may have a role to play in the extent to which parents respond to an intervention. It was argued in the introduction of this study that innovation in the form of brief, cost-effective interventions is being accompanied by the call to provide evidence-based approaches (Walsh, 2003). However, in the quest to deliver innovation and evidence, effectiveness is often not formulated satisfactorily, nor is it straightforward (Corrie, 2003) as one needs to differentiate between innovation and effective therapeutic decision-making. The provision of an informational or other support programme may, therefore be necessary but not sufficient. Differences on pretest scores and posttest scores in the experimental group and control group could well have been influenced by other factors and not necessarily the support programme.

It is noted here that this study does provide some insight that the underlying concerns of parents could be maintaining anxieties, despite supportive intervention, because of factors which may be particular to them, such as the diagnosis of cystic fibrosis and the long-term and demanding nature of the treatment regime. It invites consideration of further research

to explore and compare the nature of these parents' anxieties with those whose children have different illnesses.

The absence of a follow-up study, which may have provided answers to this observation, is a shortcoming. It is suggested, however, that such a recommended study is implemented in a different group, simply because of the limits to which one ought to subject families in which a life-threatening illness is already a daily concern. Research ought to be mindful of not being a nuisance or hindrance.

Future study might also consider the surprise results in the experimental group (see Table 7.8), not contemplated in the formulation of the original hypotheses. They were found in three subscales of the Brief Symptom Inventory, namely, obsessive-compulsive ($p < 0.01$), interpersonal sensitivity ($p < 0.01$) and hostility ($p < 0.05$). Some surprise results in the control group (see Table 7.8) were found on two subscales of the Brief Symptom Inventory, namely anxiety ($p < 0.05$) and phobic anxiety ($p < 0.05$). While these results ought to be interpreted with caution because of the small number of items used and the advice on the scale's use provided by Derogatis (1993) that reliable interpretation is best achieved on the the Global Severity Index, they nevertheless hint at a possible area of further research.

8.4 CONTEXT OF THE STUDY

In a discussion of the merits, shortcomings and suggested improvements for a study of this kind, it would be necessary to consider the driving forces which affected its implementation. It is argued here that the modern, changing environment of medical practice, coupled to the increasing inclusion of psychologists in multi-disciplinary teams, exerts pressure on the way the psychologist is expected to make a contribution. These pressures are driven by efficiency demands, on the one hand, and the search for evidence for the efficacy of interventions, on the other hand. A discussion of this follows.

One is reminded of the argument by Strawbridge (2002) that, whereas the quality of a therapeutic relationship is widely recognised as the most significant factor in successful therapy, there is an increasing tendency to emphasise 'technical expertise' (her term), accompanied by a desire to package and manualise treatment.

There would appear to be some discomfort for psychologists working in a medical environment and feeling these pressures. In this regard, Kaslow et al (1997) remark that, in conducting family-oriented treatment outcome research, we continually find ourselves caught between our scientist and practitioner sides, trying to find a balance between engaging in good clinical practice with paediatric patients and their families and conducting methodologically sound research.

The quest for evidence-based practice in the name of scientific responsibility and to legitimise the cost of the psychologist's position in the hospital's annual budget, is, however, accompanied by the tendency to create 'McJobs' (Strawbridge, 2002). The work of the psychologist is being influenced by the expectation by managers to be brief and efficient and, when evidence of usefulness is sought, equally efficient. For these reasons, elegant and time-consuming research is not supported and, therefore, as Corrie (2003) remarks on the subject of information, innovation and the quest for legitimate knowledge, when rigorous, objective enquiry is not possible, and where there is an absence of empirical data, it is becoming imperative to seek out alternative (if less rigorous) sources of knowledge to make informed decisions in practice.

Considerations of an ageing population and cost-containment are, no doubt, influencing government policy. For that reason, the UK Department of Health's press release (2002) is not surprising when it states that the National Service Framework for the health service should include objectives of user-friendly, interdisciplinary service, with rapid referral, information and support for carers and families, services that help people with long term conditions fulfil their own responsibilities as partners, parents and carers, and the development of the concept of the Expert Patient. To promote this, the somewhat revolutionary step of sending a copy of all medical correspondence regarding a patient (for example, between clinician and general practitioner) to the patient also, becomes law in the UK during April, 2004.

Other factors affecting the priorities of clinicians include the concept of clinical governance and yearly appraisals as well as hospitals being rated for their performance (star ratings).

8.5 LIMITATIONS

Having described the context and pressures involved in conducting this research on parents of children with cystic fibrosis, it is acknowledged that there were several limitations of the study.

It is speculated that the small sample sizes and limited number of contacts provide only a partial observation of the plight of these parents and that one cannot confidently generalise to a wider population. The small sample size requires one to interpret significant findings with caution as, similar to the observation made by Capelli et al (1989) in their research on parental care and overprotection of children with cystic fibrosis, the results may be an artefact of the small sample size.

A possible selection bias might have been that the parents might have been highly motivated to participate in the study. It was the researcher's perception that they were generally dissatisfied with the health care system.

If one could have improved the sample size to include parents of children older than six years of age, one benefit of more data might have been achieved (for example, a comparison of children with school going children with parents of children who are not yet in school). On the other hand, while such research might have been theoretically possible, restrictions in the workplace in terms of time and resources, prevented consideration of a broader study.

Greater follow-up work, to gather information on how the informational support programme used in this study might be improved, is suggested as a worthy research undertaking. It might cast light on why, for example, after using the programme, parents in the experimental group confirmed less depression but not anxiety

While pragmatic considerations were mainly responsible for conducting this limited study, there was, nevertheless, confirmation of clinical impressions gained by the researcher, namely that delivery and use of an appropriate informational support programme contributed towards an improvement in some aspects of parents' psychological functioning.

A study of this kind also demonstrates that psychologists are able, despite limited time and support, to conduct research of relevance to their involvement in modernising health care settings.

8.6 THE FUTURE OF PSYCHOLOGISTS IN PHYSICAL HEALTH CARE SETTINGS

In a discussion of the contemporary involvement of psychologists in health care settings, it is useful to be reminded of how opinions have changed over time. A quarter of a century ago, Lubin, Nathan and Matarrazzo (1978) observed that the involvement of psychologists in health care settings had been increasing at a relatively steady rate for over a decade.

However, Tefft and Simeonsson (1979) cautioned then against unrealistic expectations, with a rather balanced view, which is worth quoting in full:

Our experience in health care settings, most notably pediatric departments and children's hospitals, have strengthened our belief in the potential value of increased involvement by psychologists. However, our observations have also forced an awareness that this potential may not be fulfilled owing to psychologists' limited understanding of the setting creation process. Rather than becoming discouraged, we can further our understanding and realistically address issues and problems that will inevitably arise, whether we are prepared for them or not. While this does not guarantee that our values and intentions will be implemented satisfactorily, the odds shift much more in our favour. (p. 559).

Indeed, over a period of time the odds have shifted. Ogden (2000) points out that recognition of the psychologist's role in health care settings is being formalised by the use of the term 'clinical health psychologist' or 'Chartered Health Psychologist' in the UK, while, across Europe, Australia and the USA, the term 'professional health psychologist' or 'health psychologist' is being used (Marks et al, 1999). One ought to note, however, that counselling and educational psychologists are, at the same time, retaining their professional titles but holding positions in general hospitals.

However, while psychologists are increasingly involved in multidisciplinary teams, a central component of clinical governance has emerged in the form of evidence-based practice (Corrie, 2003), reflecting the principle that the delivery of therapeutic interventions should be informed by evidence of effectiveness (UK Department of Health, 1997). This as mentioned earlier in this discussion, surely poses a dilemma for the practitioner because, within limited time and financial constraints, it is not possible for the therapist to react spontaneously and innovatively to the patient and, at the same time, engage in research of some legitimacy along the lines of traditional, scientific rigour.

Moreover, as Bor and du Plessis (1997) point out, dilemmas may be more prevalent for counselling psychologists in health care settings because, apart from not being inclined to initiate empirical research, they are nevertheless caught between two seemingly irreconcilable positions. They are expected by the National Health Service to do outcome research when this may be unwelcome, focussing as they do on therapeutic process. In this regard, Bor and du Plessis (1997) add that the counselling psychologist may struggle to maintain a balance between research activity and the provision of an efficient service.

On the other hand, Walsh (2003) suggests that counselling psychologists cannot dismiss the development of evidence-based practice because many of the fundamentals of practice and philosophy derive from such research.

Therefore, in a professional climate of cost-containment, brief therapy and research of limited scope, all occurring while psychologists are finding acceptance in multidisciplinary teams in general hospital environments, suggest the need for both innovation and responsibility for the profession. This is likely to be accompanied with considerable change in forms of practice and research, not necessarily meeting the requirements of traditional practice, nor scientific rigour, but contributing, nevertheless, in a dynamic way, to greater acceptance in multidisciplinary teams.

Finally, it is perhaps appropriate to mention that one may, in a spirit of enthusiasm, be expecting too much. As Sabbath and Stein (1990) remark, success in the collaboration and integration of physical and psychological services may remain difficult unless there is mutual understanding of the realistic capacities and limitations of each professional's therapeutic interventions.

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APPENDIX A

PERCEIVED UNMET NEEDS SCALE

Column A lists needs which parents have in managing their child. Please select, from columns B, C, D, E & F your degree of help required in respect of each need. Circle the option which applies to you.

A	B	C	D	E	F
	Already getting help but would like more	Getting enough help	Not getting help but don't want it	Not getting help but need it	No problems
Improving child's behaviour problems	1	2	3	4	5
Dealing with night time disturbances / waking	1	2	3	4	5
Teaching of self-help skills (dressing, undressing)	1	2	3	4	5
Help with management / discipline problems	1	2	3	4	5
Help with improving child's mobility	1	2	3	4	5
Help with problems with child's appearance	1	2	3	4	5
Help with teaching child positive, new skills	1	2	3	4	5
Help with reducing inappropriate social behaviour(s)	1	2	3	4	5
Assistance with child care at home	1	2	3	4	5
Help with developing communication skills	1	2	3	4	5

	Already Getting help but would like more	Getting enough help	Not getting help but don't want it	Not getting help but need it	No problems
Help with child minding / baby sitting	1	2	3	4	5
Help in coming to terms with child's condition	1	2	3	4	5
Help with child's hearing problems	1	2	3	4	5
Help with marital difficulties / stresses	1	2	3	4	5
Measures to improve housing	1	2	3	4	5
Financial help	1	2	3	4	5
Help with sight Problems	1	2	3	4	5
Information about services for child	1	2	3	4	5
Advice / Information about child's condition	1	2	3	4	5
Chance to discuss child's progress / de- velopment regularly	1	2	3	4	5
Class / workshops to learn how to help own child	1	2	3	4	5
Emergency service for times of difficulty	1	2	3	4	5

APPENDIX B

TRANSCRIPT OF CASSETTE

Introduction

Hello.

Your baby has been diagnosed with having cystic fibrosis. The chances are you've already been told a great deal about it, but there's so much to take in, you've probably found it all a bit bewildering.

The aim of this cassette is to give you some basic information about CF and to answer the questions which come up most often. To do this, we've invited a number of professionals to talk to us.

On side one, we'll be talking about the disease itself and how it is inherited. We'll be covering diet and physiotherapy.

On side two, we'll be talking about drug therapy and discussing a number of other issues.

Let's start with Dr Chris Rolles, who is a Paediatrician specialising in the treatment of children with CF.

Dr Chris Rolles

Right. Well, I've been involved with cystic fibrosis since 1970 and I've found it particularly interesting because I've seen many changes and I've seen the despair that many of us have, as professionals, many years ago, turn to enthusiasm as the whole scene in cystic fibrosis gets better.

Throughout that time, I've dealt with older people with CF, younger people, children who were ill, children who were well, but I've had to take on the task of talking to people when their child is newly diagnosed, in the situation which you are in.

Now, I know that, however carefully I explain it, because there is so much to learn and because it is such a shock to many people and often very frightening, you may take it in temporarily and then, subsequently, you can't remember what people have told you.

Response

Parents do worry about how they are going to remember everything.

One of the functions of this tape is that it gives you a chance to listen to the information and then, if you feel you've got to a point where you can't take in any more, or you're feeling a bit overwhelmed by it all, you can just stop the tape and listen again some other time.

You may also want other members of your family or friends to listen, so that you can discuss it with them.

O.K. Dr Rolles, one of the first questions parents ask, when they're told their child has CF, is "What about life expectancy? How long is my child going to live? Can you tell us something about that?"

Dr Chris Rolles

The overall outlook now is so good that, if someone is born with cystic fibrosis, and they have the best of modern treatment, and the family can take part, as members of the team, then the life expectancy, even if there are no new developments at all, may be well up to the ages of forty or more.

But, of course, for me to say that life expectancy is only up to the age of forty, with no new development, is silly, because of course there are new developments coming on line all the time.

So, I feel now that, instead of seeing this as a gloomy, nasty condition, which takes lives away in childhood, it is now a condition that, with the best of care even as it is, you live well into adult life. But, with modern treatment coming on line, the expectancy, and the well-being, is even greater.

Response

Next, I'd like to bring in Professor Bob Williamson, who is a geneticist, specialising in cystic fibrosis. Professor Williamson, first of all, could you explain what cystic fibrosis is.

Prof Bob Williamson

Cystic fibrosis is a disease which children inherit when they get a gene, which doesn't work properly, from each of their parents.

The lungs don't function properly because the mucous isn't moist enough to flow easily.

The digestive system doesn't work properly because the duct from the pancreas, into the gut, gets blocked.

The problems that children face with their digestion can be coped with, even though they have to take a large number of pills every day.

But the problems with the lungs seem to get worse, just in spite of all of the treatments that we give. The lungs become clogged up with the sticky mucous and the infections that keep occurring and, eventually, the problems with the lungs are life-threatening ones for young people with cystic fibrosis.

Response

And how do you actually get cystic fibrosis?

Prof Bob Williamson

Well, you don't catch cystic fibrosis. It is a genetic disease. It is passed on from parents and, like many genetic diseases, there are a very, very large number of people who carry the gene defect. But, if two carriers have a child, there's a one in four risk that that child will inherit the gene, that doesn't work properly, from both parents, and have the disease.

Ninety percent of children with cystic fibrosis are born to families with no known previous family history. Lots of things are passed on from parents to children: How tall the child is, the colour of their eyes, the colour of their hair.

Cystic fibrosis is a very simple thing because it only involves one gene. Many of the things we think of usually involve several genes but cystic fibrosis just involves a single gene and, in this particular case, it is a gene that controls the rate at which water and salt pass across the cells that line the lungs and line the gut.

And, in the case of cystic fibrosis, when both copies of the gene don't work properly, then the cells can't pass enough water across their surface, and enough salt across their surface, and so the mucous becomes very sticky and clogs up the lungs and clogs up the pancreas and the intestine.

Response

One question that comes up quite often is whether one or other of the parents is to blame for the fact that their child has CF.

Prof Bob Williamson

You can only have a child with cystic fibrosis if both parents carry the gene defect. The child inherits the gene that doesn't work properly – one gene from father, one gene from mother – and, so, both the father and the mother equally carry the gene defect, and equally pass it on to the child.

Response

And how likely is it that parents, who have had one child with cystic fibrosis, will have a second child who also has cystic fibrosis?

Prof Bob Williamson

If two carriers of cystic fibrosis have a child, there is a one-in-four risk that child is going to have cystic fibrosis, there's a two-in-four risk there's going to be a healthy carrier, and there's a one-in-four possibility that they're going to have completely unaffected genes.

If you've had a cystic fibrosis child, your chances are still one-in-four next time. Whenever two carriers have a child, it is always a one-in-four chance.

Response

What about other members of the family?

Prof Bob Williamson

Once a family knows that cystic fibrosis occurs, obviously the family members want to know whether they are at increased risk, and usually they are.

The person who is a carrier of cystic fibrosis has inherited the gene from either the father or mother, and any brothers or sisters will have a fifty-fifty chance of being carriers themselves.

We are very keen that any member of a cystic fibrosis family, who wants to be tested, should go either to their GP or their geneticist and ask for a cystic fibrosis carrier test. You never know what the risk is until you've been screened and, if you are screened, then you have all the options. You can choose whether to totally ignore the information and take a chance or you can choose to go for genetic counselling, for ante natal diagnosis or for any of the other options that exist.

Response

Now, on to something else. Can you tell us: Are some people with CF more ill than others?

Prof Bob Williamson

There are a lot of different ways in which you see cystic fibrosis. There are some very severe cases, some very mild cases.

Doctors can predict, to some extent, how severe the disease is going to be, but most of the cases are going to have the lung and digestive problems that we see so often in cystic fibrosis.

Some children, for some reason, do very much better than we would predict, some children don't do as well.

Response

Thank you, Professor Williamson.

I'd like to move on to the management of CF now. There are three key elements here: diet, physiotherapy and drug therapy.

We'll start by asking Louise McAllister, who is a Senior Paediatric Dietician, to tell us about diet in CF. Louise, over to you.

Louise McAllister

One of the main things we're trying to do, initially, of course, is to help the children to grow well. The main reason we are making sure that the children are well-nourished is to give them strong breathing muscles and also to allow them to resist infection.

The breathing muscles are very important because, if they become weak, then the child won't be able to shift some of the mucous that's around and, if it stays around the lungs, it can become infected, and that, of course, is what can make the children very unwell. So there is a direct link between keeping a child well-nourished and allowing them to fight infections.

Response

Now, could you just tell us: What makes the diet of a CF baby or toddler different from other babies and toddlers?

Louise McAllister

It may well be that the diet of the CF toddler or baby is just normal and one tends to only alter this if you are having problems with weight gain. And the main change that will happen is that you may well use more fats or sugar in the diet to allow a higher calorie intake.

So, enough food, to achieve normal growth in these children, the use of pancreatic enzyme supplements, and the use of vitamin supplements, are the three things that may be different for their typical day.

Response

OK. Can we just take those points one by one?

Louise McAllister

Let's start with: Enough food to achieve normal growth.

Many of the toddlers and children will have very high requirements. They've got to have very high needs for certain aspects of their food intake. This is really because there are two factors that interfere with the normal way that the body handles food.

The first is that there is a poor absorption from the gut, into the body, of the food that is taken in.

The second is that the body is using a lot of fuel or energy. It burns off a lot to be able to function.

And it is these two things that requirements can be high and you might need a little bit of advice on how to achieve that with your child.

Response

OK. So, to be specific, what sort of milk should the baby with CF be given?

Louise McAllister

Most babies with CF can cope well on breast milk or an ordinary infant formula, together with an appropriate enzyme supplement.

In some cases, extra powders may need to be added into these milks or into expressed breast milk to achieve good weight gain but this isn't always necessary.

Response

And what about the toddlers diet?

Louise McAllister

The diet for CF does tend to be a diet that is quite liberal in the use of fat, which includes things like cream and oil and butter and full cream milk and foods that are high in sugar, which will include things like sugary drinks, jam, cakes ... this type of thing.

So, a typical day for a child may well be that the breakfast is just the same as the rest of the children in the family, but you might then choose to have full cream milk or even a very high fat milk at breakfast. You might put a glucose powder, in addition to sugar, on their breakfast cereals, extra butter on their toast, even things like peanut butter. And, throughout the day, foods could be fried. You could actually choose foods that are high in fat.

Response

All this must sound quite worrying for parents.

Louise McAllister

I think parents find it rather daunting when they are first told that diet is important, but many parents will say that it becomes so instinctive, after a while, that they certainly don't have to give much thought to it on a day-to-day level.

Response

Right. Now the second point: Pancreatic enzyme supplements. Can you tell us what they are?

Louise McAllister

Enzyme supplements are used to replace the fat that, in CF, eight five to ninety per cent of children will not be producing the normal enzymes that are needed to digest food. These are normally released from the pancreas, following meals, and help to break down the food that you eat, so that the body can get the goodness from it.

Many drug companies have produced these enzymes that can be taken with meals to replace the natural function that would have been performed by the body. These can either be in the form of powder, which tends to be used for infants, particularly under three months of age, or in the form of small granules, which have a coating, allowing this chemical to be released in the right part of the gut, to perform digestion.

So, the majority of infants and children with CF will be taking these pancreatic enzyme supplements with most of their meals and snacks – everything that needs to be digested.

Response

And how do you know how much enzyme a baby or toddler should be given? Do they all have the same amount?

Louise McAllister

There is quite a variation in the number that children will take per meal. Infants may well need just one enzyme capsule per feed but many will need a lot more than this, and this gives no indication of how ill your baby is because the amount of enzymes that the pancreas is producing is a separate problem to the problem to the problem that can occur in the lungs, and it is the lung problem that affects the ultimate health of your baby.

Response

OK. Let us move on to the third point: Vitamin supplements. Can you tell us about them?

Louise McAllister

All children with cystic fibrosis will be having a vitamin supplement and the main reason that this is done is to provide extra vitamins that are normally lost in the stools in cystic fibrosis.

The vitamin supplements for infants are just in the form of a liquid – the same type of thing that would be used for infants without cystic fibrosis.

Response

Right. Louise has covered the three key elements in diet. Now I'd like to bring in Joan Wilson, who is also a dietician and works with Dr Rolles' team.

Joan, what advice would you give to parents, whose rebellious two year old refuses to eat?

Joan Wilson

I think the important thing to realize is that it is not only cystic fibrosis toddlers that have the refusal problems.

I think the best thing is not to fuss with the child and not to force the child to eat but rather just to remove the plate and not to replace that meal with any food or give subsequent snacks, so that the children learn to eat at mealtimes.

Response

But what if the toddler is not putting on enough weight?

Joan Wilson

If the toddler isn't putting on weight, there are a number of high calorie supplements that we can resort to. These are based on milk and are fortified with vitamins and minerals, and are prescribed by your doctor. But, before we would resort to these, we would look, very closely, at the diet and see how we can incorporate more high calorie food in order to encourage weight gain.

Dr Chris Rolles

There is another point here. The fact is that, if we can keep their nutrition going well, and they're eating, and they're putting on weight, they tend to have better chests.

If we can treat their chests with good physiotherapy and antibiotics, when they need it, then they tend to improve their appetite. And so, to answer the question "What do you do if they're not putting on weight?", obviously includes looking at supplementing their feed but maybe a reason why a CF child is not putting on weight is because their chest infection is not being totally controlled and we have to look at their chest problems as well.

Response

Thank you, Dr Rolles.

The second area of treatment we'll be talking about is physiotherapy.

Christine Ireland is a physiotherapist with many years experience of chest problems in CF. Christine, could you tell us about your role?

Christine Ireland

Yes, my role as a physiotherapist is dealing with your child's chest. As your baby has cystic fibrosis, there is a tendency for them to have thicker mucous on their chest. Therefore, we need to keep the chest as clear as possible.

The techniques involved are very simple and straightforward and will ensure that you have plenty of time to be taught how to do them.

The main principles are positioning your baby, and by that I mean gently tipping them down so that gravity can help drain the secretions, patting your baby's chest, to help loosen the secretions, and gently shaking his chest.

By doing these three different techniques, it will help clear the chest.

Response

And will the baby cough the mucous up?

Christine Ireland

If there is mucous there, the baby will cough it up.

Don't worry if you do not hear your baby cough. It doesn't mean that their chest is full of secretions. They will cough, when necessary. You can't expect a young infant to cough and spit out. We don't normally expect that until the child reaches the age of five.

So, don't worry if your baby is coughing and you do not see any mucous. They will automatically swallow it. That's not dangerous. It is just a natural process of helping to clear their chest.

Response

Christine, could you tell us how often a baby or young child should have physiotherapy and how long each session should last?

Christine Ireland

We would recommend that they have physiotherapy, usually, not less than twice a day for the very young infant and, approximately, ten minutes per session.

As the child grows and they develop, and they are up and running around, we recommend that they have physiotherapy at least once a day, even when their chest is well, to keep them well. It becomes an established part of their daily routine.

By that stage, the sessions would go to no more than fifteen minutes, at the most.

Response

And do you recommend that one parent should become really expert or do you prefer to have more person who knows how to do the physiotherapy?

Christine Ireland

It is important for more than one person in the family to take responsibility for helping with the physiotherapy, just in case one person is ill or is not able to carry out that procedure. It is important that they're able to delegate responsibility and also that the child is used to having physiotherapy from other members of its family or from friends.

So, we would certainly recommend that several members of a family – maybe two or three – are able and comfortable to do the physiotherapy and that the child is happy with them doing it.

Response

And who is going to teach them how to do it?

Christine Ireland

The physiotherapy will be shown to you by the physiotherapist involved in the cystic fibrosis clinic.

They will take plenty of time in showing you what to do and ensuring that you feel safe and competent in doing it for when you go home.

Response

And does the physiotherapy change at all as the child gets older?

Christine Ireland

Yes. Each child is treated individually and they will have their own, individual programme.

As the child becomes older, they're able to be more mobile, and we place more emphasis on exercise. Also, as they start to get older still, we ask them to take some responsibility for starting to do their own physiotherapy.

From the age of three onwards – two or three – we'll start teaching your child how to do very simple breathing exercises. By the time they're about eight or nine, we'll encourage them to be more active in doing their own physiotherapy. It is something that you can ask them to start doing it, a few minutes on their own, and then you can go and see them continue or, alternatively, you can leave them for the last few minutes of their treatment, finishing off themselves.

Response

You mentioned exercise. What sort of exercise should the child be doing?

Christine Ireland

We encourage them to take part in all games at school and to be as active and as fit as possible.

Certainly, if they have particular interests, like swimming or running, then we encourage them to take those up.

For the younger child, often a trampoline, at home, is used to help.

Response

What do you advise if the child doesn't want to do the physiotherapy?

Christine Ireland

This is always a classic question.

I can't stress to you enough the importance of starting off to do physiotherapy at a very early age. It is true to say that, even with young babies, some babies love having their physiotherapy. Most do. But there is an occasional infant that doesn't like being physically touched and physically handled. When you do have a young toddler that refuses to have physiotherapy, although we make the recommendation of ten or fifteen minutes, once or maybe twice a day, it may be better to reduce the amount of time that you spend with the child and incorporate it into games, during the day.

Try hard not to lose the thread of blowing exercises, breathing and coughing, and doing some patting on the chest, but don't push it and don't persevere. Often,

they're going to get really fraught, yell and scream, and do bear in mind that they are ventilating their chest while they're doing it.

Dr Chris Rolles

There is another point that there are children who find it very difficult to tolerate physiotherapy, that we have a few times met parents who find it very difficult to do physiotherapy. They're frightened that they're going to hurt their child or they suddenly feel, somehow, that they're very incompetent and very worried.

Christine Ireland

I do want to stress that physiotherapy is not painful and it does not hurt your child.

Response

Thank you, Christine.

And that brings us to the end of side 1. Now, turn your tape over to continue the programme.

Hello again. On side 2 of this programme, we'll be talking about drug therapy and another of other issues, including emotional support, school, relationships with brothers and sisters, the importance of clean air, and the outlook for the future.

We'll start with drug therapy, the third key area in the management of CF. Dr Rolles, apart from immunization against things like whooping cough and measles, and inoculation against flu, which are all essential in CF, where else does drug therapy come in?

Dr Chris Rolles

Many experts, who deal with cystic fibrosis, believe that, by using a very simple antibiotic all the time, flucloxacillin, it may reduce the likelihood of some germs getting into the mucous in the lungs and settling in.

So, even with the best physiotherapy in the world, occasionally chest infections will still occur, and they are more likely to occur in CF, and, for this reason, antibiotics are used much more often with chest infections, and even with bad colds or flu, in order to prevent germs getting into the lungs.

Response

With all the bad publicity that antibiotics have had in the media, aren't parents going to worry about this?

Dr Chris Rolles

The problem in CF is that even a cold or flu can reduce the resistance in the lungs a little bit and, if you've already got these thick mucous secretions there, then a mild cold or cough can initiate, or begin, a chest infection with a nasty germ.

So, we have a different policy. We're much more vigorous and we, in the hospital, in contact with your GP, may well prescribe antibiotics fairly readily.

Response

So, the position regarding antibiotics is rather different in CF.

Next, I'd like to introduce Judy Maddison, who is a CF nurse. Her role in the pattern of care has become increasingly important over the last few years. Judy, would you like to tell us a bit about it?

Judy Maddison

My role is a very varied one. I tend to act as a sort of co-ordinator for you, looking at you, as the individual, what type of care you and your family are going to need and, hopefully, help you through.

Every new family has got a lot of questions, especially when there is a new baby around.

You've probably met a lot of professionals who have told you a lot of things and I'm hopefully there to talk to you, go through things again, clear points with you and, basically, answer those little niggles that, perhaps, you're not quite sure who to ask.

I work with all the families, so I've got experience which comes, practically, from the parents. I think there's no better source than passing on information from one parent to another about a trick they've tried that has worked.

Response

Judy, those early stages, when parents first learn their baby or toddler has CF, must be a very difficult time.

Providing emotional support to parents must also be a very important part of your role.

Judy Maddison

Obviously, we do appreciate that it is a pretty devastating thing to be told and it is probably the main area that the nurses do come in.

We've got a lot of time for you. Nurses understand what you are going through although, obviously, we have not been in the position you are in. We've got the time to talk and, more importantly, we've got the time to listen.

Nobody is going to mind if you cry, if you want to shout.

It is understandable that you are going to feel angry and upset. They are normal emotions and your nurse is there to help you work through them.

Response

And you must also have an important role to play as a link with the health visitor and the GP.

Judy Maddison

I don't just work in the hospital. I actually work out in the community, which means I know a lot of the health visitors and their GPs already.

I tend to go, and I will introduce myself if I don't already know your health visitor, and then, together, we will help you over the initial stages and then, as your child develops, again I do the same with the GPs. We go, we discuss the type of care you're going to need and, as those needs develop, we will develop with you.

The idea is that you get an individual care, not just based from the hospital, but from those people that are at hand, such as the health visitors out in the community as well.

Response

Dr Rolles, would you like to add anything here?

Dr Chris Rolles

One thing that's quite important, isn't it, is that CF isn't something that goes away. At the moment, we don't have a cure. What we have is increasingly good forms of treatment and the way we work, in Southampton, is a very common pattern, that we

would see children with CF, probably, early on, at least every two weeks or every month and then, once things are going well, we might see people every two to three months, in the clinic. And, in our clinic, each time you come to the clinic, you will meet all the members of the team.

In addition, we do something which is fairly common now throughout the country, and that is, once a year, we have a clinic visit which is a rather special one, which takes a bit longer and this is popularly known, in many parts of the country, as the MOT because things are tested, blood is taken, there may be X-rays and various other things to determine how the last year has gone and, perhaps, make plans and decide what our targets are for the coming year.

Response

And what would you say to parents about their role in this?

Dr Chris Rolles

The rest of the team tell you how things are going and advise you on how to do it, but the actual person dealing with the child, nearly all of the time, is you, as parents.

So, we would like to think that you join us, as part of that team.

Response

OK. Back to Judy again. Judy, on the question of emotional support, is there anyone else, apart from the nurses themselves, to whom parents can turn?

Judy Maddison

There's another very important area which is actually organized by the CF Trust and these are volunteers, who are parents themselves, who are willing to listen and help in whatever way they can. They really are a very good source of support. They've

all got their own children and they really do understand exactly how you feel and they are very well worth contacting.

Response

The CF Trust is also a very good source of information on any benefits and allowances you might be entitled to. They have all the latest details on what is available.

So, if you have any questions, give them a ring.

Now, on to the subject of school. Judy, a lot of parents worry about what to tell teachers and classmates. How do you handle this?

Judy Maddison

Quite often I go and see the teachers before the child actually goes to the school.

We talk about their understanding and I will explain the disease further or correct any misunderstandings they may have. We also talk about the practical issues. Is the child likely to become unwell in the classroom and what should they do if that happens.

We do ask them about watching for the diet, allowing the child to have snacks and, perhaps, some schools don't even allow breaks.

The main thing is for the teachers to feel that they understand what the disease is and they feel supported.

We do also offer to actually talk to the other children in the class. This is something I would only do if the parents asked me to as I feel it is important it is done with their consent and with the child knowing what's going to happen.

Response

And who is in charge of the enzymes and food supplements - the teacher or the child?

Judy Maddison

This varies tremendously from school to school. It is really important to go in and talk to the class teacher.

Each school has their own, individual policy. Ideally, they allow the child to keep the enzymes with them so that they have them as soon as they go into the canteen to eat. However, some schools won't allow that, and you need to sort out the best system for your child, with your school.

Response

What about school trips? Do they pose any problems?

Judy Maddison

Again, this is something that varies tremendously from school to school.

If it is a day trip, the schools will normally take them without any worries at all. With some extra teaching and some practical support, we find most schools will try very hard to ensure that the children don't miss out on trips.

Response

Right. I've got one more question for you. What about brothers and sisters and their relationship to the CF baby or child? Jealousy can be quite a problem, can't it?

Judy Maddison

Things with siblings can be very difficult.

Obviously, your affected child is going to need a lot of time spending with them, in the form of physiotherapy, coming up to the hospital.

They're probably going to be allowed foods that their brother and sister aren't going to be able to have quite so freely.

And, so, there's a good chance that resentment will build up. It's very important to realize that this can happen and that it is a very natural thing to do.

Try and make time for your other children, in the same way that you're making time to do physio or specially preparing snacks. Make time for that other child.

So, when they come in from school, for instance, don't get straight into the physio. Make time for the other child as well. Do things together as a family, not just something that is important to the CF child. Time for the sibling is the biggest and easiest way of keeping sibling rivalry down and stopping the resentment.

Response

Thanks very much, Judy.

Dr Rolles, is there anything else you would like to add at this point?

Dr Chris Rolles

Yes. One other factor which is really over to the family rather than to us, as the professionals, is to try to make every attempt one can to keep the air, that the child is breathing, as clear as possible. The CF lungs really can't handle either nicotine very well or smoke very well. And although I, as a paediatrician, would like to think that

no children are subject to other peoples' cigarette smoke, I realize that it is not an easy thing to prevent. But, in CF, I feel it is particularly important.

Now, if this child is going to be in an environment where there is smoking, the choices you have are to try and reduce that or stop it altogether, if you can. If that's not possible, at least you can try and smoke in rooms where the child doesn't ever go or you can go out onto the balcony, or go miles away, or do whatever you can.

Response

Well, that's a clear enough message.

Professor Williamson, could you come back in now and tell us something about the outlook for the future?

Prof Bob Williamson

Thirty or forty years ago, children with CF often died within the first few years of life.

So, I think, that although at the moment cystic is still a very severe disease, for the vast majority of people that have it, it is a hopeful situation because many of the developments, that are taking place just now, are beginning to solve the problems that we find with lung infection, with sticky mucous and with the digestive tract.

And I think that, over the next period, even leaving aside gene therapy, we're beginning to see better and better treatment, particularly for the infections and the mucous that sticks in the lungs.

Response

You mentioned gene therapy. Could you tell us about that?

Prof Bob Williamson

In the case of gene therapy, what we want to do is to put the gene that works properly back into the lung cells that have a defective gene in them, and hope that the gene we put in makes the protein that carries the water and salt across the surface of the cells.

So, you need to spray the gene into the lungs, using a nebuliser, in just the same way as anti-asthma drugs are put into the lungs. And, a lot of the effort now is going into working out whether it is better to carry the gene in with a virus or whether it is better to carry the gene in with a fat particle.

And, all of these different techniques, which are being tested in many labs throughout the world, are eventually going to be put together, to give the safest and most effective form of treatment.

Response

And how close are we to perfecting it?

Prof Bob Williamson

It will still be a few years. I don't want to give people the impression that this is going to happen tomorrow. It will be some time yet before we can be certain it's absolutely safe and before we can be certain that it works to the extent that it needs to work.

But there's certainly hope for the future.

Response

Dr Rolles, before we go, could you sum up your general feelings about the future?

Dr Chris Rolles

I feel very optimistic. I think that, with a much more vigorous approach from doctors and the professional staff, with parents becoming involved in the team in an active way, with regular clinics, with vigorous treatment of infections, and better techniques of physio, and better diets, and better enzymes, that, really, CF is no longer that awful, dreaded thing from the past.

And, one final warning: Don't go to a library and read up old books about your health because, even things that were written five years ago are unnecessarily pessimistic compared to how we look at CF today.

So, if you're going to read anything about it, read things that are very up to date, probably from the CF Trust, or talk to people who know what is going on currently.

Response

And, if there's anything else at all that you'd like to know more about, the Cystic Fibrosis Trust is there to help you.

So, just give them a ring or you could write if you prefer. Good bye and thank you for listening.

The telephone number of the Cystic Fibrosis Trust is 01814647211. And you can write to them at Alexandra House, 5 Blythe Road, Bromley, Kent BR13RS.

APPENDIX C

CONSENT FORM

Participation in this research will involve completing four simple questionnaires and the usage of a free support package provided by the Cystic Fibrosis Trust.

Participation is voluntary. You are free to withdraw at any stage without giving a reason.

Participation or withdrawal will not affect your medical treatment in any way.

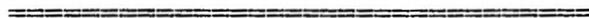
All information gathered remains confidential and will be protected by me, the researcher.

Your assistance with the research is appreciated.

J Marshall

Chartered Psychologist: _____

Date: _____



I have read the patient information sheet provided by the researcher and have satisfied myself that I understand it.

I voluntarily agree to participate in the research.

NAME: _____

SIGNED: _____

APPENXIX DPatient InformationResearch on support of parents will ill children

We are researching parents' needs following the diagnosis of their child's illness. The information we collect will help us to understand your needs and the usefulness of a support programme which we will be offering. We believe that participation in the project may also help other parents who have children receiving treatment.

Taking part in the study would involve meeting the researcher and completing four short-form questionnaires, at your convenience. The researcher will also explain further about the study and be available at all times for questions and help. A free support package, provided by the Cystic Fibrosis Trust, will be offered to you.

A follow-up meeting, about a month after your first meeting with the researcher, is anticipated. The researcher will review the appropriateness of the support with you.

Participation in the study is entirely voluntary and does not affect your treatment at the hospital in any way. You may withdraw from the study at any stage, without having to explain your reasons. It will also not affect your medical treatment.

All information given will be entirely confidential. The researcher will protect the confidentiality of information by assigning a number (and not a name) to you.

Thank you for considering taking part in the study.

J Marshall

Chartered Psychologist
Peterborough District Hospital

Researcher: Jerome Marshall, C.Psychol
Telephone: 01733 874122 (Peterborough District Hospital)

APPENDIX E

Approval to commence study



Our ref: NJS/JS

Mr J Marshall
Chartered Psychologist
The Cedars Family Unit
PDH

28 November 1995

Family Consultation Service

PETERBOROUGH DISTRICT HOSPITAL
THORPE ROAD
PETERBOROUGH
PE3 6DA
TELEPHONE 01733 874000

Reply to: Ext. 4504

Dear Mr Marshall ^{3 copies}

A PSYCHOLOGICAL SUPPORT PROGRAMME FOR PARENTS WHOSE CHILDREN HAVE A SERIOUS ILLNESS
No. P95/32

Thank you very much for forwarding me a copy of your revised Consent Form.

I confirm I have taken Chairman's action enabling you to commence your study.

I do wish you well and would appreciate your forwarding a copy of your completed findings to Mr Ron Smith (Secretary) at Edith Cavell Hospital.

With kindest regards.

Yours sincerely

N SHORTALL
Chairman
Peterborough Ethics Committee

cc Mr R Smith

Head Office

53 THORPE ROAD, PETERBOROUGH, PE3 6AN.
TELEPHONE 01733 318100, FAX 01733 318139.