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The experience of transferring to adult health care for adolescents with cystic fibrosis

Maree T. Russell
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**THE EXPERIENCE OF TRANSFERRING TO
ADULT HEALTH CARE
FOR ADOLESCENTS WITH CYSTIC FIBROSIS**

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Post Grad Diploma (Health Sciences),
B.App Sc (Nursing), RN.**

**A Thesis submitted in partial fulfilment
of the requirements for the degree of**

Master of Nursing

**at the
School of Nursing
Faculty of Health & Human Sciences
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Perth, Western Australia.**

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Abstract

As a result of improved treatment and management, adolescents with cystic fibrosis (CF) now have a longer life expectancy. Consequently, more adolescents will be transferred from paediatric to adult health care. Currently, transfer to adult health care takes place on an adhoc basis. Little research however, is available on adolescents with CF and the transfer process to adult health care. This transfer may be viewed as a significant life event for these adolescents and their families. A descriptive approach was used in this study to investigate the experience of transferring to adult health care for adolescents with CF. Seven adolescents with CF and their parents provided data on their perspective of the experience of the transfer to adult health care. Semi-structured interviews, based on Roy's Model of Adaptation, were conducted to obtain the data. The data were initially categorised into Roy's adaptive modes and then analysed using content analysis. From the findings it is apparent that the experience of transferring to adult health care was influenced by the developmental stage of the adolescent, and parental adaptive tasks. Haphazard preparation also contributed to a negative experience of transferring. Implications for nursing practice include the development and implementation of a planned programme for the transfer to adult health care. Future research will incorporate an evaluation of the transfer programme.

Declaration

"I certify that this thesis does not incorporate, without acknowledgment, any material previously submitted for a degree or diploma in any institution of higher education and that, to the best of my knowledge and belief, it does not contain any material previously published or written by another person except where due reference is made in the text."

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Chapter I

Introduction

Background

Cystic Fibrosis (CF) is a genetic disorder resulting in the dysfunction of exocrine glands; it is mainly restricted to, and is the commonest autosomal genetic disorder, in the Caucasian race (Harris & Super, 1991; Jackson, 1989). CF is considered to be a chronic illness, it lasts longer than six months and the onset may be rapid or slow with varying degrees of restriction as a result of the illness. The illness may also involve episodes of exacerbation of the disease process (Bates & Linder-Pelz, 1987; Gilliss, Rose, Hallburg & Martinson, 1989).

Variation in the severity of symptoms of CF gives rise to a range of different problems with which the child and family have to live and cope. Respiratory problems, such as wheezing and a dry non-productive cough (which often becomes paroxysmal), are present in almost all children with CF. In addition, secondary pulmonary infections can frequently develop, often necessitating hospitalisation for treatment of the superimposed infection. With progressive pulmonary involvement the chest may become barrel-shaped and there is often clubbing of the fingers and toes; deterioration of the lungs is ongoing. Children with CF may also experience gastrointestinal problems, including malabsorption and pancreatic insufficiency (Brooks, 1987; Jackson, 1989). As malabsorption of protein and fat occurs, those with CF are likely to be underweight. Consequently, a diet high in calories and protein is recommended with the addition of pancreatic enzymes to promote normal growth and weight gain, and to compensate for the extra workload of respiration (Brooks, 1987; Dodge, 1989). At present there is no cure for this illness (Wilmott & Fiedler, 1994). Improving and maintaining pulmonary function, and preventing infection are the foci of management strategies.

Significance of the Study

Adolescence often heralds an escalation of symptoms which may result in frequent clinic visits or hospitalisation for the adolescent with CF (Dibble & Savedra, 1988; Nagy & Ungerer, 1990). Adolescence is defined as the period in the life span that begins with puberty and lasts until physical and cognitive maturity has occurred (Blos, 1962). For many of those with CF life expectancy ended with adolescence; however, this has now changed. Data from the United States of America cite the median age of death for those with CF as 18-20 years; some deaths occur in infancy, whilst some CF sufferers have lived to 40 years of age (James & Mott, 1988). For a child born with CF in 1990, in England and Wales, the median life expectancy is estimated to be 40 years of age; this increase has doubled over the last 20 years (Elborn, Shale & Britton, 1991). In Victoria Australia, a child with CF is estimated to have a 91% chance of living to the age of 20 years and a 65% chance of reaching 30 years of age (M. Hibbert, Victorian CF Register Co-ordinator, personal communication, August 22, 1994). The increase in life expectancy for individuals with CF is a result of advances in treatment and management of the disease (Dibble & Savedra, 1988). Consequently, more adolescents with CF will be transferred from paediatric to adult health care for management of their illness.

Although life expectancy has increased for this population it is much shorter than normal. So why transfer to an adult health care facility? The literature suggests that adolescents can be more appropriately cared for in the adult rather than in the paediatric setting (Blum, 1991; Cappelli, MacDonald & McGrath, 1989). Adolescent independence and self-sufficiency can be promoted, and adult-type problems, such as fertility and genetic counselling, can be more easily managed by health care providers familiar with adult health issues (Boyle, di Sant'Agnese, Sack, Millican & Kulcycki, 1976; Schidlow & Fiel, 1990). Life expectancy is also increased for children with CF when cared for in a specialist centre, as opposed to care by the local paediatrician (Phelan & Hey, 1984). Those with CF living in Victoria, Australia, were found to have an 80% chance of living to 20 years of age, whereas in England and Wales the chance of surviving to 20 years of

age was only 62% (Phelan & Hey). The major difference in the care provided was that 90% of those with CF in Victoria were cared for in a specialist centre and the majority of those in England and Wales were cared for by the local paediatrician. The transfer of adolescents with CF to an adult health care facility only began in the fairly recent past. At present no clear criteria exist to determine if an adolescent is adequately prepared for transfer (Cappelli et al., 1989).

Paediatric hospitals across Australia were informally surveyed for information pertaining to the transferring of adolescents with CF to adult health care (Table 1.1). As there are no paediatric hospitals in Tasmania or the Northern Territory, they were not surveyed.

Table 1.1

Transfer Policies of Paediatric Hospitals in Australia.

State	Transfer Policy	Age for Transfer	Transfer	CF clinic at adult hospital
W.A.	Yes	16-19 years	adhoc basis	Yes
N.S.W.	No	18 years	adhoc basis	Yes
Queensland	No	indefinite	No	No
S.A.	Yes	18 years	adhoc basis	Yes
Victoria	Not yet implemented	nil specific	adhoc basis	Yes

The paediatric hospital in Perth Western Australia, has developed an admission and discharge policy which states that all children with a chronic illness are to be transferred, preferably by age 16 years and strongly encouraged by the age of 19 years, to adult health care (Princess Margaret Hospital for Children [PMH] 1991). Currently this is not strictly enforced and transfer takes place on an adhoc versus a structured basis (L. Hofer, Cystic Fibrosis Co-ordinator, PMH, personal communication, April 9, 1992). That is, the transfer occurs with no established criteria, and little or no preparation of the adolescent and/or family for this event. Preparation may include an orientation tour of the adult hospital for the adolescent. Parents were not encouraged to join the tour as the

adolescents were presumed to be sufficiently mature to undertake this activity alone. The decision to transfer appeared to reside with the paediatrician.

At a paediatric hospital in New South Wales, it is hospital policy to provide care for adolescent patients until they are 18 years of age regardless of the illness, but there are no strict guidelines for transfer (J.Y. Minnis, Director of Nursing, The Children's Hospital, Camperdown, personal communication, April 16, 1992). At this hospital it is also usual for transfer to an adult setting to be arranged on an adhoc basis.

In Queensland, the paediatric hospital does not have any guidelines for admission and discharge of patients with CF (L. Clark, CF Nurse Consultant, The Royal Children's Hospital, Brisbane, personal communication, April 29, 1992). In the past those with CF either continued to be managed at the paediatric hospital or were referred individually to adult physicians. A CF clinic is only now (1992) being established at an adult hospital in Brisbane.

In South Australia, the paediatric hospital has a formal admission and discharge policy. Hospital based care is provided until the patient is aged 18 years. Transfer to adult health care is planned by examining criteria such as, living independently, no longer attending school, or having joined the workforce. This planning for transfer to adult health care is undertaken on an individual basis and may be delayed beyond the 18th birthday if the patient is unwell or in the terminal phase (K. Pippett, Clinical Nurse Consultant, The Adelaide Children's Hospital, personal communication, October 20, 1993).

In Victoria, the paediatric hospital has formulated a transition policy for the transfer of adolescents to adult health care but this policy has not yet been implemented. To date, the transfer has taken place on an adhoc basis with no age specified (T. Morton, Charge Nurse, Royal Children's Hospital, personal communication, June 3, 1994).

In discussing transition issues generally for youth with disabilities, Blum (1991) noted that prevalence lists of chronic conditions excluded conditions that the youth considered to be of importance to them, for example, acne. The adolescents' perspective

was that health professionals trivialise the adolescents' concerns by failing to acknowledge conditions that the adolescents consider to be important. Blum (1991, p. 103) succinctly captures the adhoc situation of transferring adolescents with a chronic illness to adult health care when describing transfer from paediatric to adult health care as being "...primarily by default rather than by design", that is, the transfer occurs with little or no preparation or planning. The timing of transfer appears to be linked to a chronological age during adolescence.

Another concern was that paediatric nurses providing care for adolescents with CF have identified a reluctance by the adolescents to transfer to adult care. Of concern are the anecdotal remarks of some adolescents with CF, such as, "transferring is a death sentence!", and the adult teaching hospital "is the place where children with CF die" (L. Hofer, Cystic Fibrosis Co-ordinator, PMH, personal communication, April 9, 1992). The adolescents' perceptions have the potential to influence and jeopardise a successful transfer. To adequately prepare the adolescent for transfer to adult health care, these and any other concerns will need to be addressed in the preparatory stage prior to transfer. The apparent lack of planned preparation for transfer and subsequent influence on adolescents transferring to adult health care, the negative perceptions of transfer held by some adolescents, and the effect of the transfer on the family unit require investigation. Through understanding the transfer experience, effective nursing care and preparation for transfer can be provided for adolescents with CF and their families.

Purpose of the Study

The purpose of this study was to describe the experience of transferring to adult health care for adolescents with CF. Little was found in the literature relating to the adolescent's experience of transferring to adult health care, and what was considered significant to the adolescent and family. Because CF and the transfer process affects the whole family, both the adolescent and parent were interviewed. In most cases, parents will have been responsible for the daily management of the adolescent's CF, as well as

supporting and nurturing their adolescent. The parents then, bring their own unique perspective on the experience of transferring to adult health care. By understanding the transfer experience, effective nursing interventions can be planned and implemented in order to prepare both the adolescent and family for the transfer to adult health care. Knowledge gained from this study can be used as a basis for developing and formulating guidelines to facilitate a smooth transfer process for the adolescent, family, nurse and other health care providers.

Research Questions

1. What is the experience of transferring to adult health care for the adolescent with cystic fibrosis?
2. What is the perspective of a parent, of an adolescent with cystic fibrosis, on the transfer of the adolescent to adult health care?
3. What are the implications for nursing practice in preparing adolescents with cystic fibrosis, and their families for transfer to adult health care?

Chapter II

Literature Review

Introduction

A review of the literature found little information on the experience of transferring to adult health care for the adolescent with CF. No studies were found in relation to transferring to adult health care from the perspective of the adolescent with cystic fibrosis (CF), parents or the family. Much has been written on the topic of coping with a chronic illness, however, the emphasis has mainly been on chronic illnesses per se, rather than studying individual chronic illnesses such as CF.

Coping is seen as the way one changes in order to deal with and live with the changing environment (Austin, 1990, Canam, 1987; Roy & Andrews, 1991; Savedra & Dibble, 1989). An individual is said to be coping when the outcome is effective in promoting the well-being of an individual. Through coping, the individual has adapted or changed to meet the requirements of a given circumstance in the changing environment. The level of coping is exhibited in the individual's response or behaviour to a given situation and may have a positive or negative outcome (Roy & Andrews). One situation in which the individual is required to develop adaptive coping strategies is that of living with a chronic illness. As chronicity is a fluctuating state, coping with the changes in health and ability may necessitate frequent revision of strategies. In the current study, the adolescent and family must cope with the transition from childhood to adulthood, CF, and the transfer to adult health care. By examining an individual's or family's degree of coping with a chronic illness or major life event, such as transfer to adult health care, the level of adaptation can be ascertained and the need for nursing interventions can then be determined. Consequently, the literature was reviewed first from the broad perspective of coping with a chronic illness, followed by adolescents' experience with CF, and finally the transfer of adolescents to adult health care.

Coping with a Chronic Illness: Ill person's perspective

Strauss and Glaser's (1975) classic research examined the effect of chronic illness on the quality of life and subsequent coping, of both the chronically ill person and the family. To determine how the ill person and family manage to live as normal a life as possible despite the chronic illness, the focus was on daily requirements whilst living at home and not during hospitalisation. Data was gathered on the social and psychological aspects of living with a chronic illness, and therefore, the effect on quality of life. The majority of the subjects were adults with chronic illnesses: rheumatoid arthritis, ulcerative colitis, Parkinson's disease, and terminal stage diseases. By examining quality of life issues, such as activities in the home, the ability to go on outings, strategies for coping with the illness were used as the basis for the development of a chronicity model. It was found that the participants needed to cope with changes to lifestyle because of the illness, day to day management problems, and the effect of the illness on both the individual and family. Strauss and Glaser concluded that people with a chronic illness face common problems, or adaptive tasks, regardless of the actual type of disease (Table 2.1). Because of these common problems they suggested that the medical and categorical approaches to chronic illness be abandoned in favour of this chronicity model.

Table 2.1

Chronicity Model Adaptive Tasks.¹

1.	Preventing and managing medical crises
2.	Managing regimens
3.	Controlling symptoms
4.	Normalising
5.	Managing the illness trajectory
6.	Re-ordering time
7.	Dealing with a lack of social contact
8.	Dealing with family relationships & finances

¹ Derived from Strauss & Glaser, 1975

According to Strauss and Glaser (1975) chronically ill people and their families needed to accomplish the adaptive tasks to be able to live optimally with the illness. Individuals with CF and their families, may also be expected to carry out these identified tasks to cope with the chronic illness. Although this chronicity model provides a broad understanding of the experience of living with a chronic illness, it does not allow for the unique responses of individuals and their families to the same illness (Woods, Haberman & Packard, 1993).

As a group distinct from children or adults, adolescents were not studied by Strauss and Glaser (1975). The lack of adolescent inclusion may have been a reflection of adolescent issues not yet emerging as an entity on their own. Portions of Strauss and Glaser's chronicity model have subsequently been used to investigate adolescents and adults, as a group with a chronic illness, as well as adolescents with CF, but not in relation to transferring to adult health care (Salmond, 1987; Yarcheski, Mahon, Kraynyak-Luise, & Baker, 1987).

Meeting the health care needs of chronically ill persons has also been identified as important for coping with a chronic illness. Salmond (1987) conducted a descriptive study based on Strauss and Glaser's (1975) chronicity model to ascertain the chronically ill person's perception and prioritisation of health care needs. Subjects were recruited from three specific disease groups: myasthenia, epilepsy, and cardiac conditions. The subjects' ages ranged from 15-70 years. The study reported that differences in health care needs were found to occur at the time of diagnosis, and during a medical crisis. The subjects prioritised a range of health care needs, with information on diagnosis and treatment being the highest. The next highest priority was knowledge of and access to services and resources, which then gave the subjects a feeling of control over their illness. Control included being consulted, and being part of decision making in matters related to health care. The author suggested that this priority of health care needs can be guardedly generalised to all those with a chronic illness, as variations across illnesses showed more similarity than differences. The study by Strauss and Glaser also found

more similarities across illness groups than differences and concluded that those with a chronic illness shared common problems and adaptive tasks. In both studies, however, not all chronic illnesses and age groups were represented, which may reduce the generalisability of the results.

Parental Coping

Parental coping and the influence of chronic childhood illness on the family has also been studied. Krulik (1980) investigated the 'normalising tactics' of 20 mothers with a chronically ill child, aged 6-10 years. The chronic illnesses of these children were CF, acute lymphoblastic leukaemia, and other malignancies. The normalising tactics were used by mothers to help their child cope with the chronic illness by reducing the child's sense of being different to siblings and peers; and to make the situation normal for the family. Krulik identified three major areas in which these tactics were used: management of medical regimens, changes in body appearance and body functions, and threats to the performance of the child's roles. Tactics included giving the siblings vitamin pills when the chronically ill child took medications; incorporating the child's physical therapy into the family's physical exercise routine; inviting friends over to play indoors when the chronically ill child could not go outside; and arranging tuition for school work so that the child would not fall behind in school work. In this study, mothers perceived that they were successful in normalising aspects of the chronic illness, and in imparting a sense of control over the illness to the child. Therefore, the child and family were able to cope with the chronic illness.

Hymovich (1981) investigated the impact of chronic illness, and the coping of families who had a child with a chronic illness from a parental perspective, and subsequently developed an assessment tool. The data obtained was related to living with a child with CF, and the coping skills employed by parents to solve problems. Findings from subsequent research (Hymovich, 1984), with families of children with other chronic illnesses, were used to refine this tool; called the Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ).

Using the CICI:PQ, Hymovich and Baker (1985) examined parental perceptions of the impact of CF on family functioning. In this exploratory study, the sample comprised 103 mothers and 58 fathers with various family structures and differing life cycle developmental stages. The ages of the children ranged from less than one year to less than 20 years. Twenty-three percent of the children were adolescents. The main areas assessed by the parents completing a likert-type questionnaire were self concerns, parent needs, parent relationships and parent coping strategies. No differences were found between the mothers' and fathers' responses in the perception of the impact of CF on their family functioning. Parental concerns were related to the child's future, comfort, information on the child's condition, and growth and development issues. As the study results were not presented in respect to the childrens' ages or developmental stages, it is not evident which concerns were related specifically to the parents of the adolescent group. The study thus provides no delineation between concerns of parents with children and parents with adolescents. Yet again only the overall group experience is described which provides little direction for aiding parents with adolescents in dealing with concerns related to adolescence.

McCubbin (1984) also studied parental strategies for managing family life when a child has CF. The childrens' ages ranged from three months to 28 years, with a median age of nine years. The data was obtained from a questionnaire completed by 95 mothers and 90 fathers. No significant differences were found between the mothers' and fathers' coping strategies. Three coping patterns were identified. The first was related to family dynamics and parental outlook on life; for example, the degree of family unity and ability to function as a unit. The second focussed on parental strategies in developing relationships; for example, using social support to increase feelings of individual identity and self-worth. The third coping pattern concerned affiliations with other parents of a chronically ill child, and health professionals; for example belonging to parent support groups, and using health professionals as resource persons. Through the use of these

coping patterns the parents were seen to be coping with the stresses imposed by CF and thereby adapting family life when a member has CF.

Adolescents with Cystic Fibrosis

Studies have investigated varying aspects of the adolescents' and young adults' experience with CF. A descriptive approach was used by Brissette, Zinman, Fielding and Reidy (1987) to focus on subjects' concerns related specifically to CF and its treatment. Twenty-eight adolescents/young adults with advanced CF, aged 16-37 years, and their families were interviewed by their home visiting nurse over a period of six months to 3 years. The initial frequency of visits was weekly for the first month, then fortnightly for a month and thereafter monthly. After each visit the nurse recorded "...problems spontaneously brought up for discussion by the patient or family" (Brissette et al., 1987, p. 89). Three major categories of concerns were derived from the data: CF management, growth and development, and family relations. The CF management category included concerns related to treatment compliance, nutrition, and hospitalisation. In the growth and development category, the concerns revolved around daily activity, and the impact of physical and social limitations. Also included in this category was performance at work or school, with the subjects found to be ambivalent towards both education, and the future. Family relation concerns were manifested by the impact of stress from a chronic illness on the marital relationship as well as the family unit. It was not until after one year of contact with the nurse, that the subjects freely discussed difficulties experienced in family relationships. Discussions about anxieties relating to death and dying were uncommon, even after a year of contact with the one nurse (Brissette et al., 1987). This reluctance to discuss sensitive issues supports Hymovich's (1987) observation of the need for a trusting relationship between those receiving, and those providing care. Continuity of care by the same nurse will also support the development of a trusting relationship. The ensuing rapport will then provide the client with a firm basis on which to discuss sensitive issues.

Boyle et al. (1976) interviewed 27 people with CF, aged 13-30 years, to determine their level of daily functioning, psychological stress, and awareness of the future. The majority of the sample reported that they experienced isolation, with half the sample stating that they had no close friends. The adolescents avoided any discussion on the future, whilst the young adults were mainly concerned with examining their lives in retrospect, rather than looking to the future. Also, all were hesitant in discussing issues of death and dying and employed denial and avoidance mechanisms to deal with this aspect of living with CF. Despite some negative findings subjects were deemed to be coping adequately with living with CF.

It is over 18 years since this study was conducted, and the result may be a reflection of the then shorter life expectancy. In the intervening years, life expectancy has been lengthened. More recent studies have found adolescents actively planning for the future and not experiencing social isolation (Smith, Gad & O'Grady, 1983; Yarcheski et al., 1987). In opposition to these findings, Brissette et al. (1987) found subjects to be indecisive in matters related to education and the future.

The findings of the preceding studies on individuals with CF were based on a sample of subjects with a large range in age. Results were not given by age, therefore, it is difficult to know if, or how, the variance in ages and developmental stages of the subjects affected the results of these studies.

Other studies on CF have specifically involved adolescent subjects. Yarcheski et al. (1987) attempted to validate three of Strauss and Glaser's (1975) adaptive tasks: re-ordering of time, social isolation, and family relations. Using a likert-type questionnaire the responses of 30 adolescents with CF were compared to 30 healthy adolescents. The variables studied were future time perspective, loneliness, and perceived maternal expressiveness. Yarcheski et al. chose these adaptive tasks because they were also considered to be experienced by adolescents without a chronic illness, as well as being relevant to adolescent development. Future time perspective involved one's perception of being able to predict, control, and structure the future. Time perspective included

managing and organising one's time and was also influenced by one's attitude towards the future. Loneliness was the absence of friendships, social relationships, and social activities. Maternal expressiveness was the affective attachment of the child to the mother and the visible display of affection. No difference was found between the study and control groups in any of the three variables. The authors then questioned the validity of the adaptive tasks for adolescents with CF. The fact that no differences were found may be a reflection of the adolescents' adaptation to, and coping with CF. Amongst the CF group considerable variability was reported in future time perspective, yet the variability of this result was not discussed in detail. The authors considered the variability to be related to the CF adolescent's acceptance or rejection "...of the fatality of their disease" (Yarcheski et al., p. 257). Although the results were dissimilar to Salmond (1987), this difference may be accounted for by the differences in the subjects' ages in the two studies.

Smith et al. (1983) quantitatively investigated the clinical status of adolescents with CF, psychosocial functioning, and life change. The sample consisted of 26 adolescents with CF, aged 12-18 years. The adolescents were asked to rate selected life events, the impact of the event - whether it was seen as positive or negative - and the magnitude of the event for them. Some of the life events were "...death of a family member, moving to a new home, and failing a grade" (Smith et al., p. 321). Adolescents with CF who had a poorer health status reported more negative life events with a greater impact, than did the adolescents with CF in better health. These negative events were said to have a greater influence on those adolescents who had a poorer health status. Events that were perceived to have a negative effect on well being "...may actually predispose toward or participate in the development of poorer health" (p. 233). However, the authors found that 81% of the CF sample had future plans for a career and/or to attend college: no corresponding figures were given for the normal adolescent group. It could therefore, be inferred that in spite of the negative life events the adolescents with CF in this study were adapting to living with the chronic illness.

Transfer to Adult Health Care

Few research studies were found in the literature that specifically addressed the transfer of adolescents with a chronic illness to adult health care. Court (1991) investigated the outpatient needs of young people in a major Australian city with insulin dependent diabetes mellitus (IDDM). The study focused on transfer from a paediatric diabetes clinic to an adult diabetes clinic when there was no transition phase. A questionnaire was sent to 100 IDDM subjects, of whom 70 replied. All the subjects had transferred care from the paediatric hospital between one and five years prior to the study. The age range of the subjects was 17-27 years, with the mean age being 20.5 years. The mean age at which they were diagnosed with IDDM was 8.5 years; demonstrating a long-term association with IDDM for the subjects. Transfer to adult health care was reported as having occurred between the ages of 17 and 19 years for almost all the subjects. The study results were generated from the answers to five main areas of enquiry: a) the ideal age to transfer from adolescent to adult service; b) desirable features of a young adult service; c) professional staff regarded as most important in an adult clinic, in order of priority; d) rating physician characteristics; and e) any other needs. Court found that the ideal age to transfer was between 17-20 years. Privacy and confidentiality were the most desired features, the most important staff member was the diabetes specialist, the most important physician characteristics were "one you like and can talk to" (p. 154), and information on, and complications of, IDDM were the needs with the highest priority. Twenty-six of the subjects stated that they currently received care for their IDDM from a private endocrinologist, 33 attended an adult hospital diabetes clinic, nine were managed by a GP, and two received no professional management. The results were not discussed in detail by Court, other than to state that the replies indicated a diversity in needs of young adults, and the responses could be used to evaluate an outpatient service. Court also identified a general lack of knowledge about the transfer process of adolescents to adult health care.

Cappelli et al. (1989) developed a three phase study to examine the readiness of adolescents with CF to transfer to adult health care. In the first phase a questionnaire was developed with input from three adult CF patients and 35 health care workers from one paediatric and one adult CF clinic. The questionnaire content included knowledge and behaviours considered necessary for transfer to adult care. The combination of health care workers and the adult CF patients was considered to be an expert sample, and therefore enhanced construct validity of the questionnaire. The results of the questionnaire development, phase 1, showed that the health care workers and adult CF patients agreed on the behaviours and knowledge required by an adolescent to demonstrate readiness to transfer to adult care. In phase two, the questionnaire developed in phase one was given to adolescents with CF to complete. At the same time, each adolescent was rated by a caregiver, familiar with that adolescent, on presumed ability to cope with the transfer. It was not clear from the report if the caregiver was a family member or one of the health care workers from the CF clinics. It could be hypothesised that a parent and health care worker may arrive at differing conclusions as to the adolescents' ability to cope with the transfer. The caregivers performing the rating of the adolescents were unaware of the adolescent's questionnaire score at the time the rating was performed. Using the questionnaire behavioural sub scale score and the caregivers' rating, 58% of the sample was deemed ready to transfer to adult health care. The ratings of the caregivers suggested that the adolescents in the 17-19 age range were most likely to transfer successfully, although the exact ages of the participating adolescents were not given. This age range for transfer to adult care mirrors the Court (1991) finding in young adults with IDDM. Phase three, the follow-up after transfer, was reported to be in progress. Included in phase three is further evaluation of the questionnaire as a predictor of readiness of adolescents to transfer to adult health care.

Neither adolescents with CF nor their parents had any input into the questionnaire developed by Cappelli et al. (1989). The caregivers' ratings and the questionnaire did not appear to include nor consider the adolescent's developmental stage, but was more

aligned to chronological age. Although adolescents may have sufficient knowledge to correctly complete the questionnaire, actual behaviours in everyday life may not be reflective of their knowledge base. It has also been suggested that it is inappropriate to rely solely on parents' or other adults' ideas in preference to asking the group of interest, that is adolescents (Faux, Walsh & Deatrick, 1988; Field & Morse, 1985). Without investigating the adolescents' perception an incomplete picture of an event which impacts on their life would be obtained, thereby hindering the employment of a total and appropriate approach to transferring to adult health care.

Summary

Many studies have examined strategies used by individual's and family's to cope with a variety of chronic illnesses. As well, the experience of adolescents with CF has been investigated from concerns related to CF and its treatment, future time perspective, and psychological functioning. There is, nevertheless, a distinct lack of published research studies that have investigated the perspective of adolescents with CF and their transfer to adult health care. Two studies were found in the literature that studied the topic of adolescents transferring to adult health care with only one related to adolescents with CF but from the perspective of health care workers. Both studies used a questionnaire format to obtain information on predetermined topics. Although this information is valuable, it may not necessarily have been considered important to the adolescents and families in transferring to adult health care. As well, adolescents with CF have a shorter life expectancy than those with IDDM which may have coloured the adolescents' and parents' perspectives.

The optimal way to conduct research on any particular group is to ask the members of that group for their thoughts and perceptions and not just rely on parent, teacher or other adult inklings on the topic to be investigated (Faux et al., 1988; Field & Morse, 1985). Adolescents with CF were recruited for this study in order to obtain a comprehensive view of the experience of transferring to adult health care from their

perspective. As parents play an important role in the life of the adolescent with CF, parents were also recruited to add their individual perspective of transferring. Without this knowledge, provision of care for adolescents in planning and transferring to adult health care may be inappropriate and unacceptable to the adolescents and parents.

Chapter III

Conceptual Model

The conceptual model chosen for this study was Roy's Model of Adaptation (Roy & Andrews, 1991). The development of this model began in the 1960's and has been continually refined over the last 20 years through use in nursing education, clinical settings, and nursing research. This model allows for a continuing process of individual adjustment in response to adaptation needs and is applicable to individuals, families, groups or communities (Andrews & Roy, 1991a). This Model has particular relevance for this study as the nurse's assessment of all possible interactions of the individual must be validated with the individual prior to formulating a plan of action. This ensures the inclusion of the individual in decision making in relation to the care required to aid adaptation to the situation.

Roy's model incorporates the concepts of stimuli, coping mechanisms and adaptive modes, and adaptive or ineffective responses (Andrews & Roy, 1991b). The combined outcome of these concepts on the individual results in behaviours which further influence the individual in the continuing adaptive process. This interaction is depicted in Figure 3.1. A description of each component of the model is presented in more detail.

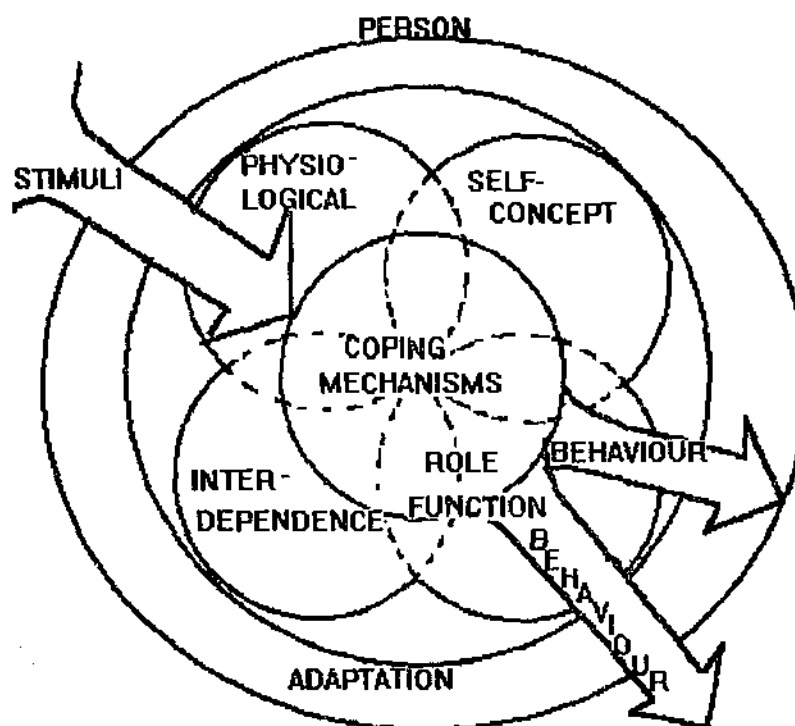
Components of the Model

Stimuli. Responses of an individual are prompted by the pooled effect of stimuli, which are described as focal, contextual, and residual (Andrews & Roy, 1991a). The focal stimulus is the primary focus of attention; it is the immediate cause of concern for the individual and precipitates a behavioural response. In this study the focal stimulus was the transfer of the adolescent with CF from paediatric to adult health care. Contextual stimuli are all other factors that affect behaviour in a positive or negative way. For the adolescent with CF some examples of contextual stimuli may be the

physiological condition, interactions with family, friends and health care personnel, age and developmental stage. Residual stimuli are the individual's beliefs, attitudes, and experiences which are seen to have an undetermined effect on behaviour and their influence on the individual has to be confirmed by the individual. Possible examples of residual stimuli were the attitude to the new hospital or relationship with the paediatric physician.

Figure 3.1

Interrelationship of Components of Roy's Model.²



² From The Roy adaptation model: The definitive statement (p. 17), by C. Roy & H.A. Andrews, 1991, Norwalk, Connecticut: Appleton and Lange. Copyright 1991 by Appleton and Lange.

Coping Mechanisms and Adaptive Modes. Roy's model describes an individual's capacity to respond positively in any situation, as their adaptation level (Andrews & Roy, 1991a). This adaptation level is achieved by using one's coping mechanisms and adaptive modes. Coping mechanisms have been generally classified as the regulator subsystem and

the cognator subsystem. These subsystems involve neural, endocrine, chemical, and cognitive pathways that activate coping mechanisms. Coping mechanisms, which are either intrinsic or attained means of responding to circumstances, are observable as behavioural responses. Behaviour is described as any internal or external reaction to any situation. These behavioural responses are manifested in the four adaptive modes: physiological, self-concept, role function and interdependence. The adaptive modes are further expanded.

Adaptive or Ineffective Responses. Through application of the model components, the resulting behavioural responses are assessed by the nurse, in conjunction with the individual, as either adaptive or ineffective. These behavioural responses then act as further stimuli on the individual in the continuing process of adaptation (Andrews & Roy, 1991a).

Adaptive Modes

The four adaptive modes of Roy's model, physiological, self-concept, role function, and interdependence, provided the framework for this study. When Roy first developed the model she identified nine categories or needs in the physiological mode to identify body responses to stimuli (Andrews & Roy, 1991b). These biological sub-categories have since been refined to five basic needs and three special functions. The basic needs identified are oxygenation, nutrition, elimination, activity & rest, and protection. The special functions are divided into the senses, fluid and electrolytes, and complex neural and endocrine functions (Andrews & Roy).

The self-concept mode is comprised of the psychological and spiritual aspects of the person and divided into the physical self and the personal self (Andrews, 1991a). The physical self embraces body sensations or feelings, and body image. The personal self relates to self-consistency, self-ideal, and moral-ethical-spiritual self. Self-consistency can be seen in an individual's response to a situation and is accompanied by verbal comments on that situation. Self-ideal pertains to one's capabilities and desires. Moral-ethical-

spiritual self is founded on one's belief system and self evaluation. The right of the individual to information related to medical and hospital routines and procedures is also included in this subsection (Nyqvist & Sjöden, 1993).

The differing roles of an individual in society are explained in the role function mode (Andrews, 1991b). This mode is based on expectations in behaviour of one person to another and the roles are classified as primary, secondary, and tertiary roles. The primary role is comprised of the majority of behaviours displayed during a particular period of time. One's primary role is related to age, gender, and developmental stage (for example a 16 year old female adolescent). Secondary roles are achieved, require specific performance and are associated with one's primary role (for example a daughter or sister). Chronic illness is described as a secondary role as this is not a freely chosen role. Tertiary roles are usually temporary and freely chosen in relation to one's primary and secondary roles. Tertiary roles enable obligations associated with performing primary and secondary roles to be met. This could be the football team coach, a member of a club and also includes hobbies.

Interactions for the giving and receiving of love, respect and value are described by the interdependence mode (Andrews & Roy, 1991a). The main focus is on close relationships in order to develop the feeling of security in nurturing relationships. Two specific components, significant others and support systems, have been identified by Roy in meeting these needs. Significant others are individuals with whom close, personal relationships are developed. The person or persons can be identified as the most important person/persons in the individual's life. Support systems are all other persons, groups or animals who sustain and advocate the interdependence needs of the individual (Tedrow, 1991). All four adaptive modes are interrelated and may also act as stimuli, either positive or negative, on one or more of the adaptive modes (Andrews & Roy, 1991a).

Roy's model views the person as a biopsychosocial being in constant interaction with the environment (Andrews & Roy, 1991a). Contextual stimuli, such as developmental

stage, age, family support, and the health care system, will affect how the adolescent with CF experiences the transfer to adult health care. Roy's model allows for identification of the common responses of individuals, as well as identification of the unique responses by each individual. Each adolescent will be influenced by the transfer in a unique way. The degree and strength of feelings generated by the new environment will be tempered by the adolescents' and parents' coping mechanisms. Possible negative or ineffective responses, such as not attending outpatient clinics or discontinuing necessary treatments, will then become evident. By application of the adaptive modes, behavioural responses to the event of transferring can be identified for both the common and unique responses of the adolescents and parents. Roy's model, then, provides a broader base for analysing individual's singular responses, whereas the Strauss & Glaser (1975) model identifies only the common group responses to living with a chronic illness.

Behavioural responses related to the transfer can only be understood in the context of the situation and not as an isolated event. In order to better understand these behavioural responses, the four adaptive modes provided the framework for the data collection tool and initial data analysis, in order to ascertain the experience of the adolescent with CF who had transferred to adult health care, as well as the experience of a parent. As a result of understanding the experience of transferring, from the perspective of the adolescent and parent, nurses can plan effective nursing interventions to assist adolescents with CF and their parents to transfer successfully to adult health care. Adaptation of individuals to, and coping with differing interactions within the environment is the goal of nursing.

Chapter IV

Methodology

Study Design

The purpose of this study was to describe the experience of transferring to adult health care for adolescents with CF. As little published research is available, a descriptive case study approach was selected.

Descriptive methods are recommended for research when little is known about a topic or to understand or describe a particular phenomenon (Burns & Grove, 1987). It is the most fundamental of research designs from which a better understanding can be gained of the relationship between individuals, behaviours, or events as they occur (Barnard, 1981). Descriptive research allows observation of naturally occurring relationships and generally one cannot make conclusions on the cause and effect of these relationships (Barnard, 1981). The case study method, which investigates a single subject or specific group, is used to enhance description of characteristics or attributes of the subject or group (Burns & Grove). In this study adolescents from a specific disease group, CF, were of interest to the investigator. Descriptive research also aids the identification and justification of nursing practice and determines similarities between individuals in the same situation (Burns & Grove, 1987). Planning of nursing interventions can then be based on the similarities between individuals, whilst at the same time allowing for differences between those same individuals.

Subjects

Specific selection criteria was used to determine potential study subjects. To be eligible for inclusion in the study all three selection criteria had to be fulfilled. The selection criteria was:

- 1) adolescents aged 11 to 20 years with a diagnosis of CF of at least six months duration;

- 2) adolescents who had transferred health care management from the paediatric hospital to an adult teaching hospital since January 1, 1991;
- 3) adolescents who had either attended the Respiratory Medicine Outpatient Clinic of the adult teaching hospital or had at least one admission to the adult teaching hospital of seven days or more, for treatment of CF.

Criteria three was included to ensure that the adolescent and parent had attended the adult hospital, interacted with the staff, and became aware of the environmental differences between the paediatric and adult hospitals. The resultant sample was one of convenience as selection of the subjects was determined by the research questions, and the availability of subjects (May, 1991).

Between January 1991 and June 1992, 13 patients with CF had transferred from the paediatric hospital to an adult teaching hospital (J. Openshaw, Physiotherapist, Sir Charles Gairdner Hospital (SCGH), personal communication, June 16, 1992). Of these, seven adolescents aged 19-20 years met the selection criteria and agreed to participate in the study. The adolescents' mothers were also included in the study to gain their perspective of the transfer to adult health care; both parents of one adolescent participated. Although not intentionally excluded, fathers were usually unavailable during interview times. The sample comprised five female adolescents, two male adolescents, seven mothers, and one father. Table 4.1 presents a summary of the adolescents' demographic data.

Table 4.1

Demographic Data of Adolescents

	Range	Mean
Age at diagnosis	birth-31 mths	9 mths
Age at transfer	18.16-19.5 yrs	18.5 yrs
Time since transfer	6-20 mths	13.6 mths
Age at interview	19-20.5 yrs	19.7 yrs

Data Collection Instrument

A data collection instrument (Appendix A) was developed specifically for this study, as no other studies found in the literature had examined the topic of transferring to adult health care from the perspective of the adolescent. Adolescents were interviewed in order to obtain a comprehensive view of the experience of transferring to adult health care, from their perspective. Without this knowledge, provision of care for adolescents in planning and during the event of transferring may be inappropriate and unacceptable to the adolescents.

The data collection instrument consisted of two sections. The first section focussed on demographic data including age, gender, occupation, age at diagnosis, and frequency of admissions before and since transfer. The second section, or Interview Guide, was based on Roy's (Roy & Andrews, 1991) four modes of adaptation: physiological, self-concept, role function, and interdependence, with the focus on the transfer to adult health care. The questions for the Interview Guide were derived by the investigator from the subsections of the adaptive modes. The Interview Guide questions were semi-structured and open-ended. This style of questioning is seen by Hutchinson and Wilson (1992) as enhancing validity of the Interview Guide because this style of question allows as much detailed information as possible to be obtained. The questions were sequenced from the least sensitive to more sensitive questions and flowed from general to the specific. Asking questions in this way builds rapport and trust between the subject and interviewer (Faux et al., 1988; Hutchinson & Wilson, 1992). An example of a less sensitive question was 'how is your health?' and a more sensitive question was 'where do you see yourself in five years time?'.

Pilot Test

Pretesting of the data collection instrument is recommended to strengthen response validity and reliability (Faux et al., 1988; May, 1991). Strengthening response validity and reliability is achieved by establishing clarity of the language, sequencing of questions,

the overall approach used by the investigator to eliminate bias, and to adjust the interview length as required (Faux et al., 1988). The data collection instrument was piloted with three adolescents. The adolescents participating in the pilot test were a 16 year old male who did not have a chronic illness, an 18 year old male with CF who did not meet the selection criteria, and a 17 year old female with insulin dependant diabetes mellitus (IDDM) who attended a transition clinic for young adults with IDDM. As two adolescents were considered to be minors, parental permission for inclusion in the study was gained before approaching both adolescents who were less than 18 years of age (Appendix B). The adolescent with CF was included as a representative of the group of interest. Input from the 17 year old with IDDM was seen as beneficial as she was in the process of transferring from paediatric to adult health care. The 16 year old male was asked to participate to ensure that the questionnaire was relatively free from jargon related to having a chronic illness. The use of non-specific language is recommended by May (1991). All three adolescents agreed the language was easily understood and non-ambiguous. The 16 year old without a chronic illness was unable to answer some of the questions, as he had never experienced hospitalisation.

Procedure

Permission was sought to undertake this study from the Higher Degrees and Ethics Committees at Edith Cowan University. Once granted, it was also necessary to obtain permission from the Research and Ethics Committees of the paediatric and adult hospitals involved, as access to medical records was sought from these institutions. All relevant committees gave permission for the conduct of this study (Appendix C).

A respiratory physician at the adult CF Clinic was contacted by the investigator to gain access to the targeted CF group. Initial contact of potential subjects was made by this and another respiratory physician by letter (Appendix D). In this letter the investigator was identified to the prospective subjects as a university student undertaking a Masters Degree in Health Science (Nursing). After allowing sufficient time for

potential subjects to contact the physicians to decline to participate, a list of names and addresses of these adolescents was given to the investigator.

All the adolescents listed as potential subjects were older than 18 years of age, and were approached directly by the investigator. The initial contact was made by telephone. An explanation of the study, including potential benefits and an estimated length of time of involvement for the study, as well as the tape recording procedure of the interviews, was given. For the adolescents willing to participate, an appointment was made to visit their home to obtain written informed consent (Appendix E). The adolescents retained a duplicate of the signed consent form. After completing the interview for demographic data with the adolescent, a parent was contacted. The study was then explained to the parent and parental participation in the interview was taken as consent. No intervention was planned and interviews were undertaken outside hospitalisation periods, so the possible risks to the adolescents were considered to be minimal. Possible risks were repercussions to treatment through either participation or non-participation in the study, as well as possible identification of the subject from data supplied. To counter these risks none of the physicians caring for the adolescents knew who actually participated in the study, and only the investigator had access to the taped interviews with all data being reported in an anonymous manner. Procedures were put in place for referral of any adolescent who became severely emotionally distressed during the interview/s, for counselling. As requested by the respiratory physician, distressed adolescents were to be counselled by him. This counselling service was not required by any of the adolescents during data collection.

Data Collection

Interviews with the adolescents and parents were conducted from March to May, 1993. Prior to commencing the study, the investigator was known to one adolescent and parent as a sibling/child had been cared for by the investigator in the paediatric hospital

setting. This prior relationship did not appear to have either a negative or positive influence on participation in the study for either the adolescent or parent.

Two interviews were conducted with five of the adolescents to establish trust and rapport, which is seen to improve validity of the data (Brink, 1991), as the participant will be more likely to give truthful answers and not socially acceptable answers. With the country subjects the preamble stage of the interview was lengthened to aid establishing trust and rapport. The five adolescents from the city were interviewed on their own. In the first interview with the adolescent demographic data was collected, and was preceded by explaining the study objectives, clarifying questions asked by the adolescents and obtaining written informed consent. The consent also included permission to access the medical record to validate information. After completing this interview, a time was arranged to carry out the second interview using the Interview Guide. The parent was asked the same questions from the Interview Guide and only interviewed once. The parent interview was usually conducted after completing the interviews with the adolescent and on a different day.

All the interviews were carried out at the place of choice of the adolescent and parent, with most of the interviews being conducted in the adolescent's home. For convenience, four interviews were conducted at the adolescent's or parent's place of work and one interview was conducted in an empty tutorial room at a university. Privacy was maintained at all interview sites. Maintaining privacy is also seen as enhancing data validity, as well as upholding and reaffirming confidentiality (Deatrick & Faux, 1991). Conducting interviews in private will minimise distractions and therefore provide consistency and stability of the situation to gather reliable and valid data.

Two of the adolescents lived in the country. For these adolescents, inclusion in the study was dependent on the adolescent's mother being present at, and participating in, the interview. The father of one of the country subjects also took part in the interview. Due to distance and time constraints, the country subjects were interviewed once in the

family home. The demographic questions were immediately followed by the Interview Guide questions.

All interviews were conducted by the investigator, tape recorded, and carried out in the style of a conversation. To reduce the possibility of distraction and flow of the interview by a tape 'running out', 90 minute tapes were used for all the interviews. The length of each interview varied from 30-60 minutes. Confidentiality was maintained as each interview was coded and only the investigator had access to this code. To maintain rapport with the subjects and unimpeded conversation flow during the interview, written fieldnotes were made immediately on leaving the interview site and not during the interview (Field & Morse, 1985). The fieldnotes included observations on non-verbal communication and interruptions during the interview. Fieldnotes are also useful in identifying possible relationships within the data and data that may need further clarification (Field & Morse).

A medical record chart audit was also undertaken at both hospitals by the investigator. The audit was undertaken to verify information related to time of diagnosis, date of transfer, frequency of admissions and length of stay at both hospitals. Collecting data from multiple sources is seen to enhance validity and reliability of the data as discrepancies can be validated by the participant and then the data corrected as necessary.

Data Analysis

The demographic data from this study was manually tabulated and then analysed in a descriptive format. After each interview the investigator listened to the recorded audio tapes to become familiar with the data collected using the Interview Guide. Each interview was transcribed verbatim. To correct any errors, the audio tapes were played simultaneously with the transcripts being read by the investigator. During the study the recorded audio tapes and computer diskettes were kept secure in a locked cupboard when not in use by the investigator. The audio tapes will be erased and the computer

diskette files will be deleted on completion of the study. The original transcripts will be kept for five years and then shredded.

Content analysis was used to analyse the Interview Guide data in order to increase knowledge and understanding of the transfer experience for the adolescent with CF and parent (Downe-Wamboldt, 1992). Content analysis "...is concerned with meanings, intentions, consequences, and context" (Downe-Wamboldt, p. 314). That is, content analysis acknowledges the experience from the perspective of an individual and connects the experience to an event/s in the individual's life.

The adaptive modes of Roy's Model (Roy & Andrews, 1991) were used for initial broad categorisation of the data. The data was then coded using the subsections of the adaptive modes (Appendix F). The definition of each category code was written on separate sheets of paper and attached to a large table top. The transcripts were read and re-read, and then data segments were cut and pasted onto the appropriate category code. To maintain the context of some statements, large portions of the transcript were left intact during categorisation. The data from the adolescents and parents were treated separately during categorisation, as they offered their own unique perspective. Nonetheless, much of the data fulfilled the criteria for classification into more than one category code, which resulted in an overlap between the categories. This multiple classification of data was also found by Nyqvist and Sjöden (1993) and is indicative of the statement that all the adaptive modes are interrelated and act as further stimuli on the individual (Roy & Andrews, 1991). Nyqvist and Sjöden (p. 62) stated that the overlap in data classification illustrates "...the complexity of nursing situations with several simultaneous overlapping patient needs." Thereby, all the influences on an individual and consequent behaviours can be examined, and not simply tasks to be achieved as is depicted by the Strauss and Glaser Model. Validity of the data coding method was enhanced as a pre-existing category scheme was used, that is Roy's adaptive modes (Downe-Wamboldt, 1992).

Concurrent with data categorisation, emerging common features of the data were noted. Identification of the common features resulted in a further scrutiny of the literature to support the findings. The common features were clustered, and with further reading of the literature integrated into four themes to describe the findings. The resultant four themes were developmental tasks of adolescence, parental adaptive tasks, transition, and chronic illness. The themes were not mutually exclusive, in that each is influenced by and influences the other themes.

Obtaining information from both the adolescents and parents can be used to determine the reliability of the research tool, which in turn improves validity of the data (Brink, 1991). To verify the data categorisation of the investigator, a Masters prepared registered nurse, experienced in adolescent respiratory medicine, was asked to categorise a sample of the data into the Roy Model adaptive mode subsections. The nurse was given a written definition of the four major adaptive modes and subsections of the model. An 80% agreement of the categorised data was unequivocally achieved between the investigator and the nurse. This high percentage agreement indicates that the data coding method was reliable (Downe-Wamboldt, 1992). Clustering of the data into themes was not verified by an outside source. However, it is felt that statements made by the subjects during data collection can be used to substantiate the choice of themes.

Study Limitations

As the subjects in this study were from a specific chronic illness group, the results are not generalisable outside this sample. This study was undertaken at one point in time, was retrospective and as such, did not examine the process of transferring as it was unfolding.

Paternal perceptions of the transfer to adult health care are under-represented, as only one father participated in the study. As well, siblings of those with CF were not included in the data collection. Accordingly, the perspective of the whole family in relation to the transfer to adult health care is incomplete.

Memory recall bias may have been a confounding variable. The length of time between the transfer to adult health care and the study interview ranged from 6-20 months. This elapsed time may have influenced the subjects ability to recall information on the transfer to adult health care. Denholm (1990) found little influence on the ability to recall the event with a four year time lapse between initial and follow-up studies. In both studies he examined positive and negative memories of adolescents hospitalised for an acute condition. The subject's replies to the questions on positive memories were similar in both studies. There was a difference found in the negative memory question replies, in that, the intensity of negative memories of painful events had "...receded and/or were replaced by memories about the quality of nursing care" (Denholm, 1990, p.103), some of which were replaced with positive memories. Hence, memory recall may only effect data related to events that were perceived by the adolescent to have had a negative impact on the adolescent as the amplitude of the negative impact appears to decrease over time.

Chapter V

Findings and Discussion

Roy's (Roy & Andrews, 1991) adaptive modes were used to categorise the study data and in so doing the adaptive modes of self concept, role function, and interdependence were clearly interwoven with the psychosocial developmental tasks inherent in adolescence and the adaptive tasks of parenting within the context of CF. Not as predominant, but still of importance, was the fluctuating influence of CF on the lives of the adolescents and parents. The adolescents and parents were also undergoing transitions. In addition to the transfer to the adult hospital, the adolescents were in transition from childhood to adulthood, and the parents in the transition from total responsibility for, to 'letting go' of their adolescent. As the participants are from a select group, the adolescents will not be referred to by gender as this may lead to the identification of an adolescent. The doctor responsible for health care of the adolescent at the adult hospital is referred to in this study as the respiratory physician, and the doctor at the paediatric hospital as the paediatrician. The study findings are discussed in this chapter.

Adolescence: Developmental Tasks

Comments by the adolescents in relation to decision making, initiating a more active role of managing CF, and planning for the future, depicted common characteristics of adolescent psychosocial development. The consistency of these comments between the adolescents and the literature then lead to the unfolding of the theme of adolescent developmental tasks.

Children with a chronic illness or disability are firstly children who have the same developmental needs as all children (Patterson & Geber, 1991). This statement is also applicable to adolescents. It is commonly acknowledged that adolescence begins with puberty and the culmination is a mature adult. Although previously considered to be the

same, puberty and adolescence are now described as two separate entities of the individual (Pinnell, Murray, Grohan-Murray, & Zentner, 1989). The adolescent period has also been defined chronologically with an end point at about age 22 years (Clark, 1991). A developmental approach, encompassing the overall maturation of an individual, with an emphasis on cognitive and psychosocial development has been described by other authors (Berger, 1983; Pinnell et al., 1989). The maturation of the individual is said to depend on successfully mastering the developmental tasks. These tasks refer to physical and cognitive growth through challenges at specific stages in the individual's life-cycle. The tasks or required activities are predictable, however, the completion of these tasks by a specific age or time period is not predictable. The journey of adolescence is considered to be individualistic and influenced by the entirety of life's experiences of the individual (Blos, 1962; Erikson, 1959; Horrocks, 1976). Adolescence requires the progression through specific developmental tasks. The developmental approach comprises the totality of an individual, as is also depicted by Roy's Model (Roy & Andrews, 1991). The categorised data of the current study was aligned to the developmental tasks of adolescence and will be used to discuss the research findings.

Developing one's own identity is seen by Erikson (1959) as the prime developmental task of adolescence. Encompassed in developing one's identity is gaining independence especially from one's parents, choosing an occupation, developing close relationships including acceptance by peers, an awareness of one's actions in relation to present and future roles, and accepting one's bodily appearance (Blos, 1962; Erikson, 1959). Each of these concepts are discussed in relation to the theme of adolescent developmental tasks.

Gaining Independence. All the adolescents in this study had gained their driver's licence, which not only allowed the adolescents to take themselves to clinic appointments but also freed the parents from this task. Acquiring a driver's licence could be seen as enhancing independence as reliance on parents for transport would no longer be necessary. Developing autonomy and self-determination by adolescents with the resultant separation from parents is inherent in gaining independence (Erikson, 1959).

For one adolescent, owning a car was the trigger to transfer to the adult hospital. This adolescent had attended a clinic visit alone and needed to be admitted to hospital for treatment. The adolescent's reply was "Oh, I can't come in today because I have to drive my car home" and the paediatrician's response was reported as "If it's getting to the stage now where you drive in, then I think you can transfer to [the adult hospital]." The adolescent agreed. The adolescent was admitted the next day to the paediatric hospital for the last time. For another adolescent, having a driver's licence and car meant a lessening of feeling confined and lonely when an inpatient. It was now possible for the adolescent to take day excursions from the hospital environment which also enhanced feelings of freedom and control over the illness. Simply knowing that the car was in the car park alleviated the feelings of isolation for this adolescent. These anecdotes reflect the adolescents' progress in developing autonomous and self-determined lives. This concurs with Blumberg, Lewis and Susman (1984) who stated that, for the adolescent, being able to drive to clinic appointments by themselves may increase their feelings of control over the illness and supports the development of autonomy.

Accepting responsibility for one's health care is also an element of gaining independence. It is presumed that the adolescent requires time, a certain level of cognitive maturity as well as the opportunity to learn to carry out these tasks (Giordano, Petril, Banion, & Neuenkirchen, 1992). For the adolescents in the current study, responsibility for day to day management of CF had mostly rested with the parents. Initiating and performing daily physiotherapy, taking control of medication regimes, and learning to balance recreational activities with work and/or study commitments were some of the tasks required by the adolescent to show self-care capabilities. Most of the adolescents in the current study initiated therapy sessions, although at times they continued to enlist parental help. One adolescent, however, had discontinued all physiotherapy as it was felt to be unnecessary and took part in no other form of physical exercise. As another adolescent described,

"it's not the hospital that's making the changes, it's me because when I was at [the paediatric hospital], I didn't want to do treatments and

I didn't want to have physiotherapy and I didn't want to do this and I didn't want to do that, whereas now I'm finding out that if you don't do it you're going to get sick, you're going to have to go into hospital, so you grow up a lot. You know when you get over to [the adult hospital] you're about 18 and you think well I've only got a few more years, if I don't start looking after myself."

The adolescent not only has to be ready to accept responsibility for self-care but the parents must be ready to relinquish responsibility to the adolescent whilst continuing to guide and supervise the adolescent (Duvall & Miller, 1985; Friedman, 1986; Horrocks, 1976). The adolescents in the current study displayed various levels of acceptance of responsibility for self-care. The parents had also relinquished responsibility to the adolescents in varying degrees.

The importance of the timing of transfer of responsibility for care has been discussed in the literature associated with adolescents with IDDM and adolescents with CF, in that parents and health care professionals tend to initiate transfer of self-care to the adolescent before the adolescent is ready for this task (Giordano, et al., 1992; Hewson et al. 1993). Ingersoll, Orr, Herrold and Golden (1986) in their study of adolescents with IDDM found that by the time the adolescent was aged 15 years, the parents rarely participated in the management of adjusting the insulin regime. This lack of parental participation was not always balanced by the adolescent assuming the task of insulin adjustments. Similarly in the current study, the parents were actively encouraging their adolescent to be self-determining and responsible, especially in relation to CF management. They would, however, like more communication from the adolescent on current management issues so as to be supportive of their adolescent.

Most of the adolescents in this study considered that they made their own decisions related to health matters. One adolescent acknowledged that most health related matters were still decided by the mother at the request of the adolescent. This demonstrates that this adolescent had not yet accepted responsibility for self-care, nor was the mother ready to relinquish responsibility to the adolescent. Other adolescents made what they considered to be important decisions in consultation with their parents. This was explained by one adolescent as,

"I certainly consult Mum and Dad, they've been dealing with it for so many years that they've got another point of view, I mean, they've coped with it for so long that I value their opinion because I've only just started really."

Three adolescents confessed to "telling fibs" to the physician, saying they had been taking medications and doing physiotherapy when they had not been undertaking these treatment measures. Untruthfulness also has ramifications for the prescription of appropriate management as the physician usually bases management decisions on the information provided by the adolescent. If the information from the adolescent is incorrect, then inappropriate or insufficient management changes may ensue. One adolescent described an event at a clinic appointment when the parent

"wanted to come in because I hadn't been doing my treatment and they didn't believe that I was going to tell the doctor. At one stage I used to go in and lie and tell the doctor I was doing my physiotherapy when I wasn't, but I don't do that now, I haven't done that for quite a while."

Horrocks (1976) describes a struggle whereby adolescents emancipate themselves from parents and other adult authority figures. The struggle can be evident in conflicts related to treatments, or parents continuing to maintain their authority and control of health issues, whilst the adolescent chooses to assert independence (Blumberg et al., 1984). Non-compliance with treatments, or discontinuation of treatments is known to occur in adolescents with cancer (Ellis, 1991). As well, insufficient compliance with treatment and poor metabolic control has been reported in adolescents with IDDM (Wysocki, Hough, Ward & Green, 1992). One such struggle may be that adolescents with CF either do not carry out treatment regimes or do so only at their own convenience. One family in the current study described an incident when the adolescent did not want to complete the physiotherapy session and was being unco-operative. The adolescent was almost accidentally tipped from the physiotherapy table as, according to the adolescent, "I was being a real ratbag!" The mother believed that the paediatrician bestowed responsibility for self-care on the adolescent before the adolescent was either ready or willing to accept it. The mother considered that, as the adolescent neither

organised equipment nor initiated therapy sessions with the mother, the adolescent did not demonstrate readiness to accept responsibility for self-care. On the way home from a clinic visit, when the mother asked the adolescent about current management, the reply was "...but it's none of your business any more!" The adolescent described this occurrence as,

"it's just that your Mum and Dad are involved in your treatment and all of a sudden you've got this independence you're responsible, and it's like Hey, this is great! You know I can just tell Mum and Dad to get lost, and you abuse it and all of a sudden you realise, like oh God! you know they're worrying and everything."

This adolescent said that upon realising that parental concern was very real, an endeavour was made to include the parents more and the adolescent was now also actively demonstrating self-care. Another adolescent surprised the mother by telephoning for pathology results; this was the first time this adolescent had taken the initiative in relation to management of the CF.

Choosing an Occupation. Another developmental task of adolescence is deciding on and planning for a career which culminates in economic independence from parents (Blos, 1962; Duvall & Miller, 1985; Erikson, 1968; Friedman, 1986). The adolescents in the current study verbalised future plans for employment. In order to achieve their plans, completing Year 12 of high school was seen as necessary by two adolescents, even though this would be attained at an age later than that considered to be usual. The other adolescents had at least completed Year 10. At the time of the interviews, one adolescent was working part-time, two others had been previously employed but were currently unemployed, and the remaining four were studying at either Business Colleges or University in order to eventually join the workforce. To supplement income, one of those studying received financial remuneration for cleaning the family home, as they do not qualify for government student assistance. At the time of data collection all the adolescents lived with their families. Only one adolescent had lived away from home and was financially independent of the family during that time. This adolescent had since returned home in anticipation of a joint work venture with the parents.

Ambivalence by the subjects with CF to both education and planning for the future was found by Brissette et al. (1987), resulting in decreased motivation in school and poor job performance for those in the workforce. The study subjects were aged 16-37 years with advanced CF, and their families were also included in the survey. Most of the Boyle et al. (1976) subjects, who were aged 13-20 years and with CF, avoided thinking of the future. Yet no difference in attitude to the future was found in the quantitative study by Yarcheski et al. (1987) between subjects with CF and those without CF, aged 14-18 years. In a quantitative study by Smith et al. (1983) 81% of the subjects with CF had future plans for work and/or study. These subjects were aged 12-18 years with CF and were compared to a control group of adolescents without CF. The differences between the Brissette et al. (1987) and Boyle et al. (1976) studies, and those of Yarcheski et al. (1987) and Smith et al. (1983) may be a reflection of the ranges in age. The Yarcheski et al. (1987) and Smith et al. (1983) study subjects were all adolescents and were compared to a control group of normal adolescents. Planning for the future is a normal task of adolescence and is demonstrated by the studies of Yarcheski et al. (1987) and Smith et al. (1983). The current study supports the findings of Yarcheski et al. (1987) and Smith et al. (1983) as all the adolescents were planning for their future.

Developing Close Relationships. Developing close relationships is described by Blos (1962, p. 100) as "...a sequence of object-relinquishment and object-finding..." on the part of the adolescent. The ties to one's parents (object-relinquishment) are changed and there is a greater involvement with peers and an interest in romantic relationships (object-finding). Although changes had occurred, the relationship with parents was still considered close, except for one adolescent who stated that "there's a brick wall between us" and conversation was mostly superficial. All but one adolescent in this study had a circle of friends with CF in common. All the adolescents also had a circle of friends without CF. The friends with whom they mainly socialised were from outside the CF group. One adolescent was engaged to be married, another was in a stable romantic relationship, and another adolescent had broken off a romantic relationship. The findings

of this study do not support those of Strauss and Glaser (1975) and Boyle et al. (1976) whose subjects with a chronic illness reported a lack of social contact and a lack of friends. On the other hand, the current study supports the findings of Yarcheski et al. (1987) in that adolescents with CF do not lack social contact. Socialising with those who do not have CF may also be interpreted as normalising the influence of CF in their life. The adolescents in the current study also showed the normal progression of friendship development.

Participation in normal social activities by those with a chronic illness or disability will encourage the realisation of developmental tasks (Patterson & Geber, 1991; Schidlow & Fiel, 1990). Social activities were engaged in by the adolescents in the current study with no display of social limitations nor isolation from their peers. Other studies of adolescents and young adults with CF (Brissette et al., 1987; Smith et al., 1983) reported similar findings. Increased peer group social activity is considered to be normal and important for all adolescents (Blumberg et al., 1984). Normalising life situations requires that the abnormality is acknowledged and that its social significance is denied (Knafl & Deatrick, 1986). In this instance the abnormality is CF and the social significance is that it will not interfere with chosen activities. The activities engaged in, however, may not always be considered conducive to one's health, for example, attending smoked-filled nightclubs.

Awareness of One's Actions. Developing an awareness of one's actions in relation to present and future roles is a further developmental task of adolescence. This is a reflection that the adolescent no longer lives simply for the here and now, but is cognisant of the influence of current actions on future prospects. Mostly, the adolescents were aware of the consequences of overdoing social engagements in relation to the effect on CF. Still, as one adolescent said, "I would rather go out and have a good time than worry about whether I'm going to get sick or not [and not go out]." Another adolescent frequently attended nightclubs and when asked if concerned about the cigarette smoke, replied "No, I'm having too much of a good time to worry." Yet another adolescent, who

also frequented the nightclub scene, said that the length of time spent in the nightclub was monitored in order to avoid coughing spasms induced by the smoky environment. Exposure to cigarette smoke in a confined space is both an example of a risk-taking behaviour and normalising a life situation. Risk-taking behaviour is a characteristic of adolescence and is attributed to a sense of invulnerability common to all adolescents (Erikson, 1968; Savedra & Dibble, 1989). Peer approval and acceptance are important to all adolescents regardless of the presence or absence of a chronic illness (Merkel, 1981; Savedra & Dibble, 1989). To be accepted by peers means participating in the same activities despite the outcome (Erikson, 1968) and the adolescents in the current study were no different. Participation in peer activities reflects the adolescent coping with CF by normalising their life.

Bodily Appearance. The remaining task of adolescence to be discussed is that of accepting one's bodily appearance. Adolescents are said to be obsessed with their appearance and think others are as interested in their appearance as themselves (Elkind, 1974). A re-evaluation of body image in relation to physical changes in adolescence is required by the adolescents (Blos, 1962). Only one adolescent in the current study was concerned with bodily appearance. This concern was due to the desire to regain 12 kilograms in weight, which would return the adolescent to a normal body weight. The large loss in weight occurred through a combination of illness and stress during the 12 to 18 months prior to the current study interview. Shortly before the interview, measures were put in place to rectify this state by augmenting the diet with overnight enteral feeds. The aspect of bodily appearance was not an issue for the other adolescents in the study.

No two adolescents in this study were at the same developmental stage, so it cannot be said that adult status had yet been fully attained as "passage through the adolescence period proceeds neither at an even rate nor in a straight line " (Blos, 1962, p. 52). The findings showed that the adolescents in the current study were progressing through the normal tasks of adolescence in conjunction with learning effective behaviours to cope with the influence of CF in their life. The Strauss and Glaser (1975) chronicity tasks of

managing regimens, normalising life and dealing with family relationships appear to be incorporated into the life of the adolescents in the current study, in a manner that is uniquely tailored by the adolescents to meet their needs.

Parental Adaptive tasks

The challenge of caring for a child with a serious chronic illness is often accompanied by marital and family distress, which can be intensified at the time of variation in developmental stages of the family unit or the individual members (Patterson & Geber, 1991). Other than to determine the family's composition in the current study, the actual marital relationship was not examined. One family was a blended family, five were nuclear families, and one was a sole parent family. A change in the agency providing health care and health professionals, has also been cited as having a compounding influence on the developmental stage of the family (Patterson & Geber). Consequently, transfer to adult health care may have an influence on the developmental stage and coping abilities of the adolescents, parents, and families. The experience of transferring to adult health care on the part of the parents, appeared to have been tempered by teaching the adolescent responsibility for self-care, allowing the adolescents to make decisions, and the desire for the best care possible for their adolescent. Subsequently, this data guided the formation of the theme of parental adaptive tasks.

The overall task of parenting, as seen by Erikson (1950, p. 231), is "establishing and guiding the next generation." However, when a chronic illness is also present the parents have to acquire adaptive tasks in order to cope with the influence of the chronic illness on the family (Canam, 1993). Eight adaptive tasks have been described by Canam for parents with a chronically ill or disabled child (Table 5.1). These tasks were formulated as a framework to assess and intervene with parents of chronically ill or disabled children. Although applicable for parents with children, not all the tasks are pertinent for parents with adolescents as some of these tasks will be handed over to the adolescent.

Table 5.1

Parental Adaptive Tasks.³

-
1. Accept the child's condition
 2. Manage the child's condition on a day-to-day basis
 3. Meet the child's normal developmental needs
 4. Meet the developmental needs of other family members
 5. Cope with ongoing stress and periodic crises
 6. Assist family members to manage their feelings
 7. Educate others about the child's condition
 8. Establish a support system
-

³From "Common adaptive tasks facing parents of children with chronic conditions," by C. Canam, 1993, *Journal of Advanced Nursing*, 18, p. 46. Copyright 1993 by Blackwell Scientific Publications Ltd. Reprinted with permission. (Appendix F)

A parental task for those with adolescents, added by Friedman (1986, p. 66), is that of "...learning to accept rejection without deserting the child." This rejection was described by one mother as no longer being able to talk with her adolescent, but had been assured by the doctors that "it's just a stage [the adolescent] is going through, I just hope it doesn't last too long." Another mother was told by her adolescent that matters pertaining to CF management were "none of your business!" In both instances the mothers continued to offer support and assistance to their adolescents. Consequently, the parents in this study were adapting to their role of guiding and supervising their adolescent to adulthood. Stevenson (1983) concluded, when investigating the influence of chronic illness on the family, that the inclusion of developmental tasks of adult subjects was lacking and required attention.

Canam (1993) asserts that parents, who had been responsible for the day to day management of the illness during childhood, exert a major influence on the adolescent. Unfortunately, some parents felt as though they were cast aside by the physicians and adolescents as no longer required in caring for their adolescent, even though the adolescent was still living at home. The parents gave the impression of feeling shunned by the physicians at both the paediatric and adult hospitals, and that the parents' expertise, gained over years of caring for their adolescent, was of no further use. This

feeling of being shunned was partly due to the abrupt introduction by the physicians of conducting consultations alone with the adolescent. The practice of consultation between the adolescent and physician had begun at the paediatric hospital for some adolescents from 16-17 years of age or from the first consultation at the adult hospital. One mother described being informed of this occurrence as,

“[the paediatrician and respiratory physician] talked to [my child] and then they called me in and just said that they'd agreed to this [transfer to the adult hospital] and [the respiratory physician] said that would I please realise that it was now patient-doctor-adult relationship and my hackles rose.”

This was the first occasion that the adolescent and parent were introduced to the respiratory physician. Moyer (1989) also found that parents felt excluded by the change of the physician conducting the consultation only with the adolescent.

From the parent's perspective, the respiratory physicians at the adult hospital preferred not to discuss the adolescent's management with them until either a crisis arose or the parents persisted until they were included in being a part of the adolescent's care. One mother explained this situation as, “I don't know whether they realised that we just weren't going to go away, that they would then have to get on with us and we were going to have to get on with them.” These parental comments may be reflective of the parents' hesitancy in 'letting go' of the adolescent, or of the desire to maintain control over the illness through consultation and inclusion in decision making matters related to CF. This desire of maintaining control over the illness through inclusion and consultation in matters was also found by Salmond (1987). Being in control of the illness was seen as a means of coping with the chronic illness.

For most of the parents, the segregation of the adolescent from the parent was a major concern. Conrad (1987) and Friedman (1986) assert that the family is a critical resource for assistance and support in the provision of health care to its members. A study by Resnick, Harris and Blum (1993) confirmed that the family is a pivotal point in promoting the well-being of youth. Lealely and Wright (1987), and Canam (1987) suggest that as the family system influences the chronic illness situation, challenges

associated with the illness should be resolved within the context of the family. Whyte (1992) found that the effect on family functioning resulting from caring for a child with a chronic illness is not consistently acknowledged. It could be proposed that it would be more beneficial to enlist parental support as an adjunct to providing optimum health care rather than alienating them, as evidenced in the current study.

Two mothers commented on the change in the relationship with their adolescents now that they no longer assisted with the physiotherapy. One mother stated that "I'm more removed from it now, because [the adolescent] does all physiotherapy so I don't really have a lot of input." Another mother, following an argument with her adolescent about health care, stated, "I thought and I knew that's when everything changed, you know between us, and it was great when we'd had physiotherapy sessions because it was time we had together." This event was seen by this mother as a turning point which resulted in a decrease in the closeness of the previous relationship between her and her adolescent. It would appear that not only do the adolescents mourn for what was, but so too, do the mothers when the caring aspect is altered in the adult-child relationship (Duvall & Miller, 1985).

As the adolescents were living at home, some parents felt that ultimately they were responsible for their adolescent and to be of help to their adolescent they needed to know about the current management of CF. Another parental comment was that the adolescents also needed someone with whom they could share their worries and concerns regarding CF. The parents saw this sharing of the adolescent's concerns as part of their parenting role. The idea of adolescents discussing problems/concerns related to the illness with parents is supported by Canam (1986, p. 175) who stated that "teenagers need an opportunity to reflect on the information they receive and be able to discuss all the possibilities available."

Transition

The categorised data portrayed a picture of two transitions, maturational and situational. Transition is described by Golan (1981) as a period of uncertainty between two states of certainty. For example, adolescence is the uncertain period between childhood and adulthood. To progress through a transition the individual needs to restructure thoughts, activities and plans for living (Golan). Transitions result in the individual changing, be it physical, role, relationship or responsibility changes (Savendra & Dibble, 1989).

Maturational transition for the adolescent was the progression from childhood to adulthood, and for the parents it was in separating from the adolescent. Family maturational transition stages appropriate to this study are "families with teenagers" and the "launching centre" (Duvall & Miller, 1985, p. 179). The "family with teenagers" stage begins when the eldest child turns 13 years and lasts for six to seven years, whilst the "launching centre" stage begins when the first child leaves home and ends when the last child leaves home (Duvall & Miller; Friedman, 1986). The adolescent with CF in the current study was the oldest child in each family and one adolescent an only child. Two families in this study have also entered the "launching centre" stage, as one of the study adolescents and the younger sibling of another adolescent with CF had left home. The adolescent with CF in this study had moved home again just prior to the interview, necessitating another transition stage.

Transferring from the paediatric to the adult hospital is a situational transition for both the adolescent and parent. The transfer to adult health care is also seen by Blum (1991) as a time of uncertainty, and of moving to an unknown environment from a nurturing environment. Many changes occur in everyday life and most could be considered minor. An expected response to change is resistance to the proposed idea; as such, it is recommended that major change be planned (Fretwell, 1985). Transferring to the adult hospital was considered a major, albeit eventual change and to decrease resistance, should have been well planned.

The paediatric hospital, in a formal admission and discharge policy, had a definite schedule for adolescents to transfer to adult care, however, this was not strictly followed. It also appeared that there was no formalised plan for introducing changes in the physician-adolescent-family relationship nor for the initiation of the transfer process by the paediatric hospital.

The process of deciding when to transfer to adult health care varied. The time interval between when the transfer was initially discussed and when the transfer occurred, ranged from three to twelve months. During this time, preparation consisted of an organised group visit by some of the adolescents to the adult hospital as a combined activity of the paediatric and adult hospitals. Few parents were orientated to the adult hospital or introduced to the respiratory physicians prior to the transfer taking place, even though some parents had wished to become familiar with the adult hospital environment. Some of the adolescents periodically discussed the transfer with their paediatrician. Only two parents were included in the initial discussion on transferring with the paediatrician and adolescent. The most appropriate time for transfer was considered to be the completion of Year 12 at school. Another adolescent had wanted to transfer earlier as the best friend had transferred. However, the unexpected death of the friend delayed this adolescent's transfer for about 12 months. One couple were not included in the discussion or decision to transfer but they did exert an influence on their adolescent. The father stated that,

“we probably delayed [the adolescent's] move to [the adult hospital] for about six to eight months because we were happy with the treatment. We didn't know what to expect at [the adult hospital]. It was probably as much our holding [the adolescent] back as [the adolescent] not wanting to go to [the adult hospital].”

Court (1991) believes that the transfer to adult health care is frequently abrupt and often without preparation or introduction to the adult service. The findings of the current study support Court's belief, as not all the adolescents were introduced to the adult setting, and for some the only preparation was a single orientation tour.

One adolescent was told at a clinic consultation that the next clinic consultation would be at the adult hospital in three months; this adolescent had been on a group visit to the adult hospital about four years previously with no further orientation since. Although clinic attendance by this adolescent at the paediatric hospital had been irregular, there was no documented clinic attendance found on chart audit for 11 months at either the paediatric or adult hospital. It is hypothesised that this sudden transfer resulted in non-attendance at clinics for this adolescent. During the study interview the adolescent commented, "Oh, I was a bit worried. It was like, you know, you go to the one place for a lot of years and know where everything is and you get used to the place and people." Cappelli et al. (1989) assert that medical care can be compromised by the random transfer from paediatric to adult health care. Frank (1992) also articulates concern for loss to follow-up, that is no longer attending outpatient clinics, by the adolescent after transferring to adult health care. An abrupt or adhoc transfer may predispose the adolescent to no longer seeking appropriate medical care. For the participants in the current study the transition restructuring resulting from the transfer to adult health care incorporated negotiating new relationships with the health professionals at the adult hospital.

Court (1991) recommends initiating young adult clinics at the adult hospital as the likelihood of the adolescent/young adult abandoning medical follow-up is reduced. The more congenial waiting area atmosphere, less crowding, timing of appointments to meet the adolescent's need, and mixing with a similar age group were presented as incentives for the adolescent/young adult to continue medical care.

During the first admission to the adult hospital one adolescent commented that "I felt like an adult, I'd never felt like an adult before." This feeling was also repeated by other adolescents. The interaction between the adolescents and the staff at the adult hospital appeared to have supported the identity formation of the adolescents (Erikson, 1968). For some adolescents in the current study the persons of most help in deciding to transfer were others with CF who had already transferred. Most adolescents in this study

voluntarily sought out those who had already transferred for information and advice. This is reflective of peer influence on the decision making of adolescents (Blos, 1962). Mostly the information provided was positive, but some was not. This was described by one adolescent as,

“a few of the other people that I knew had swapped over before me and said it was horrible and one of them wanted to come back to [the paediatric hospital] but they couldn't. Going over [to the adult hospital] not knowing anybody was pretty traumatic, whereas most of the staff at [the paediatric hospital] you knew.”

This comment reinforces Blum's (1991) statement on moving to the unknown environment of the adult hospital. One of the adolescents in the current study would prefer to return to the paediatric hospital and especially to the paediatrician. This adolescent had a negative view of the adult hospital from the depressing building structures to the "grumpy staff". Yet, another adolescent had a different view in that,

“transferring over for me, I thought was really good. I was a bit worried that I wouldn't like the staff as much as I did at [the paediatric hospital]. The staff [at the adult hospital] are really great, and as you get to know them better, they listen to you a lot more than at [the paediatric hospital].”

Other adolescents also commented that they were listened to more at the adult hospital than at the paediatric hospital. Remarks made by adolescents in this study also highlight the need for an adolescent/young adult ward at the adult hospital in order to meet the developmental needs of the adolescents. The comments included the desire to share rooms with those closer in age, the inability to freely listen to music, and a reduction in interactions with friends when visiting to accommodate for the older adults in the room. This preference of the adolescents to be together whilst being inpatients was also found by Denholm (1990).

For the parents in the current study changes in routine at clinic visits were considered major, mostly because these were initiated without prior consultation or forewarning. The most meaningful change was when the paediatrician excluded parents and conducted consultations alone with the adolescent which began at the paediatric

hospital. Some parents felt that their adolescents were not yet ready for this change and the ensuing responsibility, whilst other parents first balked at the idea but then accepted the change because

“[the adolescent] is now an adult and that's how it would be and at first I sort of thought, oh!, because it's been a part of your life for so long and then I thought well, ...it's time that [the adolescent] took responsibility for the condition and that means I'm going to have to sit and get information second-hand, which is sometimes difficult.”

Two adolescents continued to have a parent present during the consultation with the respiratory physician at the request of the adolescent. For the other adolescents the change in consultation practice appeared to have been accepted unquestioningly.

The preceding comments depict feelings of anxiety, uncertainty and an unwillingness to separate from the paediatric hospital. According to Golan (1981) these are common reactions to major changes or transitions. It was also apparent, from the current study, that some parents experienced difficulty with the timing of the transfer, even to delaying the actual move. The parental concerns given were potential interruptions to schooling, and anxiety related to unfamiliarity with the adult hospital and physicians. Parents felt that these concerns were mostly ignored by health professionals.

Chronic Illness

Adolescents with a chronic illness are normal adolescents in atypical circumstances and have the same developmental needs as all adolescents (Patterson & Geber, 1991). As far as the adolescents were concerned their illness was mainly relegated to the background of everyday life, unless they were acutely ill. The influence of having CF on daily living was more of an undercurrent and not an overriding force. Daily physiotherapy routines were arranged around other activities. As one adolescent described "I do my own physiotherapy most of the time, and if I'm going out I have to do it before [going out]." One adolescent commented that even when an inpatient, they had taken their IV drugs to university on occasions in order not to miss lectures. By combining drug therapy with university activity the adolescent illustrated both

normalising the effect of CF and coping with CF in daily life. For two adolescents, frequent admissions to the paediatric hospital had interfered with and delayed their completion of high school. Although an inconvenience, they were currently completing their studies. One mother commented that her adolescent "seems to have turned the corner...[the adolescent] doesn't seem so concerned with the fact of having cystic fibrosis anymore...is more concerned with what's in the future rather than what's happening at the moment." Although the adolescents acknowledged the need to carry out daily treatment regimes, their lives did not revolve around CF.

The portrayal of the illness as background is consistent with that found by Corbin and Strauss (1987), and Peyrot, McMurry and Hedges (1987). These authors explain that the individual with a chronic illness organises the illness and its influence within the context of their daily lives. The illness is "something to be managed and taken into consideration but certainly not the only aspect of life" (Corbin & Strauss, 1987, p. 251). When the individual is unwell, the illness does assume more importance and careful consideration. For one adolescent hospitalisation was necessary and seen as a total annoyance as it would disrupt planned studies. During the consultation with the respiratory physician, who recommended hospitalisation, the adolescent accepted this state of affairs but negotiated certain conditions. These were "Right! I have to go to Uni as much as possible, I want to go to a wedding on the weekend and that was about it and he said 'Yeah, ok we can work that out'." In this instance of being unwell the effect of CF was considered a nuisance to be swiftly dealt with so the more urgent everyday needs of the adolescent could be met. Maintaining personal power over this situation demonstrates assertiveness and independence by the adolescent. These viewpoints reflect the argument of Corbin and Strauss (1987) that the chronic illness is mostly of secondary importance to the individual and family.

One mother indicated that she never worried about her adolescent having CF unless the adolescent was unwell. This mother worried herself sick when her adolescent was hospitalised as it brought with it the confronting issue of death. Other parents freely

commented on the possibility of their adolescent not living for another five years if the adolescents failed to more responsibly manage their health. As well, two adolescents described their experience of death when friends with CF died two and three years prior to the current study. For one adolescent the friend's death was seen as unexpected as "he was really healthy, the healthiest I'd ever seen him. It was a real shock to the system and it put me off going to [the adult hospital] for about a year." In dealing with the friend's death, the other adolescent felt that "yes, it would happen but I just have to cope with everything as it came and not get super panicked." The parent of another adolescent recounted that a friend of her adolescent had died about a month prior to the study interview. During the interview with the adolescent, the friend's death was not mentioned. Brissette et al. (1987) found that discussion by their subjects on issues related to death and dying were uncommon, even after a year of contact with the one nurse. Boyle et al. (1976) also found that their subjects were reluctant to discuss death and dying issues. Not all the subjects in the current study chose to discuss issues related to death and dying. Perhaps the issue here is related to the adolescent's view of invulnerability of self, which is considered a normal phase of adolescent development (Erikson, 1968; Savedra & Dibble, 1989). When one is invulnerable, dying is not a consideration.

Transfer to adult health care may be perceived by adolescents as a negative life event which may contribute to a decline in health status. No indicator of CF severity of the adolescents was sought in this study. There were negative components to transferring but neither the adolescents nor parents perceived a decline in either physiological or psychological health status related to the transferring. Anecdotal comments of the adolescents at the paediatric hospital inferring that death followed shortly after transferring to the adult hospital were not supported by this study but may be related to increased anxiety of the unknown.

The adolescents and parents also voiced hope in the development of new treatments and the possibility of a cure. This was described by one adolescent as "it'd be great not to

have to get up in the morning and do your therapy." Yet another adolescent was "pretty optimistic there'll be a cure soon and then I'll just be normal for once." The attitude of one adolescent was that although "CF does progress you can slow it down if you look after yourself." These comments depict hope for the future and the desire to be considered normal in spite of having a chronic illness (Knafl & Deatrick, 1986; Krulik, 1980). The parents' approach to the new treatments was a little more cautious, and was related to not having hopes raised only to be dashed when the raised expectations are unfulfilled by reality.

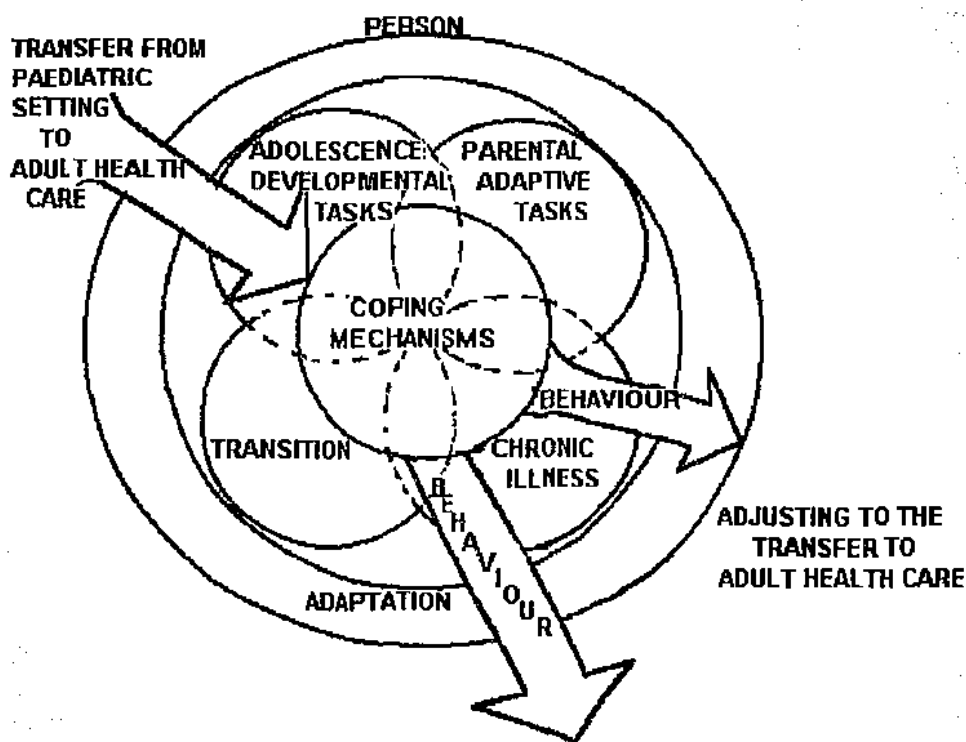
Summation

The data from this study indicates that transferring to adult health care is a major transition in the life of the adolescent and family. The experience of transferring appears to have been influenced by the developmental stage of the adolescent and parental adaptive tasks, as well as the lack of planning for the transfer. Using Roy's Model the adolescents and parents were found, overall, to be coping with the transition from paediatric to adult health care but with minimal help from health professionals. This was evidenced by the adolescents' adaptive behaviours of assuming responsibility for self-care and self-determination. Ineffective behaviours, or partial adaptation, was demonstrated by the adolescents misinforming the physicians in relation to medications and physiotherapy regimes at one stage, and potentially overindulging in social activities. The parents supported the adolescent's coping behaviours by allowing and encouraging greater decision making by the adolescents, whilst continuing to support them. The parents were coping with the double transition of letting go responsibility for their adolescent, and the transfer to adult health care. Parental coping was demonstrated by disengaging from treatments, attending clinics only at the adolescent's request, and allowing the adolescent to initiate discussion related to CF. The interactions of the study themes are pictorially presented in Figure 5.1 using Roy's Model (Andrews & Roy, 1991a). The individual restructuring required by the participants in this study for the

transition to adult health care, also incorporated negotiating new relationships with the health professionals at the adult hospital. For all who participated in this study, transfer was acknowledged as inevitable. Only the planning for, and the actual physical transfer were found to be adhoc and therefore, unsettling to the adolescents and parents.

Figure 5.1

Interaction of Study Themes using Roy's Model.⁴



⁴ Adapted from The Roy adaptation model: The definitive statement (p. 17), by C. Roy & H.A. Andrews, 1991, Norwalk, Connecticut: Appleton and Lange. Copyright 1991 by Appleton and Lange.

Chapter VI

Future Directions

Implications for Nursing Practice

The findings of the current study show that although transfer to adult health care was acknowledged by all as inevitable, the preparation for transfer was consistently stated as lacking. It was found to be based on one or more of the following: the adolescent's age, a reflection of the hospital policy, it was considered to be the right time, or completion of high school. Although a number of adolescents were aged 19 years, all may not be at the same level of cognitive maturity. For that reason, age alone may not be sufficient criterion by which to evaluate the maturity of an adolescent and readiness to transfer to adult health care. Transferring to adult health care is a major transition in the life of the adolescent with cystic fibrosis (CF) and the parents. To facilitate adaptation during the transfer process, a planned programme needs to be developed.

The goal of nursing is to provide education and support to empower the individual and family in adapting to differing situations. "Empowerment is the social process of recognising, promoting and enhancing people's abilities to meet their own needs, solve their own problems and mobilise the necessary resources in order to feel in control of their own lives" (Gibson, 1991, p. 359). A planned gradual transition from paediatric to adult health care is advocated, thereby allowing for adequate preparation of both the adolescent and parent/s (Court, 1991; Frank, 1992; Schidlow & Fiel, 1990). An important first step in planning the transfer is the inclusion of an assessment based within the context of the developmental stage and coping ability of both the adolescent and parent/s (McCubbin, 1984). By examining an individual's coping ability, potential adaptation problems can be addressed (Hymovich & Baker, 1985). The assessment of the adolescent and family could be undertaken using Roy's Adaptive Model which would result in a complete analysis of influencing stimuli being obtained, as well as current adaptation abilities.

The development of a planned transfer programme is suggested in order to teach and guide the adolescent and family in relation to the transfer. Reliable and important information will be provided, whilst incorporating the individual needs of each member of the family. Their sense of control will be enhanced, uncertainty decreased, and trust and rapport between the adolescent, parent and health professionals would be advanced (Krulik, 1982).

It is envisaged that the components of the transfer programme will include set strategies such as a formal introduction to the topic of transferring to adolescents and parents; assessment of the adolescent and parent to determine the developmental stage and appropriateness for initiating the transfer process; education sessions for parents related to adolescent development; and other concerns voiced by the individual adolescents, parents, and health professionals. Provision of group meetings between adolescents, parents, and those who have already transferred may also prove beneficial. Education sessions on adolescent development may also be required for the paediatric and adult hospital's staff. Most important though, is the involvement of adolescents and parents in all phases of the planning and preparation for transfer. This inclusion will then further empower the adolescents and parents by providing help in asserting control over factors that influence the transfer (Gibson, 1991).

The role of nursing is also seen as one of client advocate through the avenue of resource/liaison person between the adolescent, family, and health care system. As many health professionals are involved in the care of adolescents with CF, a multidisciplinary team of these health professionals, at both paediatric and adult hospitals, is advocated to jointly plan and facilitate the transfer of the adolescent and family (Hewson et al., 1993; Schidlow and Fiel, 1990). As the transfer is an integral part of the adolescents' and families' life, it is suggested that they also be included in the team meetings. This inclusion will enable all concerned parties to participate in planning the transfer. The co-ordination of the transfer plan is another avenue of nursing involvement.

A non-disease category based adolescent ward has been established at the paediatric hospital, which could provide an opportune forum to discuss transfer with adolescents of differing chronic illnesses. An adolescent ward at the adult hospital was also advocated by Denholm (1990). Currently, there is no adolescent/young adult ward at the adult hospital, instead the adolescents are admitted to the disease-based ward with adults of varying ages.

Prior to the final transfer an acknowledgment by the paediatric hospital of the separation, possibly in the form of a graduation-like ceremony, has also been recommended as an opportunity for the adolescents, parents, and paediatric staff to formally say farewell (Frank, 1992). At present, discharge from the paediatric hospital is not acknowledged formally nor as a celebration. This could be implemented at the paediatric hospital as a farewell tea or achievement certificate.

Recommendations for Future Research

As many adolescents with chronic childhood diseases now have improved survival rates, more will be transferring to adult health care. The planned transfer programme suggested in the current study will need to be evaluated for effectiveness from the perspective of the adolescent, family and hospitals. Evaluation will be a continuous process as it will include the stages prior to transfer as well as a period following transfer. As demonstration of cost effectiveness of the programme will be sought by the hospitals, this will need to be included in the evaluation.

To determine if the findings of this study are typical of adolescents with a chronic illness, it is suggested that future research investigate the issue of transferring to adult health care for adolescents with different chronic illnesses. Stein and Jessop (1989) assert that much can be gained from chronic illness research that is not based on disease categories, while Schidlow and Fiel (1990) believe that transfer is more successful when doctors at the adult hospital are familiar with the chronic illness. These viewpoints

require further clarification to determine their impact on successful transfer to adult health care.

There was also some variation in experiences between the city and rural subjects. Consequently, elaboration is required to determine the influence of geographical distance from health care on the transfer process.

Many authors have proposed models of transition focussing on the adolescent with little reference to the potential effect on the family, or the effect of the family on the transfer process (Court, 1991; Frank, 1992; Hewson et al., 1993; Schidlow & Fiel, 1990). As with many studies in the literature (Canam, 1986; Krulik, 1980; Sawyer, 1992), fathers and siblings are under represented in the current study. To provide a more comprehensive view of the impact of the transfer process, further research is required that includes the entire family. Finally, Schidlow and Fiel (1990) suggest that health professionals may be unwilling to transfer patients and consequently, may hinder the transfer process due to economic considerations by the doctor, or strong emotional attachments with the adolescent and family. Study of the influence of health professionals on the transfer process is therefore, warranted.

Conclusion

The current study gathered information that provided a valuable insight into the transfer to adult health care for adolescents with cystic fibrosis and their parents. The study focussed on the adolescents' and parents' perspectives of the transfer to adult health care as little research has been conducted in this area. Roy's Adaptive Model was used as a basis to aid development of the data collection instrument, and for initial analysis of the data.

The adolescents and parents were found to be undergoing life cycle transitions as well as having to cope with the transfer to adult health care. From the findings it was discerned that this transfer is influenced by the developmental stage of the adolescent, parent adaptive tasks, transition processes, and the chronic illness. Within the framework

of Roy's Model the adolescents and parents in the current study were found to be adapting to adult health care, however, events were described that had an unsettling effect on both adolescents and parents. These events and subsequent effects could have been anticipated and conciliated within a functioning transfer programme.

Implications for nursing practice are therefore, to mediate the transfer process by developing a programme that will assist the adolescent and parents with the transition to adult health care within a developmental context. Recommendations for future research include evaluating the effectiveness of the transfer programme, studying the ramifications of the transfer for the whole family unit, and establishing an adolescent/young adult ward at the adult hospital. The challenge for nursing here, is the appropriate assessment, planning, preparation for, and evaluation of the transfer to adult health care for the adolescent with CF and the family in order to maintain continuity of care within an holistic framework.

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Appendix A

Data Collection Instrument

Demographic Information

Code :

Current age :

Gender:

Family composition :

Occupation

*Income/year

Father

Mother

Adolescent

(*Income/year - A = <\$20,000/yr; B = \$20,000 - \$36,000/yr; C = \$36,001 - \$50,000/yr;
D = >\$50,000/yr)

Age at diagnosis :

Date of transfer :

Frequency of admissions to PMH for six months prior to transfer :

Length of stay of each admission to PMH for six months prior to transfer :

Frequency of admissions to SCGH since transfer :

Length of stay of each admission to SCGH since transfer:

Interview Guide

Code :

Physiological Mode -

1. How is your health ?
breathing/chest infections?
appetite/eating/weight?
sleep?
activities (home, outside - home, school)?
2. Any changes to your health since transfer ?
3. What medication/s do you usually take ? - any changes since transfer ?
4. Do you worry more/less or the same about your health since transfer ?
5. Are you concerned about any health problems at present?
any family concerns about your health ?

Self-Concept Mode -

1. Tell me about your first hospitalisation at SCGH.
how did you feel about yourself ?
have your feelings about yourself changed ?
2. Tell me about your second hospitalisation at SCGH.
3. How do these stays compare with your stay/s at PMH ?
4. How do you feel about being transferred ?
5. Who decided that you should transfer ?
6. Why do you think you were transferred ? how do you feel about that ?

Interdependence Mode -

1. Tell me about your relationship with your parents/
brothers/sisters/friends/nurses/doctors/others.
2. What differences have you noticed in those relationships since transfer ?
3. What kinds of things did you do to help you deal with the transfer ?
who else helped you ?
how did they help you ?
4. What things do you think could have been done differently to help you cope with the transfer ?

Role Function Mode -

1. How are decisions made about your health care ?
who makes clinic appointments ?
transport to/from clinic ?
who goes with you to clinic ?
2. Is this any different from when you were at PMH ? How?
3. What difference have you noticed in how decisions are made since your transfer ?
4. Do you think your parents treat you any differently since transfer ?
tell me about that
5. What are your plans for the future ?
where do you see yourself in one year/five years ?

Appendix B

Parent/Guardian Consent Form

Study Title : Coping of Adolescents with Cystic Fibrosis Who Have Transferred To Adult Health Care.

Investigator : Ms. Maree Russell

Ms Russell is a Registered Nurse undertaking the research component of a Master of Health Science (Nursing) Degree at Edith Cowan University.

The purpose of this study is to gain an understanding of the experience of adolescents with Cystic Fibrosis (CF), after transfer to adult health care. The information sought will be collected by tape recorded interviews, with the adolescent, of approximately 30-60 minutes duration. As well, demographic information, for example, age, family composition and frequency of admissions will be collected from the adolescent and by medical record review. The information obtained during the interview will only be discussed with the thesis supervisors at Edith Cowan University and a data analysis adviser.

All interviews will be coded by a number to maintain confidentiality. The final report will be available to all interested subjects, families and institutions. The information gained will increase knowledge and understanding of the effect of the transfer process on the adolescent with CF.

THIS IS TO CERTIFY THAT I, _____
(print name)

do freely give consent for my child, _____
(print name)

to voluntarily participate in the above named study. I give permission for the interviews to be taped. I understand that these tapes will be erased when the study is completed. In addition, I give permission for access to my child's medical record at Princess Margaret and Sir Charles Gairdner Hospitals, to validate demographic information. I agree that research data gathered for the study may be published provided that my child's name is not used. I also understand that I am free to withdraw my consent and terminate my child's participation at any time and without penalty. I know that Ms. Russell is available at 4443860, if I have any further concerns and that I may contact the Head of the School of Nursing at Edith Cowan University on 3838594, if I am unhappy about any of the research procedures. All my questions have been answered to my satisfaction.

PARENT/GUARDIAN : _____

INVESTIGATOR : _____

DATE : _____



Appendix C

Institutional Letters of Approval

Ms M Russell
18 Wade Street
Joondanna WA 6060

Dear Maree

The Committee for the Conduct of Ethical Research has considered the ethical implications of your research project.

I am pleased to advise that as the Committee is satisfied that you have addressed the ethical issues, you are free to proceed with the research programme.

Once the programme is completed the Committee would be pleased to receive a brief report from you in which you address the ethical issues and, in particular, any problems which may have arisen in the course of your project.

Yours sincerely,

Eric Graham
Executive Officer
Committee for the Conduct of Ethical Research
30th October 1992
ref 92080

cc Mrs Gerrie Sheratt



Sir Charles Gairdner Hospital

Our ref: LAS/SW
Your ref: Ext. 3528
Enquiries to: 2 December, 1992
Date:

Ms Maree Russell
18 Wade Street
JOONDANNA WA 6060

Dear Ms Russell

Re: Proposed Research - Cystic Fibrosis

Thank you for your letter dated 4th November 1992. I note on page 2 of your proposal that initial contact with potential subjects will be made by Dr Ryan, who will offer them the opportunity to be involved in your research. Provided that is followed, your study may commence.

Yours sincerely



Dr Lindsay Stewart
A/DIRECTOR OF MEDICAL SERVICES

c.c. Dr G Ryan
Ms A McGrath, Medical Records Department

Refer Enquiries to:

DJF:LS

Telephone:

340 8245



Medical Centre

8 December 1992

Ms M Russell
18 Wade Street
JOONDANNA WA 6060

Roberts Road
Subiaco WA 6008
GPO Box D184
Perth WA 6001
Telephone (09) 340 8222
Facsimile (09) 340 8111
Facsimile (09) 340 8115

Dear Ms Russell

Registration Number: 549

Title: "Coping of Adolescents with Cystic Fibrosis who
have transferred to Adult Health Care"

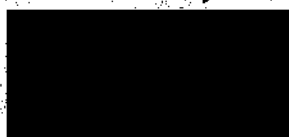
Approved: RE92-53.5 - 19 November 1992

The Medical Advisory Committee's Research and Ethics Sub-committee has recommended that approval be given for you to undertake the abovementioned research. This recommendation is subject to final confirmation by the Board of Management. You will be notified only if the Board does not adopt the recommendation.

The Research and Ethics Sub-committee has been charged with the responsibility of keeping the progress of all approved research under surveillance. If the research is not completed within six months you are asked to submit a progress report. A copy of the final results must be forwarded to the Sub-committee upon completion of the research.

Please note: Approval for studies is for three years and the research should be commenced and completed within that period of time. Projects must be resubmitted if an extension of time is required.

Yours sincerely



D J Fornby
MEDICAL DIRECTOR



Sir Charles Gairdner Hospital

Our ref:
Your ref:
Enquiries to:
Date:
GR: NJH

Appendix D

Respiratory Physicians' letter to potential subjects

16 February 1993

Dear

I have been approached by Marie Russell who is doing a Masters of Health Science (Nursing) at Edith Cowan University for which she needs to complete a thesis.

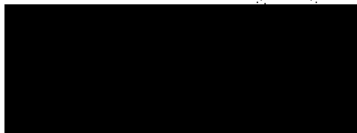
She plans to do research, the aim of which is to examine how people with cystic fibrosis cope when they transfer their medical care to a hospital for adults.

To do this she will need to see you on a couple of occasions to gather information on how transfer to this hospital has affected you and how you have coped with it. The interview will be taped. She has ethics approval from Edith Cowan University and approval from the administration from Sir Charles Gairdner Hospital. A major factor in obtaining ethics approval is assuring the ethics committee any patient information will remain confidential.

I told her I would write to you before she contacted you to inform you and to give you the opportunity to contact me if you do not wish to be involved. Whether or not you are involved will not influence your treatment here.

With best wishes.

Yours sincerely,



GERARD RYAN
Physician,
Department of Respiratory Medicine

Appendix E

Adolescent Consent

Study Title : Coping Of Adolescents With Cystic Fibrosis Who Have Transferred To Adult Health Care.

Investigator : Ms. Maree Russell

Ms Russell is a Registered Nurse undertaking the research component of a Master of Health Science (Nursing) Degree at Edith Cowan University.

The purpose of this study is to gain an understanding of the coping of adolescents with Cystic Fibrosis (CF), after transfer to adult health care. The information sought will be collected by tape recorded interviews of approximately 30-60 minutes duration. As well, demographic information, such as, age, family composition and frequency of admissions will be collected from you and by medical record review. The information obtained during the interview will only be discussed with the thesis supervisors at Edith Cowan University and a data analysis adviser.

All interviews will be coded by a number to maintain confidentiality. The final report will be available to all interested subjects, families and institutions. The information gained will increase knowledge and understanding of the effect of the transfer process on the adolescent with CF.

THIS IS TO CERTIFY THAT I, _____
(print name)

do voluntarily agree to participate in the above named study. I give permission for these interviews to be taped. I understand that these tapes will be erased when the study is completed. In addition, I give permission for access to my medical record at Princess Margaret and Sir Charles Gairdner Hospitals, to validate demographic information. I agree that research data gathered for the study may be published provided that my name is not used. I understand that I am free to refuse to answer any questions, should I feel so inclined. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty. I know that Ms. Russell is available at 4443860, if I have any further concerns and that I may contact the Head of the School of Nursing at Edith Cowan University on 3838594, if I am unhappy about any of the research procedures. All my questions have been answered to my satisfaction.

PARTICIPANT : _____

INVESTIGATOR : _____

DATE : _____

Appendix F

18 Wade Street,
JOONDANNA 6060
WESTERN AUSTRALIA

Permission to reprint Table 5.1

FAX TO: JULIE JOYNER - PERMISSIONS MANAGER
COMPANY: BLACKWELL SCIENTIFIC
Osney Mead
OXFORD OX2 0EL
DATE: 3rd February, 1995
YOUR FAX: 0011 44 865 721 205
FROM: MAREE RUSSELL
NO. OF PAGES (including this page): 1

Dear Ms Joyner,

I am a Master of Nursing student at Edith Cowan University, Perth, Western Australia, seeking written permission to use a table from an article published in the Journal of Advanced Nursing in my thesis.

The table I wish to use is from the article titled "Common adaptive tasks facing parents of children with chronic conditions" written by Connie Canam and published in 1993 in Volume 18, pages 46-53. The table is 'Table 1 Parental adaptive tasks' on page 46 and I wish to present it in the same manner as it is displayed in the article.

Your prompt attention to this matter would be greatly appreciated and a reply can be faxed to me on 619 340 8093.

Yours faithfully,

Maree Russell

Permission is granted subject to a full acknowledgement (author, title of the article, the journal / book and ourselves as publisher) on the understanding that nowhere in our text do we acknowledge a previously published source for all or part of this material.

RECEIVED
- 6 FEB 1995
JULIE JOYNER

7/2/95

BLACKWELL SCIENCE LTD.
OSNEY MEAD
OXFORD
OX2 0EL

Appendix G

Categorised Interview Guide Data

The results obtained from the Interview Guide questions have been organised within the framework of the Adaptive Mode categories of Roy's model (Table F-1) and are presented in this Appendix. An explanation of the Adaptive Mode categories is given prior to presentation of the data.

Table F-1

Roy's Model Adaptive Mode Categories.⁵

PHYSIOLOGICAL MODE	SELF-CONCEPT MODE	ROLE FUNCTION MODE	INTERDEPENDENCE MODE
Oxygenation Nutrition Elimination Activity & Rest Protection The Senses Fluid & Electrolytes Neural & Endocrine	Physical Self: body sensations body image Personal Self: self-consistency self-ideal moral-ethical- spiritual self	Primary Secondary Tertiary	Significant other Support Systems

⁵ Derived from Roy & Andrews, 1991

Physiological Mode

When Roy first developed the model she identified nine categories or needs in the physiological mode to identify body responses to stimuli. These have since been refined to five basic needs and three special functions (Roy & Andrews, 1991). The five basic needs identified are oxygenation, nutrition, elimination, activity and rest, and protection. The special functions are divided into the senses, fluid and electrolytes, and complex neural and endocrine functions. The categories included in this study were a1) oxygenation as demonstrated by chest infections and activity tolerance, b) nutrition level

as depicted by the adolescent's weight and appetite, c) activity and rest in the form of sleep and activities engaged in, and d) protection as shown by changes in the state of health. These basic needs were considered to be easily assessed without the need to undertake invasive investigations. An indication of any deterioration due to CF would also be observable in these five needs. Previous anecdotal information indicated that transferring to adult health care meant an automatic deterioration in the overall health status. It was hoped that by obtaining information on these basic needs it could be shown that there was no foundation to this anecdotal perception.

All the adolescents indicated that there had been some physiological changes in oxygenation, nutrition and protection needs since transferring from the paediatric to the adult hospital. These physiological changes were not viewed negatively by either the adolescents or parents. In fact most were considered minor and related to the stage of the disease process and not merely because of transferring to adult health care.

Oxygenation. In those with CF, bronchial epithelium is destroyed with chronic lung infections resulting in a gradual progression of pulmonary disease. The bronchial walls become weaker and the oxygen and carbon dioxide exchange is decreased (Jackson, 1989). To ascertain perceptions of the adolescent's wellness state since transfer, a description of the adolescent's general health was asked of both the adolescent and parent. The adolescent responses varied from "good" to "I've got the flu". The parent replies were "quite fit" to concern about a persistent daytime cough.

For three of the adolescents the level of their health was partly based on lung function results, which had all deteriorated since transferring to adult health care. Only one parent cited lung function results when describing the adolescent's health. The deterioration in lung function results are an indication of the gradual deterioration of the respiratory system. With chest physiotherapy and fewer lung infections this progression can be retarded (Dibble & Savedra, 1988). One mother was concerned that her adolescent would accept that respiratory deterioration was a forgone conclusion and subsequently lessen the intensity of the treatment regime. Two of the parents used fewer

hospitalisations and chest infections as indicators of their adolescent being reasonably healthy. Another adolescent gauged good health as having a non-productive cough and requiring neither physiotherapy nor antibiotics.

Nutrition. The disease process of CF prevents essential pancreatic enzymes from reaching the duodenum due to thick mucous in the pancreatic duct; digestion and absorption of nutrients is impaired. Consequently, despite a healthy diet and appetite, maintaining a stable weight can be difficult. Weight loss and a decreased appetite usually accompany a lung infection (Jackson, 1989).

Six of the adolescents felt that they had good appetites and had not required any alterations to their nutrition since transferring. Also, when well, they participated in a variety of activities which demonstrated a nutrition and oxygenation state sufficient to meet activity needs. One mother considered her adolescent's appetite to be erratic and that the adolescent did not eat well, yet the adolescent considered that the appetite was good, compared to the appetite of non CF friends. Another mother and adolescent concurred that the adolescent's appetite was improving. This adolescent's health had "...gone down a little bit..." in relation to a substantial loss in weight that occurred about two years prior to the study interview; the weight loss had been compounded by a chest infection. This weight loss and lack of appetite, had culminated in the recent introduction of overnight enteral feeds. Although the adolescent had not yet reached the desired weight goal, there had been an improvement in energy levels with an interest in eating food and said generally "I feel heaps better." The weight loss and chest infection occurred around the same time as moving from the paediatric to adult hospital. Transferring was also confounded by a very stressful job, from which the adolescent had since resigned. When unwell, all the adolescents said they suffered a decrease in weight, which required various strategies to regain, otherwise the adolescents felt that their weight was stable and reasonable. One mother was concerned that, although her adolescent was not strictly underweight, a greater reserve in body tissue was needed as a bolster for fighting infections when they occurred.

Activity and Rest. Five of the adolescents participated, in varying degrees, in household chores. For one adolescent, cleaning the house on a contract basis for the parents, was a means of supplementing income whilst a full-time student. The parents of another adolescent considered that as twice daily physiotherapy and treatments were very time consuming they did not expect this adolescent to participate in household chores. There was a discrepancy between one mother and adolescent as to whether household chores were done by the adolescent; the adolescent said yes and the mother said no. All the adolescents reported taking part in some form of social and/or sporting activity. The parents agreed that their adolescent participated in peer group social activities, which was also encouraged by all the parents. The social activities included eating out and going to the movies or nightclubs. There was a range of recreational sporting activities, such as rollerblading, swimming, tennis, golf, and walking. One adolescent stated they were a keen "nightclubber" and spent a lot of time in nightclubs. When asked if concerned about the cigarette smoke the adolescent replied, "No, I'm having too much of a good time to worry." For another adolescent the time spent in nightclubs or pubs was monitored because this adolescent was concerned about the coughing spasms that occurred as a result of being in a smoky environment.

A good night's sleep was reported by all the adolescents when they were well and the length of sleep varied from five to ten hours. If unwell, coughing spasms usually disturbed their sleep, however, no problems were experienced in returning to sleep after the spasm had subsided. Coughing during the night seemed to be more of a concern for the parents than the adolescents, as the parent's sleep was also interrupted until the coughing subsided.

Protection. Protection is concerned with the body's defence mechanisms of skin, hair, nails and the immune system. In this study, perceived changes to the adolescents' state of health and medication regimes since transfer were taken as indicators of the response of the body's immune system. Two adolescents stated that they took prophylactic antibiotics, whilst the others only had antibiotics, in any form, when unwell.

Four adolescents reported no change to medication regimes when they transferred from the paediatric hospital. Two adolescents said there had only been minor changes, such as the type of antibiotic used. One adolescent said they were taking vitamin supplements and pancreatic enzymes, which was in contrast to the mother who stated that the adolescent took no medications. This mother felt that by not taking medications the adolescent could believe that there was nothing wrong.

Since transferring to the adult hospital all adolescents believed there had been no really negative health changes. For two adolescents, there had been fewer hospitalisations than when at the paediatric hospital; this was verified by a chart audit. A change in attitude towards self-care was given as the reason for this reduction in the number of hospitalisations. For both these adolescents the initial hospitalisation was longer than the usual two week period. One adolescent had visions of being admitted to the ICU, and maybe never getting out, but neither eventuated. Both adolescents were concerned that their second admission would be a repeat of, or worse than, the first admission and consequently were rather hesitant about being readmitted. In hindsight, the longer first admission was viewed positively as these adolescents felt better acquainted with the ward staff. The second and subsequent admissions were classed as routine by the adolescents, with no untoward incidents. One mother felt that changes in health since transfer were not related to the transfer but to the stage of her adolescent's illness, that is, the gradual progression of the illness.

Current worries and concerns were also asked of the adolescent and parent. They are included here as they could be viewed as stressors on the immune system. One adolescent was worried about drug sensitivities of bacteria and the possibility of developing antibiotic resistant strains of bacteria. This adolescent also believed that a family concern was "that as I get more independent I'll get more lazy" and reduce the frequency of physiotherapy. Another adolescent was worried about catching the flu. "Going out a lot" and "overdoing it" were seen to be parental concerns by this

adolescent. The adolescent, though, "would rather go out and have a good time than worry about whether I'm going to get sick or not."

Self-Concept Mode

Psychological and spiritual aspects of the person constitute the self-concept mode which has two components. The first is the physical self, composed of body sensations or feelings, and body image. The second is the personal self and relates to self-consistency, self-ideal and moral-ethical-spiritual self. Self-consistency can be seen in an individual's response to a situation and is accompanied by verbal comments on that situation. Self-ideal pertains to one's capabilities and desires. Moral-ethical-spiritual self is founded on one's belief system and self evaluation.

Physical Self: Body Sensations. One adolescent reported that they no longer became upset when admitted to hospital and it "feels good knowing I can jump in my car if I want to" and escape the hospital environment for a while. This adolescent's parents "felt rotten" whenever admission to hospital was necessary because they live in the country and are consequently, restricted in visiting their adolescent. This adolescent also said that the first admission to the adult hospital was pretty good because "I felt like an adult, I'd never felt like an adult before." Three other adolescents also repeated this statement about being treated like an adult at the adult hospital in comparison to the rules at the paediatric hospital. Five adolescents commented on the greater freedom enjoyed whilst inpatients at the adult hospital. The only stipulation appeared to be that they needed to be on the ward for treatments and medications, otherwise they were free to come and go as they chose. This allowed two of the adolescents to continue attending lectures for their studies. For the adolescents in the current study, dependency whilst inpatients had been reduced through the greater freedom enjoyed and being given the status of adulthood.

The impetus for transferring was different among the adolescents. Two adolescents were transferred on the basis of age, that is they were older than 18 years, while another

transferred because of the idea that "at 18 you're considered an adult and most of my friends had transferred." For one adolescent the deciding factor was driving to a clinic appointment at the paediatric hospital. The adolescent's comment was "if I'm old enough to drive myself, then what am I doing here?" Completing high school was seen by two adolescents as the most appropriate stage to transfer. This decision was made in consultation with the adolescents, parents and paediatric physician. For another adolescent transferring to the adult hospital had been discussed with the paediatric physician and for the adolescent "...it just seemed like it was the right time" to transfer. Only one adolescent was not happy that the transfer had occurred and stated that they would prefer to still be at the paediatric hospital. This was related to a preference for management of CF by the paediatrician instead of the respiratory physician at the adult hospital. One adolescent had only ever had two admissions to hospital, neither of which was for treatment of a chest infection. One was for surgery when at the paediatric hospital and the other at the adult hospital for a bowel obstruction, which was treated medically. This adolescent hated being in hospital and commented that IV therapy "was creepy, having this thing stuck in your arm. I thought I'm not going to make a habit of this."

Body Image. Being observed while doing physiotherapy was an aversion of one adolescent. When doing physiotherapy the only person with whom the adolescent felt comfortable was the mother. The mother also commented that the adolescent "doesn't like coughing in front of people" either. Seeing older patients with CF "...sort of makes you look after yourself, so you don't end up with a rounded back, really bad cough, on oxygen and stuff like that" was a comment from one adolescent on what is hoped can be avoided. Another adolescent had recently had a gastrostomy tube inserted to reverse a dramatic weight loss. This had curtailed social activities but "once I get the [gastrostomy] button in I'll be going out everywhere. I'm just worried cause I can't do my pants up at the moment." This adolescent was also concerned that as sitting down was done a little stiffly at present, when out someone might ask "What's wrong?", a question

which this adolescent wished to avoid. This adolescent wished to gain another 12 kilograms and was aware that it would take time to achieve this goal. The other four adolescents were satisfied with their current physical appearance and were aware of their nutritional needs to maintain their weight. Two mothers commented that their adolescent could do with adding a few kilograms to their body mass. Although one adolescent gave the appearance of being underweight, the mother stated that the adolescent had the same build as the father.

Personal Self: Self-Consistency. Sheer determination to avoid hospitalisation was a very strong response to the threat of hospitalisation for one adolescent. If admission was looming on the horizon, treatment regimes were intensified and everything possible was done by the adolescent and mother to curtail admission. This particular adolescent had not been admitted to hospital since the age of 14 years, and infrequently before this age. During previous admissions to the paediatric hospital this adolescent was accommodated in an isolation room to prevent cross infection. This was regarded as not very pleasant and the adolescent stated that the mother also acted as guard, even to the extent of locking the adolescent in the room when the mother went for meals. These measures were encouraged by the paediatrician and cross infection was prevented. This adolescent's mother stated that the adult hospital frightened her adolescent, and the adolescent agreed. Reasons appeared to be the lack of isolation facilities at the adult hospital and the need to "...be in with everyone and all the old people." There had never been any contact between this adolescent and any other people with CF, and there was no intention of initiating any contact in the future. This lack of contact appeared to be related to the possibility of cross infection. Prerequisites for transferring to the adult hospital were described by one adolescent as accepting responsibility for and taking a more active role in the management of self-care. The adolescent perceived that maturity level was the deciding factor and not chronological age. Another adolescent hated talking about CF to people because it was perceived to generate anxiety and introspection on being sick, which is not what this adolescent chose to do as, "I've got all

these other things I want to do!" For another adolescent the implications and meaning of daily treatments for life were not for discussion.

Self-Ideal. After transferring and seeing older people with CF, aged about 22-30 years, one adolescent said "well I've only got a few more years, if I don't start looking after myself I'm gonna end up like that." The older people with CF were perceived as not well at all and their health on the decline. One adolescent saw themselves as not having anything wrong "...just a normal person who has to have therapy". As a consequence, hospitalisation and any subsequent explanations to friends regarding one's whereabouts were to be avoided. Yet, another adolescent believed that "you can't hide something like this and if you do, then you're not going to have many friends" and imparting information about CF to friends was a gradual process. For one adolescent completing Year 12 was an achievement, as when in Years 9 and 10 most of the others with CF gave up and dropped out of school. This adolescent was also at the stage of wanting to give up school and then decided that "...if I dropped out I just had nothing else to go to...so I stuck it out and tried to get a good qualification." Year 12 was completed at about age 18 and this adolescent is now nearing the completion of a course to enhance prospects within the workforce. Another adolescent, aged 19 years, was also undertaking to complete high school to be able to follow the career of choice.

When the subjects in the current study were asked 'where do you see yourself in one year's time?' five adolescents said they hoped to be in the workforce. One adolescent will still be completing a study course. One adolescent is currently employed part-time and another adolescent is hopeful of being self-employed. All the adolescents were actively participating in planning for their future. Three adolescents planned to be living independently of their parents and another two adolescents hoped to have begun purchasing a house. As far as their health status was concerned, two adolescents hoped for an improvement in health and the others hoped to at least maintain their current health status. Two of the adolescents were very interested in the prospects of better treatment regimes to retard the progression of the illness. One adolescent made the

statement that "health wise I'll still be going for another 50-60 years." This statement does not appear to be a realistic goal at this point in time. This adolescent also stated that they do not usually make long term plans. Two adolescents would like to travel but cited that difficulties in providing for continuation of care whilst away were a hindrance. One of these adolescents stated that "others with CF have done it, so it can be done." The second adolescent commented that "you can't really organise trips, can't really move around much because of CF." These differing views highlight the impact that CF can have on future planning for those with CF.

The adolescents were also asked where they saw themselves in five year's time. To be married was a desire of two adolescents and although having children was an option, neither were prepared to jeopardise their health status with the stresses of pregnancy. All the adolescents hoped to be part of the workforce and living independently from their parents. Maintaining a stable health status, with little deterioration, was hoped for by all the adolescents. As one adolescent stated "CF does progress and you can slow it down if you look after yourself." Two adolescents were very hopeful of a cure for CF. One of the adolescents comment that "it'd be great not to have to get up in the morning and do your therapy." Another adolescent was "pretty optimistic there'll be a cure soon and then I'll just be normal for once."

Moral-Ethical-Spiritual. One adolescent learnt to ask questions of the physician related to management of CF as a result of an incident with drug sensitivities of a sputum culture. This adolescent had developed resistance to many antibiotics and became rather anxious when viewing the results alone. Instead of saying nothing the adolescent's anxiety was dissipated after requesting and receiving an explanation of the results from the doctor. A few of the adolescents felt that the doctors at the adult hospital "actually listened to them" and sought their opinion on CF management, as opposed to the perceived paternalistic attitude of the doctors at the paediatric hospital. One adolescent described an incident that occurred when IV therapy was being initiated on the first admission to the adult hospital. After three unsuccessful attempts to insert the IV

cannula, the resident doctor left to replenish supplies, the adolescent hid and refused to allow that doctor any further attempts at cannulation. Finally, and on the first attempt, a registrar successfully inserted the IV. This adolescent had never before experienced the unsuccessful insertion of an IV cannula and was distressed by this episode. Parents reported a dilemma when the doctor/patient/parent relationship changed. The parents had been an integral part of treatment and management for many years and suddenly they felt they were no longer required.

Role Function Mode

The differing roles of an individual in society is explained in the role function mode (Andrews, 1991b). This mode is based on expectations in behaviour of one person to another and the roles are classified as primary, secondary and tertiary roles. One's primary role is related to age, gender, and developmental stage. The primary role is comprised of the majority of behaviours displayed during a particular period of time, for example a 16 year old female adolescent. Secondary roles are achieved, require specific performance and are associated with one's primary role, for example a daughter, sister and student. Chronic illness is described as a secondary role as this is not a freely chosen role. Tertiary roles are usually temporary and freely chosen in relation to one's primary and secondary roles. Tertiary roles enable obligations associated with performing primary and secondary roles to be met. This could be the netball team coach, a member of a club and also includes hobbies.

Primary Role. All the adolescents were currently living with their families of origin. Chronologically, all the adolescents are nearing the end of the adolescent stage of development (Berger, 1983). One adolescent believed that transferring was a good thing because "it wakes you up!" The criteria given as being ready to transfer was that "you have to be responsible, you have to know that you got to take your drugs, you got to do this, you got to do that" and this doesn't just happen at any particular age. Another adolescent believed that at age 16 or 17 years it would "probably be you know, a fair

enough time to swap over." The reason given for this age was that "as you get older you get quieter, as you're younger you're much more active and noisy...and at [the adult hospital] you just can't be like that, the old people, that sort of limits you." For this adolescent it was also a perception that the staff at the paediatric hospital wanted some evidence of better self-care before being able to transfer. The adolescent commented "I think they probably wanted to see me look after myself better and to grow up a bit more."

Two adolescents commented on the influence in their lives of the death of a friend with CF. Although everyone was at a different level in regard to their health, one adolescent felt, that in the first instance, it was easier to deal with death away from those in a similar situation, that is, away from the CF group when a friend with CF dies. This adolescent's friend had died at the adult hospital about three years prior to the study interview. When another adolescent was contemplating transfer to the adult hospital, about two years before the study interview, a close friend, who also had CF and had transferred, died unexpectedly. The outcome of this friend's death was a 12 month delay in transferring to adult care for the adolescent in this study. The mother of another adolescent spoke on the recent death, about two months prior to the study interview, of her adolescent's friend, who also had CF. The adolescent was interviewed prior to the mother and this friend's death, or any issue related to death, was not mentioned by the adolescent. The adolescent's mother said that the friend's death

"was quite an ordeal for [the adolescent] to go through...and that's another thing that knocks them back, so many of their friends passing away...it gets to the stage where they start thinking 'My God, y'know everyone's going, what's going to happen to me, when am I going to go?' sort of thing."

Another mother commented that "my attitude is, if you are going to have a life and it's short, at least have a happy one and enjoy yourself." One adolescent verbalised the attitude of some parents as "oh well, they're going to die anyway, let them have some fun while they're at it." For this adolescent life is "as normal as possible and I just fit treatment in around it."

Decisions regarding health care were made by each of the adolescents. Three adolescents usually conferred with their parents for a second opinion; as one adolescent stated "they've coped with it for so long that I value their opinion because I've only just started really." Making health care decisions began whilst still attending the paediatric hospital for three adolescents. This was because the outpatient clinic visits revolved around the adolescents with minimal parental input. One adolescent stated that "Mum does it all" in relation to health care decisions. For this adolescent it was important to continue to include either one or both parents at clinic visits. The mother said "I'm trying to make [the adolescent] more responsible. [The adolescent] recently rang for some test results and it's the first time [the adolescent] had done that without me instigating it." As all the adolescents had acquired their drivers' licences, parents were no longer required for transport purposes and the adolescents mainly took themselves to clinic appointments.

Secondary Role. The adolescents are sons and daughters, brothers and sisters with one adolescent being an only child. One adolescent is engaged to be married, another is in a romantic relationship and another had recently ceased a romantic relationship. All the families to which these adolescents belong were families with teenagers. One family had a sole parent while the remainder came from two parent families; one family was a blended family. One adolescent had a sibling who also had CF and yet another adolescent had a sibling with insulin dependent diabetes mellitus. All other siblings were regarded by the adolescents and parents as fit and healthy. Four adolescents were studying either full or part-time at higher education institutions. One adolescent was completing high school, two were doing courses specifically to gain access to employment and another was studying at university. One adolescent was working part-time and two were seeking work. Both the unemployed adolescents had been employed in the past.

One adolescent discussed very little regarding health matters with the parents, mostly conversation was of a superficial nature. Another adolescent saw the parents as having tried to make life normal, with treatments fitted around the adolescent's life,

which "...was going to be just like any other kid with any long term future in front of them." This adolescent also believed that parental concerns were that the adolescent would not maintain the same standard that they set, especially if living away from home. Another adolescent felt frustrated with the adult hospital system. When the adolescent had given permission for hospital staff to discuss current and intended treatments with the adolescent's parents the hospital staff replied, "oh we don't like doing that." Consequently, the parents felt that their adolescent and the hospital were excluding them from participating in their adolescent's management, which then led to conflict within the family. Supported by parents, the responsibility for the final decision to transfer rested with another adolescent. This decision making was also deemed by the adolescent to be a logical consequence of being an adult.

Great interest was expressed by adolescents and parents in the outcome of current trials on new treatments in the United States of America (USA). One adolescent's mother wished some of the trials to be conducted in this country so that those with CF would not have to raise funds in order to travel to the USA to participate. One adolescent verbalised reluctance to participate until more testing was done because "anything could happen, like you might not get that, you might get something else." Also, this adolescent acknowledged initial abuse of the power associated with being given control over health management, for example refusing to do physiotherapy.

Being a parent is classified as a secondary role. All but two parents were in paid employment; one parent was currently seeking employment and another was doing a course of study to join the workforce. One mother saw her role as providing moral support for her adolescent, especially when admitted for the first time to the adult hospital. This mother also suggested that when aged 16-17 years the adolescents should be transferred "...because they're not kids any more and are starting to think about life." An acknowledgment was made that some 16 year olds would not be ready for the transfer. Also it was suggested that the issue of transferring to adult health care should be mentioned to the adolescent and parent/s when the adolescent was aged 15 years.

One mother was concerned about her adolescent's health, when over a period of three to five months no improvement was made in the adolescent's state of health. Interaction at clinic visits had only been between the adolescent and the physician. This mother then attended a clinic appointment with her adolescent and made sure that she was able to speak to the physician and subsequently corrective action was instituted. This mother also believed that the only worry her adolescent should have "...is whether [the adolescent's] fringe looks any good in the morning" and all other worries should be shouldered by the parents. Anger and annoyance at the adult hospital for casting aside the parents was also strongly voiced by this adolescent's parents.

One adolescent was described by the mother as ceasing to take all medications after leaving school when aged 15-16 years. Cessation of medications resulted in arguments between the adolescent and parents and the adolescent left home. Prior to leaving school this mother would, if needed, "...physically drag [the adolescent] off to the hospital for appointments and make [the adolescent] take the tablets." Once the adolescent left school the idea "...that if [the adolescent] didn't take the tablets there was nothing wrong" seemed to develop.

Seeing a beautifully dressed young girl, with CF, wearing an oxygen mask and carrying an oxygen cylinder at the adult hospital was described as terrifying by one mother. This incident lead the mother to admonish the adolescent to intensify treatments or they too would require oxygen therapy. Another mother preferred her adolescent to be in a romantic relationship as she thought this would make the adolescent more responsible for health care. One mother was concerned that as her adolescent now attended outpatient clinics alone, the adolescent forgot to ask what the mother considered relevant, for example a comparison of current and previous lung function tests. The mother gave the impression of feeling left out as she now had a markedly reduced input into the management of her adolescent's health care. One mother was surprised to be asked to participate in this study, for she thought it would be a

continuation of excluding the parents in favour of the exclusive doctor/patient type relationship.

When the parents were asked where they saw their adolescent in a year's time, all the parents hoped their adolescent would be in the workforce, even if part-time. Two parents thought their adolescent would still be completing study courses. Three parents felt that their adolescent would still be living at home, whilst the parents of another adolescent had instigated a plan whereby the adolescent would be living independently in a year's time. In the area of health, one parent believed that the adolescent's health would be much the same as now. Two other parents were hopeful of an improvement in the health of their adolescent. As one mother stated, in relation to new treatment advances, "things look a lot more rosy for us than what perhaps they did 10 years ago." Concern, that hopes raised by the new genetic engineering treatments would be dashed, was voiced by one mother. Previously this mother had kept a tight control over allowing any treatment to raise unattainable hopes. There was also concern regarding a new virulent strain of *Pseudomonas* and the ramifications of the adolescents becoming infected with it.

The parents were also asked where they saw their adolescent in five year's time. Four of the parents hoped that their adolescent would be married or in a long term relationship. Two parents felt that unless their adolescent took greater responsibility for maintaining their health care all other goals would be too late. As one mother said "I don't know whether [the adolescent] will be here in five year's time." Another mother was hopeful that her adolescent will be alive, while yet another mother said "we pin our hopes on better treatment." Overall for the parents, the biggest issue appeared to be that the adolescent would learn to responsibly manage their health care.

Tertiary Roles. Only two adolescents belong to any clubs, one to a swimming club and the other to a tennis club. One adolescent attended a gym twice a week but otherwise exercise for the adolescents was rather sporadic.

Interdependence Mode

Interactions for the giving and receiving of love, respect and value are described by the interdependence mode (Andrews & Roy, 1991a). The main focus is on close relationships in order to develop the feeling of security in nurturing relationships. Two specific components, significant others and support systems, have been identified by Roy in meeting these needs. Individuals with whom close, mutual relationships are developed are considered to be significant others. The person or persons can be identified as the most important person/persons in the individual's life. Support systems are all other persons, groups or animals who sustain and advocate the interdependence needs of the individual (Tedrow, 1991).

Significant Other. For all but one adolescent, the parents were considered as significant others to the adolescents. This one adolescent described difficulty in the relationship with parents and explained that "there's a brick wall between us." A younger sibling was seen as this adolescent's significant other as the adolescent perceived that they both had similar problems with their parents. Apart from exchanging pleasantries, discussions rarely occurred between the adolescent and parents. The adolescent's mother corroborated this circumstance with the statement that "we tolerate each other." One mother believed that she and her adolescent get on reasonably well apart from "having the same problems with [the adolescent] as I had with my mother when I was her age." Relationships between siblings were regarded as good by six of the adolescents; one adolescent was an only child. Three of the parents also felt that the sibling relationship was good and three others felt that their children were close to each other. One adolescent was engaged to be married, another in a romantic relationship, whilst a third had recently ended a romantic relationship.

Support Systems. Parents, friends and the CF Nurse at the paediatric hospital were seen, by the adolescents, to be supportive. When one adolescent was admitted to the adult hospital for the first time, the mother accompanied the adolescent "as moral support and once [the adolescent] got into a room well [the adolescent] virtually said

goodbye." This dismissal was viewed positively by the mother as showing that her adolescent was growing up. Four of the parents periodically go to clinic appointments with their child, when asked to by the adolescent. This can be purely from the company aspect, or it may be from a transport perspective if the adolescent is feeling too unwell to accomplish this task on their own.

When preparing to transfer, talking to people with CF already attending the adult hospital, was helpful for four adolescents. Three adolescents took part in a programme to 'Check-Out' the adult hospital; this was also described as beneficial by the adolescents. This programme was run jointly by the paediatric and adult hospitals to introduce the adolescents to the relevant areas and staff of the adult hospital. When one adolescent, that had missed out on the 'Check-Out' programme, attended their first outpatient clinic at the adult hospital the adolescent was accompanied by the paediatric CF Nurse. After transferring, another adolescent was given a tour of the adult hospital by a member of the staff. This adolescent was not impressed with the hospital and was vocal about the hospital being a gloomy and unfriendly place. The adult hospital was seen as a stark contrast to the bright and airy environment of the paediatric hospital. The atmosphere of the adult hospital was also described as quiet, subdued and depressing as opposed to an atmosphere full of life with children laughing and crying at the paediatric hospital. Two adolescents were given neither a tour of, nor introduction to the adult hospital. Both had visited friends with CF when inpatients at the adult hospital and said they had a vague idea of what to expect. Neither adolescent was concerned about the transfer nor that they were not involved in the introductory programme to the adult hospital.

The paediatricians were described as "treating you like a child" by one adolescent. The paternalistic style of the paediatricians, when changing medications, was viewed as upsetting and infuriating to one adolescent and mother. This adolescent was to be commenced on permanent antibiotic therapy, which to this adolescent meant that the CF disease process had markedly advanced. It transpired that it was the policy of this group of paediatricians to treat all their patients with CF with permanent antibiotic therapy.

Subsequently, after seeking further information elsewhere, the adolescent discovered that the antibiotic therapy was not a reflection of the stage of CF and was then able to accept and agree with the permanent antibiotic therapy.

Access to a supply of drugs, sufficient to last between clinic appointments, was seen as a problem for two families. When at the paediatric hospital a three months supply was prescribed at each three monthly clinic appointment. At the adult hospital the limit dispensed was only for four to six weeks, which for the country adolescents necessitated an extra trip to Perth. Another annoyance for those living in the country was that departure from clinic appointments always seemed to coincide with the afternoon peak-hour traffic. One mother was not impressed that at her adolescent's first clinic appointment the medical record could not be found. This mother "...thought they would have been efficient enough to at least have read her case notes and have them to hand" for the first clinic appointment. One adolescent remains optimistic that "one day I reckon they're going to turn around and say I can go back to" my paediatrician. This adolescent was extremely reluctant to transfer to the adult hospital and preferred to attend the paediatric hospital as the adult hospital was viewed as a horrible and depressing place. According to this adolescent's mother "nothing's better, [my adolescent's] got this rosy picture" of the paediatric hospital and nothing can compete with it.

All the adolescents had friends with whom they socialised. Friends were also viewed by the adolescents as supportive by visiting when the adolescents were inpatients or making contact by phone. For one adolescent, friends were helpful in that the older friends did the explaining about CF to newer friends. One mother commented that her adolescent joked that "I don't have any friends, just a heap of parents!"