THE UNIVERSITY OF CALGARY

Social Skills of Children with Cystic Fibrosis and Their Siblings

by

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A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE

PROGRAMME IN CLINICAL PSYCHOLOGY

CALGARY, ALBERTA SEPTEMBER, 1996

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0-612-20894-X



Abstract

Social adjustment is an area of special vulnerability for children with chronic or life threatening pediatric conditions and their siblings. This study investigated the social skills of children with a particular chronic illness, cystic fibrosis (CF), and their siblings. Ninety two children ages 8 to 18, and their parents, completed the Matson Evaluation of Social Skills with Youngsters (MESSY). No differences in social skills were found among children with CF, their siblings, and the normal comparison group on the child self reports, mother's reports, or father's reports. Across all groups, it was found that children tended to over report their positive social skills as compared to mothers and fathers' indications. Significant differences were reported between boys and girls according to the three different report sources. Implications of these findings for assessing children with a chronic illness and the measurement of social skills are discussed.

Acknowledgements

I would sincerely like to thank all of the many people who supported me throughout the completion of this project. To the CF clinics across Canada and the schools within Calgary that provided the backbone of the study, the participants, my deepest gratitude. It couldn't have been done without you.

I thank the members of my committee, Dr. Bonnie Kaplan, Dr. Mike Boyes, and Dr. Mark Montgomery for their time, input, and dedication to strengthen this research project. As well, to the members of the Behavioral Research Unit, your patience and consistent help is very much appreciated. And especially to my supervisor, Dr. Deborah Dewey. She was always available for late night questions, reassurance, and impeccable reviews and deserves my deepest gratitude. Her thorough understanding of this field and of research in general was my greatest asset.

Finally, to my family and friends. Their love and support crossed many boundaries. A quiet understanding and encouragement provided motivation to continue as well as the stability to find a balance.

Bravo Zulu.

Dedication

To the families of children with chronic illness that provide their children with a consistent environment of love and support so that their children's lives may become rich and full.

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Introduction

About 10% of children experience a serious chronic physical illness. This constitutes about 50% of pediatric practice. These conditions usually last about 3 months, but often much longer. Many, such as asthma, diabetes, arthritis, and cystic fibrosis, for example, have no real cure. Modern medicine attempts to limit the extent to which these diseases interfere with normal life and reduce the severity of the impact on the child. Aside from physical symptoms that accompany any childhood illness, children and adolescents with chronic health conditions have long been considered at substantial risk for increased psychosocial morbidity.

Pediatric chronic illness is a term used to designate childhood illnesses that can be progressive and fatal, or associated with a relatively normal life span, but are usually accompanied by impaired physical or mental functioning (Clark, Striefel, Bedlington, & Naiman, 1989). There are many aspects of the effects of chronic illness on children that are not understood. Further, many questions concerning the mental health and adjustment problems of children with chronic health problems and their families remain (Cadman, Boyle Szatmari, & Offord, 1987).

Cystic fibrosis (CF) is a severe childhood disease which affects approximately 1 in 2,000 children at birth. It is the most common genetic disease affecting Caucasians today (Thompson, Hodges, & Hamlett, 1990). The inherited recessive genetic abnormality can destroy the lungs and cause serious impairment of the pancreas, intestines, and liver.

Specifically, CF is a hereditary congenital chronic disease of mucous glands throughout the body resulting primarily in pancreatic insufficiency and pulmonary disorders. In patients with CF, the normal mucus that traps inhaled particles in the bronchial tubes is excessively thick and resistant to removal. This narrows air passages and impairs breathing. As time goes by, chronic infection progressively destroys the bronchial passages and, together with the plugging of airways ultimately leads to respiratory failure (Welsh & Smith, 1995). Over the years diagnosis has come earlier in life and is more accurate. There are also better treatments. Pancreatic failure is rarely life-threatening and digestive problems can be controlled. Current advances in medical treatment have delayed the progression of lung disease. However, lung impairment or disease accounts for more than 90% of the disability and death in patents with CF (Welsh & Smith, 1995).

Treatment for CF involves a complex, time-consuming, and multidimensional treatment regimen designed to maintain health and enhance survival (Drotar, 1995). In addition to antibiotics taken to prevent infection and drugs to break up mucus, families are also expected to help with CF therapy. At home, postural (bronchial) drainage is performed with chest percussion. Here patients lie so their head is tilted downward and someone then pounds gently and rapidly on their back or chest to clear mucus from airways (Welsh & Smith, 1995). Physiotherapy and chest muscle training is used, and breathing exercises help improve ventilation and posture. Other aspects of disease management includes specific diet

requirements (i.e., low fat, high protein) and maintaining good fitness levels to improve lung capacity. With adherence to this regimen, CF, for most patients, remains relatively stable throughout childhood and adolescence. Thus, a disease that formerly posed a very real threat of death in early adolescence can now be reasonably managed, enabling more than half of CF patients to survive into their late twenties or beyond.

Current life expectancy for individuals with CF is approximately 29 years (Drotar 1995), with males expected to live slightly longer than females. As long term survival of persons with CF increases, concerns about quality of life and coping become more salient. It is therefore, now more important than ever to understand how the presence of this severe childhood illness affects the psychological and social development of its' patients as well as other family members.

It has been suggested that social adjustment is an area of special vulnerability for children with chronic or life threatening pediatric conditions and their siblings (Clark et al., 1989; Ferrari, 1984; La Greca, 1992; Lavigne & Ryan, 1979). Further, there is a large amount of literature concentrating on the effects of a pediatric chronic illness on the psychosocial adaptation of the child with chronic illness and their siblings. Much of the research has indicated that these children experience an increased risk for psychological maladaptation. However, the social skills of children with chronic illnesses and their siblings is an area of adaptation that has not been included in the study of adjustment.

A child's social skills affect long term behaviours such as the

development of peer relations and long term emotional adjustment (Wierzbicki & McCabe, 1988). Certain aspects of having a chronic illness, such as prolonged absences from school and perceptions and attitudes of peers towards a child with a chronic illness, may be detrimental to the development of social skills (La Greca, 1990). Similarly, there may also be conditions associated with chronic illness that positively affect social skills, such as increased involvement with adults. Social skills are an important aspect of psychosocial adaptation, as these skills are necessary to adapt to a social environment and to build interpersonal relationships (Matson & Ollendick, 1988). However, whether social skills are a particular area of vulnerability for children with a chronic illness has yet to be determined. Further, few studies have investigated the social skills of siblings of children with a chronic illness. Therefore, the purpose of this study was to investigate the social skills of children with a particular chronic illness, CF, and their siblings.

A second purpose of this study was to examine differences between children's self reports of their own social skills and parent reports of their children's social skills. In the past, research has often utilized only one reporter, usually a parent or a teacher, to evaluate children's psychosocial adaptation. In the area of social skills, where perceptions of children's social skills have been shown to vary with different informants, children's self reports and the discrepancies between child and parental reports may be particularly important to assess as they may provide different information (Schor, Stidley, & Malspeis, 1995).

Psychosocial Adaptation of Children with a Chronic Illness

The breadth and depth of the research investigating the effects of a chronic illness on children's psychosocial adaptation is large. In the 1970's there was popular support for the hypothesis that children with a chronic, physical disease showed maladjustment, low self-concept, increased anxiety and immaturity, and social isolation more frequently than any normative group of children (Tavormina, Kastner, Slater, & Watt, 1976). This popular belief, however, was not documented by sound research. At that time, most of the studies in the literature were based on assumption, clinical impressions, and subjective evaluations (Tavormina et al., 1976).

The belief that chronic illness affects social development, and hence, the adjustment of a child is based on the transactional approach to development. This framework posits that a child interacts with, and influences, their environment and in so doing changes it. This changed environment in turn influences the child and changes him/her. The child's physical illness may similarly modify the expected developmental progression. Illness affects a child's interactions with the physical and social environment and aspects of this environment, such as parents, siblings, peers, or school systems. In turn, these environments are altered as a result of the child's illness. Each change in either the child or the environment contributes to changes in the other. Therefore, the entire social system in which the child is developing is affected (Perrin & Gerrity, 1984). From this theory it is easy to see how the presence of a chronic illness could affect the adjustment of a young child, as well his or her

family.

Bakwin and Bakwin (1972) present three different ways in which chronic illness can be conceived as influencing development:

- (1) The illness may interfere with the normal activity of the child;
- (2) it may make the child feel different from his peers with detrimental effects on self-concept;
- (3) the illness may foster inappropriate parental attitudes and behaviours, ranging from overprotection to rejection...The illness may become a rationale for failure or for enlisting sympathy or tyrannizing parents, teachers, and siblings (p. 131).

These influences and changes may lead to a wide range of functioning in any or all of psychological, social, academic, or peer areas.

Early research on the effects of chronic illness on children focused on the magnitude of risk chronically ill children had for developing diagnosable psychiatric disorders (Thompson et al., 1990). Studies, such as that performed by Tavormina and colleagues (1976), tested the popular hypothesis that chronically ill children are especially vulnerable to psychopathology. Results from this work showed that the presence of a chronic illness did not increase the vulnerability of the child to psychiatric conditions. Researchers then began to investigate psychological adjustment of children with chronic diseases. Factors such as personal adjustment, self-concept, dependency, withdrawal, peer relations, and

school functioning were examined (Stein & Jessop, 1984). Further, behavioral adjustment was also a variable used to assess the psychological adjustment of children with chronic health conditions (Gortmaker, Walker, Weitzman, & Sobol, 1990). Results from this research found that children with chronic illnesses displayed little increased risk for severe adjustment difficulties; however, particular concerns were noted in social areas of functioning (Cadman et al., 1987). This included concerns such as loneliness and social withdrawal. These findings have led current research to concentrate on the psychosocial adjustment of children with a chronic illness.

Research that has investigated the psychosocial adjustment of children with a chronic disease has reported varied and inconsistent findings (Cadman et al., 1987). Some research has reported that children with a chronic disease experienced a greater risk for social maladjustment (for a review see Lavigne & Faier-Routman, 1992), while others have reported only a small degree of risk (Gortmaker et al., 1990; Stein & Jessop, 1984). Still other researchers have concluded that children with a chronic illness do not experience increased risk for adjustment difficulties (Ungerer, Horgan, Chaitow, & Champion, 1988). It has been suggested that a number of factors may be responsible for the inconsistencies in the research findings. The type of illness being studied, variability of disease severity, the method of reporting, how adjustment was conceptualised, the sample size, and the use of an appropriate control group have all been suggested as factors affecting results in any particular study (Spirito,

DeLawyer, & Stark, 1991; Ungerer et al., 1988).

Lavigne and Faier-Routman (1992) performed a meta-analysis on 87 studies that investigated children's adjustment to physical disorders. Overall adjustment was based upon adjustment questionnaires that included measures of internalizing and externalizing symptoms (e.g. Achenbach's Child Behaviour Checklist) or a measure of the children's self esteem (e.g. the Piers-Harris Self Concept Scale). Included in this study were diseases such as asthma, deafness, burns, CF, inflammatory bowel disease, cancer, diabetes, and arthritis. The illnesses were then categorized as sensory disorders, neurologic disorders, fatal disorders, and nonfatal disorders. Results indicated that children with physical disorders were at increased risk for overall adjustment problems, both internalizing and externalizing symptoms. Further, they also found that children with these disorders exhibited lower levels of self-esteem and self-concept compared to healthy children.

When the contributing factors to social adjustment have been considered independently, it has been shown that social withdrawal is one area that has differentiated chronically ill children and a normal comparison group (Drotar et al., 1981). Specifically, children with chronic illnesses were found to show higher levels of social withdrawal than a normal comparison group. Drotar and colleagues (1981) also found a positive relationship between physical status and social withdrawal, suggesting that greater physical impairment is associated with increased difficulties in maintaining activities outside the home, including peer

relationships.

Similarly, Cadman et al. (1987) in the Ontario Child Health Study found that children with a chronic illness are at a high risk for social problems. In particular, children with a chronic illness had a smaller quantity of contacts with friends than that observed in healthy children. Social isolation was believed to be a contributing factor to low self esteem and thought to be an antecedent of psychosocial problems.

Psychosocial Adaptation of Children with Cystic Fibrosis

Although a number of studies have investigated the psychological and psychosocial adjustment of children with chronic illnesses, it has been suggested that in order to examine specific areas of psychosocial adjustment it is necessary to look at individual diseases and characteristics to determine the interplay between many contributing factors (La Greca, 1990; Lavigne and Faier-Routman, 1992). Thus, in the present study, by only examining children with CF, disease characteristics were held constant. This eliminated a confound often found in many of the studies of children with chronic disease and will help us understand the role of a particular disease in influencing psychosocial adjustment.

Early studies in the area of the psychological effects of CF on children concluded that there were profound social and emotional consequences for the child (Tavormina et al., 1976). Later, Thompson and associates (1990) reported that children with CF are intermediate in psychopathology between psychiatrically referred and non-referred children. Thompson et al. (1990) showed that youngsters with CF display higher levels of

psychopathology than their healthy peers; specifically, higher levels of anxiety and internalising disorders.

Drotar et al. (1981) compared the adjustment of children with CF, as rated by parents and teachers, with the adjustment of their healthy siblings, normal children, and other chronically ill children. Using a behaviour checklist (Louisville Behaviour Checklist for mothers and School Behaviour Checklist for teachers), they found that the children with chronic illnesses as a whole had less adequate adjustment; however, the children with CF achieved an age adequate level of adjustment overall. They also found that adjustment was not related to the severity of CF. While adjustment for children with CF does not appear to be of concern, specific factors within this measure, including social withdrawal and irritability were higher for children with CF as compared to their siblings and their healthy peers. In a review of the relevant literature, Spirito et al. (1991) concluded that the research evidence suggested that social withdrawal was an area often affected by CF. Specific concerns children with CF reported included anxiety about lack of acceptance by peers, isolation, rejection, no close friends, and teasing by peers. La Greca (1990), in a review of the literature, reported that children with CF seem to encounter more peer social difficulties than healthy controls. These findings suggested that while children with CF do not appear to consistently manifest behaviourial problems, the development of social skills is one area that may be influenced by the presence of this chronic illness. However, no studies have specifically examined the social skills of

children with CF.

Psychosocial Adaptation of Siblings of Children with Chronic Illness

The field dealing with the effects of a childhood illness on the family environment has been a recent area of popular study. One particular area of interest is the effect of a child with a chronic life-threatening illness on their siblings. Many studies have shown that there is an increased risk for behaviourial problems and poor psychological adjustment of siblings of children with a chronic illness or disability (Ferrari, 1984; Lavigne & Ryan, 1979). However, the results of recent studies have reported that these findings are not consistently replicated by current, methodologically sound research (Stewart, Stein, Forrest, & Clark, 1992).

In reviewing the early literature Lavigne and Ryan (1979) found that in general, siblings of children with a chronic illness seem more likely to experience adjustment or behaviourial problems and they appear at risk for certain types of disturbances at certain ages. Specifically, they tend to be more withdrawn socially and more irritable than their peers (e.g., these children are reported to be more lonely than their peers). In their study, Lavigne and Ryan looked at the youngest and oldest sibling between the ages of 3 and 13 of children who had had plastic surgery, a congenital heart disease, or experienced a blood disease (i.e. leukemia). They reported that siblings of children with chronic illnesses appeared to be more likely to experience adjustment or behaviourial problems than normal comparison peers, and that they were 'at risk' for certain types of disturbances at certain ages. Specifically, siblings between the ages of 3 and 6 years were

more likely to show elevated incidence of overall psychopathology, whereas in older siblings, ages 7 to 13, emotional concerns such as loneliness; were of greater incidence. Differences were also found between the disease groups. Siblings of children who had had plastic surgery were more likely to display behavioral signs of psychopathology, as compared to siblings of children with blood disease who tended to show more likelihood of emotional problems. The relative severity of the diseases did not appear to affect the adjustment of these siblings.

Although few studies have examined the effects of chronic illness on siblings' social functioning, the results of some studies suggest that this may be an important area of investigation. Consistent with other research, the Ontario Child Health Study (Cadman, Boyle, & Offord, 1988) found that the siblings of children with chronic health problems were generally at little increased risk for psychiatric disorders or social maladjustment. The exceptions to this were that they were at an increased risk for emotional, internalising disorders such as depression and anxiety, and they had increased difficulty getting along with peers. The results of Ferrari (1984) support this conclusion. He, as well, failed to support the view that siblings of chronically ill children were uniformly at greater risk of psychosocial impairment than siblings of healthy children. However, in contrast to the Ontario Child Health Study, Ferrari (1984) found that there are certain psychological areas in which the siblings of chronically ill children may have particular difficulty. The areas he identified were different from those indicated by Cadman et al. (1988). Specifically, he found that these children were at a greater risk for externalising disorders. Ferrari also noted that there may be positive effects on the siblings in this environment. He found that this type of environment may facilitate development of interpersonal skills, particularly prosocial behaviour and social competence in the siblings of children with chronic illnesses (Ferrari, 1984).

A recent study by Stewart et al. (1992) did not support past findings of behaviourial problems in siblings of children with chronic disease (i.e., CF, Duchenne muscular dystrophy, pulmonary atresia). Specifically, the authors did not find any increase in behaviourial problems of siblings ages 6 to 17 of children with chronic illnesses. The healthy siblings were, on average, well adjusted on measures of self-concept, anxiety, and depression. This lack of difference in the psychosocial adjustment of siblings of chronically ill children compared to normal comparison peers was also supported by Thompson, Curtner, and O'Rear (1994). They investigated the psychosocial adjustment of 19 well siblings of 19 chronically ill children using the Behaviour Problems Index. Results showed no significant differences on any of the behaviourial subscales between well siblings and a control group. These results suggest that there is not a direct relationship between chronic illness in a child and psychopathology among his or her siblings. Thus, it has been suggested that the impact of childhood chronic disease may be conceptualised as a risk factor that may or may not be mediated by other individual or family characteristics (Lobato, Faust & Spirito, 1988).

Although there has been a fair amount of literature examining the

effects of a chronic illness on a healthy sibling, there have been few studies dedicated to examining the social skills of the siblings of children with a chronic illness. There has been one recent study that has suggested that social skills may be an area of concern for these siblings. Noll et al. (1995) found that there was recognition of the potential impact of sickle cell anemia (SCA, a childhood chronic disease) on the psychological well-being of healthy siblings: "anecdotally, siblings of children with SCA are described as having increased potential to be irritable, aggressive, and socially isolated" (Noll et al., 1995, p. 167). However, this study found that siblings of children with SCA did not show greater than average problems with peer relationships. Siblings between the ages of 8 and 18 who were closest in age to the ill child did not show any of the anticipated problems with peer relationships. They noted that if siblings of children with SCA had difficulties with peers, these problems were the result of factors other than the presence of a chronically ill child in the family such as personality traits like shyness or different interests.

Although the above studies do not provide us with consistent findings about the psychosocial adjustment of siblings of children with chronic illness, they do suggest that the social environment of siblings of children with a chronic illnesses are changed to some degree compared to those of healthy children. These changes in the social environment may influence the development of their social skills.

The Effects of Gender and Age

Past research has investigated the effects of gender and age on

psychosocial adjustment of children with chronic illnesses and their siblings. Results indicate that boys with chronic illness may have more problems in the area of psychosocial adjustment than girls (Lemanek, Horwitz, & Ohene-Frempong, 1994; Eiser, Havermans, Pancer, & Eiser, 1992). Lemanek et al. (1994) reported that sickle cell disease (SCD) had a greater impact on adolescents and boys as compared to elementary age children and girls. This impact was seen mainly in the area of social adjustment in relation to personal adjustment. La Greca (1990) suggested that conditions that limit physical activity might produce greater social consequences for boys, given the athletic components of much of their peer interaction. Gayton and Friedman (1973) reported that adolescents with CF had greater adjustment difficulties. They suggested that this may be due to a vulnerability stemming from the dependency that may develop with their parents who are often the providers of the necessary physical therapy. Lavigne & Ryan (1979) also suggested that adjustment differences according to gender may be seen in the siblings of chronically ill children, with boys exhibiting more behaviour problems and girls showing personality problems and learning problems.

Studies that have investigated the effects of age have found that it is a significant factor in the adjustment of children with chronic illnesses.

Results indicated that younger children with chronic illnesses were more affected in terms of school tasks and achievements whereas older children experienced difficulties in areas of social adjustment (Eiser et al., 1992).

For siblings of children with illnesses, however, age did not appear to be a

significant factor. Eiser reported that age did not play a significant role in the adjustment of siblings to the presence of a chronic illness. Further, Lavigne and Ryan (1979) did not find that the siblings' age relationship to the ill child was significant. In other words, whether the healthy children were older or younger than their ill sibling did not influence their adjustment.

Social Competence

Research in the area of social competence began in the late 1950's with an attempt to move the mental health field away from a disease model of classification and toward an emphasis on client strengths (Cavell, 1990). Social competence in its ideal entails effective functioning within social contexts. Lemanek, Horwitz, and Ohene-Frempong (1994) conceived of social competence as a multidimensional construct consisting of behavioral, cognitive, and emotional indices, and evidenced by good peer relationships and meaningful interactions with adults. Cavell (1990) identified three different areas that social competence is often defined as which assess different subsets of social functioning. These areas were the products of social functioning, the requisite skills of social functioning, and the social functioning itself. The products of social functioning include facets such as social attainments and peer acceptance. It is this area that is often measured in research studies by conducting peer-based assessment and ratings. Assessment of the skills of social functioning focuses on the specific skills that are deemed necessary to generate behaviour that is considered appropriate or competent for a given stimulus or task. Finally,

social functioning itself distinguishes between competence and performance. Specifically, social functioning is the use of requisite skills in appropriate situations.

Cavell (1990) reformulated these three different areas of social competence into a tri-component model of social competence. At the top of the hierarchy is social adjustment, defined as the extent to which individuals are currently achieving societally determined, developmentally appropriate goals. Next is social performance. This is the degree to which an individual's responses to relevant, social situations meet socially valid criteria. The final component, social skills, refers to specific abilities that enable one to perform competently within social tasks. The presence of these skills does not necessarily guarantee effective social performance. Children may occasionally choose social goals that lead to poor performance despite possessing the necessary skills, or they may lack the incentive for using their social skills. However, adequate social performance is not possible without social skills. In short, social skills are a necessary but insufficient determinant of effective social behaviour.

Social Skills

Social skills are defined as specific, identifiable skills which some believe form the basis of socially competent behaviour (Spirito, DeLawyer, & Stark, 1991). Social competence can be seen as the effectiveness of an individual's performance on a given task. Social skills are the component processes that allow the individual to behave in this competent manner on any one task (Gilbert & Gilbert, 1991). Matson and Ollendick (1988) propose

that there are a number of theoretical constructs that define how a child builds social skills. These constructs include moral reasoning, altruism, avoidance of conflict, learning to reinforce others, and enhancing peer acceptance. Therefore, social skills are the ability to adapt to a specific environment and avoid conflict with others.

From a developmental perspective, social behaviours can be built through modelling, practice and reinforcement. This reinforcement can be provided through two distinct groups children encounter, family and peers. It is hypothesised that children who are unacceptable to their peers may be deprived of a number of important experiences which in turn would lead to less developed social skills, or further maladaptation (Matson & Ollendick, 1988). Therefore children with chronic illnesses who experience initial rejection by their peers may not be given the opportunity to reinforce their positive responses in social situations. In addition, children with chronic illnesses are subject to interruptions in their daily activities (e.g., school absence, hospitalisations) and lifestyle modifications (e.g., medication requirements, decreased activity level). These interruptions and modifications in turn may disrupt the children's development of social skills by limiting opportunities for peer contact and calling attention to these children in ways which may increase social anxiety (Nassau & Drotar, 1995).

It is suggested that children with a chronic illness and their siblings do not receive the same opportunities for modelling and practice of social behaviours as do their healthy peers (LaGreca, 1990). They do not then obtain as much positive reinforcement for the skills they develop and as a result they demonstrate poorer social skills as compared to their peers. However, due to the interactional effects between the family and peer groups, the negative effects of a chronic illness on social skill development may be mediated, and if given positive experiences within the family or other environments, children with chronic illnesses may have the opportunity to develop age appropriate social skills.

There have been no studies that have examined the social skills of children with chronic illnesses or their siblings. However, as previously mentioned, social skills are seen as one area that may be influenced by the presence of a chronic illness. This stems from the belief that social skills play a significant role in psychosocial adjustment, and from past research findings that suggest that the psychosocial adjustment of chronically ill children is a risk area.

Parent Report Versus Child Self Report Measures

It has only been recently that young children and adolescents have been recognised as a source of information concerning their own behaviours. Past research has tended to rely on parent or teacher reports to provide indications of not only how children act, but also how they feel. However, studies have found that grade school children are capable of giving well-defined and clinically useful descriptions of their own behaviour and peer interactions (Bierman & McCauley, 1987). In general, children's reports have been found to be poorly correlated with peer nominations, parent, and teacher reports (Schneider & Byrne, 1989;

Weissman, Orvaschel, & Padian, 1980). This may indicate that children provide different information than that which is available from other sources. For this reason, children's self reports are becoming more acceptable in clinical assessment and are beginning to be seen as an important source of information and an integral part of assessment and therapy. Future research is required to determine whether systematic differences exist between child and parental reports and hence consider which information is objective and/or valid (Schor et al., 1995).

Research has looked at differences between child self report as compared to information gathered from other sources on various measures. In a study that compared the results from clinical interviews with both parents and psychiatric inpatient children, parents were found to report more conduct-related problems and children were found to report more anxiety and somatic symptoms (Hodges, Gordon, & Lennon, 1990). Findings in the area of socialization indicated that student self-ratings were more positive than their parent ratings of social competence (Adelman, Taylor, Fuller, & Nelson, 1979). Research has also shown varying degrees of discrepancy between how children perceived their social competence, and how parents and teachers rated their observed social skills. It has been shown that perceptions of children's behaviour and adjustment, with social competence being one facet, varied depending on the observer. For example, variations in observers' ratings occurred when describing children's social behaviour; however, independent raters' ratings indicated social behaviour was consistent across settings (Lemanek et al., 1994). Schneider and Byrne (1989) found parent ratings of social behaviour did not correspond with other sources of information, including child self reports. They suggested that parents may lack objectivity when reporting their own child's behaviour and that parents may not be adequately acquainted with the 'norms' of children's social skills. They concluded that adults view children's social behaviour through a 'lens' that is focused on the dimensions of social competence most visible to them, such as politeness or compliance. This is supported by Weissman et al. (1980) who reported poor agreement between mothers and children on children's social functioning scales. Therefore, in the area of social competence results indicate that parents' and children's ratings differ.

Child self report has been used infrequently to measure the adjustment of children with chronic illness and their siblings. However, studies that have compared parent and child reports have found that they yielded quite different results (Ferrari, 1984; Lavigne & Faier-Routman 1992). Lavigne & Faier-Routman (1992) conducted a meta-analysis of 87 studies of children's adjustment to physical disorders. Their results indicated that the degree and type of adjustment problems identified in children with pediatric disorders differed across raters. Differences were seen particularly between parent and teacher reports on internalizing and externalizing symptoms. Specifically, teachers reported that children with physical disorders were more likely to display internalizing rather than externalizing symptoms. This difference did not emerge with parent ratings. They noted there have been few studies that have examined

children's self reports and view this as a glaring omission in our understanding of the psychological problems of children with physical disorders especially in light of discrepancies between other sources of information.

Studies involving various informants rating the risk of psychosocial adaptation within chronically ill children have shown disparate results. Parents have been found to indicate greater maladjustment in children with chronic disease as compared to teachers and physicians (Lemanek et al., 1994). This supports the hypothesis that parents are too close to their children to effectively consider their adaptation. Eiser et al. (1992) reported that parents' ratings may be biased, and that differences resulted between mother's and father's ratings. In their study, mothers of children with various childhood chronic illnesses reported differences in their children's adjustment that were not supported by other data. For example, according to mothers there were age differences pointing to increased adjustment problems with older children where this trend did not appear in fathers' reports. Fathers, however, perceived their children as more dependent and more likely to have difficulties with peers compared to mothers' reports.

It may also be that parents' perceptions of their children's adjustment may be coloured by their own functioning levels (Daniels, Moos, Billings, & Millar, 1987). For example, Daniels and colleagues (1987) found that compared to fathers of chronically ill children, depressed mothers of chronically ill children reported that their children (both ill and healthy) had more problems. This finding suggests that some parents of chronically

ill children may be overly pessimistic toward their healthy children. This may result in these parents becoming overly sensitive to their healthy children and finding problems that do not exist. Ferrari (1984) studied the differences between maternal, paternal, and self reports of healthy siblings of chronically ill children. Results indicated that fathers overestimated sibling's global self-concept scores and mothers predicted higher levels of anxiety in siblings compared to what the child reported (Ferrari, 1984).

In a recent study that specifically investigated social competence in asthmatic children, Zbikowski and Cohen (1995) found that parents of asthmatic children rated their children lower in terms of social competence than parents of non-asthmatic children despite the asthmatic children being rated as equally socially acceptable by their peers. They hypothesised that parents of chronically ill children may be concerned about aspects of peer social competence, such as understating the number of close friends their asthmatic children have.

Summary and Hypotheses

There has been much research investigating various psychological effects of a chronic illness on children and their siblings. Over time contradictory results have been found. Whether or not pediatric disease influences psychosocial development is becoming increasingly important as the life expectancy for these children rises. In order to address concerns related to previous research and specify the exact components of adaptation, methodologically sound research is required. This study was designed to take into account many of the suggestions made by previous

researchers and to increase our understanding of the effects of a specific chronic illness on a certain area of psychosocial functioning. This study looked at three main areas. These included the social skills of children with cystic fibrosis, the social skills of physically healthy siblings of children with cystic fibrosis, and differences between parental reports of social skills and children's self reports.

It was deemed to be critical to specify a certain pediatric disease in order to eliminate any potential differences that may exist across illnesses. A population of children with CF was used in this study. Previous results suggested that children with chronic illnesses often have difficulty in psychological development, particularly social areas such as peer relations (Cadman et al., 1987; La Greca, 1990; Spirito et al., 1991). Thus, it was hypothesized that children with CF would have less well developed social skills than their healthy siblings and their peers.

Likewise, the presence of a chronic illness within a family environment has been shown to have an impact on the adjustment of the ill child's healthy brothers and sisters (Ferrari, 1984; Lavigne & Ryan, 1979). In this project, it was hypothesized that siblings of children with CF would show better social skills than their ill brothers and sisters; however, they would have poorer social skills compared to their healthy peers.

Frequently when studying children, the children themselves are left out of the equation. In the past, it was not standard practice to ask children to report on their own symptoms or feelings. This has been shown to be a deficiency in this area of research. While accuracy of child and parent

reports can often not be determined, children do provide different information from what is obtained from other sources, especially in the area of social skills where parents may not see their children interacting with their peers (Adelman et al., 1979; Weissman et al., 1980). In addition, how the children themselves perceive their own social skills is equally relevant information in evaluating their adaptation. Differences have also been reported between maternal and paternal reports of their children's behaviour (Daniels et al., 1987; Eiser et al., 1992). Thus, it was hypothesized that there would be significant differences between the three sources of reports (maternal reports, paternal reports and child self reports) concerning the children's social skills.

Across all groups (CF, siblings, normal comparison) it was believed that generally parents' ratings of the children's social skills will be poorer than the children's self reports of their own social skills. It was also believed that the amount of difference between raters would differ with the group. Combining the CF children with the sibling group it was expected that a greater difference between maternal and paternal reports and child reports would be seen in those families where there was a child with a chronic illness as compared to normal comparison families with healthy children.

Method

Subjects

Families of children with CF were recruited initially through the Cystic Fibrosis Clinic at Alberta Children's Hospital. Other hospitals across western Canada were also approached and asked for their cooperation in obtaining participants. Permission was gained to mail questionnaires to families of children with CF from Alberta Children's Hospital (Calgary, AB), Victoria General Hospital (Victoria, B.C.), Royal University Hospital (Saskatoon, SK), Regina General Hospital (Regina, SK) and Winnipeg Children's Hospital (Winnipeg, MB). Thirty-nine families from Alberta Children's Hospital (ACH) were sent questionnaires. The response rate was 49%. Winnipeg Children's Hospital was sent 45 questionnaires. Nine percent of these questionnaires were returned. Ten percent of the 20 questionnaires sent to Victoria General Hospital were returned. Thirty questionnaires were sent to Regina General Hospital and 15 questionnaires to Royal University Hospital. Due to the fact that many of the participants from Saskatchewan resided in small towns, we were unable to determine whether they were from the Regina or the Saskatoon clinic; however, the combined response rate for the Regina and Saskatoon CF clinics was 25%. One response was returned without a return address. Overall, the total response rate for CF families was 23%. This resulted in a sample of 32 children with CF and 17 siblings of children with CF.

Normal comparison children without chronic illnesses were recruited through elementary, junior high, and high schools in the Calgary Public and Separate School Boards. Principals sent out initial letters of interest to parents through regular classrooms in their schools (see Appendix A). Two thousand initial letters were sent through the Calgary School Boards (2 Elementary, 1 Elementary/Junior High, 2 High Schools. 2 K-12 schools). One of these schools was located in Airdrie, a small town north of Calgary. It was hoped through this school we would access a rural population to match that of the CF group. These letters resulted in 45 families agreeing to participate as part of the normal comparison group. Normal comparison families were also obtained through friends and acquaintances of the researchers. In total, 55 packages were sent to families within the Calgary area. Twenty-six families returned the questionnaires, for a return rate of 46%. This resulted in a total of 50 participants in the normal comparison group.

All normal comparison families were screened for the presence of a chronic illness, learning disabilities, and attention problems. In the initial letter sent to parents it was specified that in order to be eligible to participate in the study, families should not have any children with those concerns. In addition, the General Information Questionnaire asked the parents to indicate if any member of the family had been diagnosed with a chronic illness, learning disability, or attention difficulty. None of the returned questionnaires indicated that any children had been diagnosed with a chronic illness or attention problem. In one family, a child was identified as having a learning disability (slow reading). It was decided to include this child in the normal comparison group as one of the children in the

experimental group (i.e., CF and siblings) also had a diagnosed learning disability.

Sociodemographic information was collected on all participants and examined for group differences (Table 1). An alpha level of .05 was used to determine if differences existed in this data. No differences were found between the age of children in each group ($\mathbf{F}(2,91)=1.25$, $\mathbf{p}=.29$). Similarly, the gender breakdown of the groups was similar (\mathbf{X}^2 (2, $\mathbf{N}=99$) = .27, $\mathbf{p}=.87$) and there were no differences among groups in the number of siblings ($\mathbf{F}(2,96)=.27$, $\mathbf{p}=.77$). No differences were found between group in the incidence of learning disabilities or attention problems (learning disabilities, \mathbf{X}^2 (4, $\mathbf{N}=99$) = 3.08, $\mathbf{p}=.54$, attention problems, \mathbf{X}^2 (4, $\mathbf{N}=99$) = 2.51, $\mathbf{p}=0.28$). All groups were asked if they had received counselling that may have affected their children's social skills. There were no group differences in the number of families who reported receiving counselling (\mathbf{X}^2 (2, $\mathbf{N}=99$) = 5.87457, $\mathbf{p}=.05$).

Group differences were found in family residence $(X^2 (8, N = 99) = 33.69, p < .01)$. Significantly more families in the experimental groups (i.e. CF and siblings) lived in smaller towns or rural areas compared to the normal comparison group, the majority of whom lived in a large city. No significant group differences were found for mother's education or occupation (designated as SES; Blishen, Carroll, & Moore, 1987) (education, $X^2 (12, N = 99) = 17.73, p = .12$; occupation $X^2 (8, N = 99) = 8.03, p = .43$). Likewise, there was no group difference in mothers' marital status ($X^2 (8, N = 99) = 17.73$).

N = 99 = 11.97, p = .15. All fathers in the study were married. Significant group differences were seen in fathers' education $(X^2 (12, N = 89) = 29.34, p < .01)$ and differences in fathers' occupation approached significance $(X^2 (12, N = 89) = 17.92, p = .06)$. Specifically, fathers of children in the normal comparison group were more highly educated and held higher status jobs than fathers of children in the experimental groups. These significant variables were controlled for in subsequent analyses.

A number of variables specific to children with CF were also examined. Characteristics of the CF children were examined through the use of descriptive statistics, namely frequencies. Children with CF were generally diagnosed early with 67% diagnosed within the first year of life. Likewise, 83% of the parents of children with CF indicated that CF symptoms were seen in their children during the first year of their child's life. On a scale of 1-5 (1=not at all severe to 5=extremely severe), the severity of the children's illness was rated as moderate (M=2.39, SD=0.89). Twentythree percent of parents indicated that their children's CF had become worse since first being diagnosed, and 40% reported that CF symptoms had improved. Parents reported that the care of their child with CF was somewhat demanding (1=not at all demanding to 5=extremely demanding; \underline{M} =2.72, \underline{SD} =0.96) within the home. In general, mothers took responsibility for helping their children with in home therapy. Mothers reported spending an average of 2.3 hours per week, while fathers spent 0.93 hours per week doing therapy. Seventy-seven percent of the children had been

Table 1. Sociodemographic Characteristics by Group

| Variable | Grp 1 (CF) | Grp 2 (Sibs) | Grp 3 (NC) |
|---|------------------------|-----------------------------|------------------------|
| | N=32 | N=17 | N=50 |
| Age | X = 12.99 | X = 12.87 | X = 13.41 |
| Sex - Male | 13 | 8 | 20 |
| Female | 19 | 9 | 30 |
| # of sibs - 0 | 6 | 0 | 10 |
| 1 | 16 | 14 | 19 |
| 2 | 6 | 2 | 11 |
| 3 | 2 | 1 | 10 |
| 4 | 2 | 0 | 0 |
| # of CF sibs - 0 | 25 | 0 | N/A |
| - 1 | 5 | 15 | |
| - 2 | 2 | 2 | |
| With LD - no | 31 | 17 | 49 |
| - yes | 1 | 0 | 1 |
| With ADD - no | 31 | 16 | 50 |
| - yes | 1 | 1 | 0 |
| Counselling- no | 22 | 12 | N/A |
| -yes | 10 | 5 | |
| Social Skills Counselling- no -yes | 27 5 | 13 4 | 48 2 |
| Residence - large city - small city - town - rural | 13 3 6 10 | 9 3 0 5 | 44 6 |
| Mom marital status - married - separated - living together - never married - divorced - widowed | 29 0 2 1 0 | 17 0 0 0 0 0 | 42 1 0 1 6 |
| Mom education - no HS - some HS - HS diploma - some PS - PS diploma - U degree | 1 | 1 | 1 |
| | 3 | 0 | 2 |
| | 6 | 4 | 9 |
| | 5 | 4 | 8 |
| | 10 | 5 | 7 |
| | 5 | 3 | 23 |

| Variable | Grp 1 (CF) N=32 | Grp 2 (Sibs) N=17 | Grp 3 (NC) N=50 |
|--------------------|--------------------|-----------------------|--------------------|
| Mom SES | | | |
| -1 | 14 | 6 | 13 |
| -2 | 3 | 6 2 7 2 0 | 3 |
| - 3 | 9 | 7 | 18 |
| -4 | 6 | 2 | 12 |
| -5 | 0 | | 4 |
| -6 | 0 | 0 | 0 |
| Dad marital status | | | |
| - married | 29 | 17 | 43 |
| - separated | 0 | 0 | 0 |
| - living together | 0 | O | ő |
| - never married | 0 | 0 | 0 |
| - divorced | 0 | 0 | 0 |
| - widowed | 0 | 0 | 0 |
| Dad education | | | |
| - no HS | 3 | 1 | 0 |
| - some HS | 7 | 3 | |
| - HS diploma | 3 | 2 | 2 2 2 |
| - some PS | 6 | 2 4 5 | 2 |
| - PS diploma | 5 | | 10 |
| - U degree | 5 | 2 | 27 |
| Dad SES | | | |
| -1 | 7 | 2 | 0 |
| -2 | 5 | 2 5 | 7 |
| - 3 | 8 | 4 | 10 |
| -4 | 6 | 4 | 12 |
| -5 | 1 | 1 | 2 |
| -6 | 2 | 1 | 12 |

hospitalized at one time for disease related concerns. The average number of times the children had been hospitalized within the last year was 0.4 (range 0-3 times). Generally, CF did not appear to have a large impact on the children's school attendance. All of the children currently attended school and missed less than 1 day per month. On average 8.7 days of school were missed per year.

Measures

General Information Questionnaire

A general information questionnaire was designed to obtain sociodemographic and health information from each of the families. For both the CF families and the normal comparison families, questions were asked regarding the physical and mental health of each family member. Questions concerning occupation, parental education, and marital status were also included. Both parents occupation was used to determine an occupational level which was used for socioeconomic status. These figures were based on an occupational index by Blishen et al. (1987). In addition, parents of children with CF were asked specific health questions related to their child's illness.

Measure of Social Skills

The Matson Evaluation of Social Skills for Youngsters (MESSY) was used for this project. This measure was developed by Matson, Rotatori, and Helsel (1983). It is a questionnaire format designed to measure individual children's social skills. It was intended as a device to identify children with social skill deficits. High scores on the MESSY indicated a high degree of

inappropriate social skills, or a lack of appropriate skills, while low scores indicated better overall social skills. In order to obtain a total score, inappropriate skill questions were added together then a total appropriate score were subtracted from that number. Psychometric properties for the MESSY were adequate with a strong inter-item reliability of alpha=.95. Split half correlations were high at r=.88 (Spearman-Brown) and r=.81 (Guttman) (Matson, Macklin, & Helsel, 1985; Matson & Ollendick, 1988). The scale is reported to have good internal consistency and to correlate well with other measures of social skills such as direct behaviour observation of child social behaviours and a teacher nomination measure of social competence (Spence & Liddle, 1990). There were two versions of the MESSY, a child self report questionnaire and a parent/teacher rating scale.

Child self report form. The child self report was appropriate for children aged 4 to 18 years. It consisted of 62 questions which described a wide range of positive and negative social behaviours. Each question was rated on a 1 to 5 Likert scale (1=not at all to 5= very much). Examples of questions are T pick on people to make them angry' and T share what I have with others'.

According to Matson, Rotatori, et al. (1983), scores on the MESSY child report form can be calculated for all 62 questions to give a total score, or on five factors. These factors were labelled Appropriate Social Skills, Inappropriate Assertiveness, Impulsive/Recalcitrant, Overconfident, and Jealousy/Withdrawal by Matson, Rotatori, et al. The eigenvalues for these factors were 10.59, 4.3, 1.91, 1.18 and 1.09 respectively. Spence and Liddle

(1990) found seven slightly different factors with their factor analysis. Their first two factors were Appropriate Social Skills and Aggressive/Antisocial which strongly resembled Matson, Rotatori, and colleagues' original first two factors. Spence and Liddle reported strong eigenvalues for both these factors, 10.62 and 5.57 respectively. Together they accounted for 53% of the total variance. The remaining 5 factors did not correspond with Matson, Rotatori, et al.'s originally reported factors. Because of the inconsistencies in the previous factor analytic studies, this study used only the first two factors, as determined by Matson, Rotatori, et al. for the child report analyses (Appendix B). A third factor, calculated by combining factor 2 with the remaining 3 factors was also used to look at total negative social skills for the children.

Parent report form. This questionnaire form was originally designed to be used as a teacher report of their student's social skills. However, this teacher report form has been used with parents in previous research (Matson, Compton, & Sevin, 1991) and was used in this capacity in the current study. The parent rating scale consisted of 64 questions which were similar to those on the child form. Sample questions were 'Feels angry or jealous when someone else does well' and 'Is friendly to new people he/she meets'. Each question was ranked on a 5 point scale, from 1= not true to 5= very true. There were only two factors reported for the parent report version of the MESSY (Appendix C). Factor 1 was identified as Inappropriate Assertiveness/Impulsive factor, with a reported eigenvalue of 26.19, and Factor 2 was Appropriate Social Skills, with an eigenvalue of

8.25 (Matson, Rotatori, et al., 1983).

In many of the previous studies, the questions of the MESSY were read aloud to the children. As this was the first time that children as young as 8 years old were asked to complete the MESSY on their own, a single question was added to the parent form of the MESSY. Both parents were asked, concerning the child who they were completing the form for, "How much help did you provide your child in filling out their questionnaire?" The range of possible answers were on a five point Likert scale of 'No help at all', 'Some help', and 'A lot of help'. Mothers' answers ranged from 1-5, with 69% answering 1 and 93% responding 1 or 2. Fathers' answers ranged from 1 to 3. A one-way analysis of variance indicated that there were not any differences between groups based on how much helped they received from either parent (Mom \mathbf{F} (2,88) = 3.024, \mathbf{p} = .054 and Dad \mathbf{F} (2,51) = .921, \mathbf{p} = .405).

Procedure

Approval to conduct this study was obtained from the Alberta Children's Hospital Research Committee and the Conjoint Medical Ethics Research Board at the University of Calgary. The proposal was also approved by the Faculty of Education and each of the Chairs of the Calgary School Boards. A thesis research grant was obtained from the University Research Grants Committee at the University of Calgary.

CF Group

All CF families were recruited through a CF clinic in Western Canada. Pediatric CF clinics in hospitals in Victoria, Vancouver,

Edmonton, Calgary, Regina, Saskatoon, and Winnipeg were approached through their nurse co-ordinator and/or head physician. They were initially contacted by phone and asked whether a brief summary of the research proposal could be sent to them (see Appendix D). All hospitals agreed to review the proposal. After a period of approximately two weeks the clinics were contacted again and asked if they would agree to help with the project. All hospitals except for Vancouver and Edmonton agreed. Each participating hospital was asked to provide the researchers with the number of families involved in their CF clinic who had at least one child with CF between the ages 8 and 18. Where available, the clinic also provided the number of siblings who were also within this age range. Packages with the required number of questionnaires were put together, coded, and sent to the nurse coordinator at each hospital. It was then the responsibility of the clinic to address and mail the packages to the appropriate families. Each package included a stamped and addressed return envelope. Through this method only the CF clinics themselves were aware of which families received packages. In this way anonymity was maintained until individual families decided to participate

Each package included a letter explaining the study to the parents (Appendix E), two copies of the consent form with instructions on how to complete the questionnaires (Appendix F), two copies of the child consent form (Appendix G), a general information questionnaire (Appendix H), as well as the child and parent report forms (Appendix I and J). Where the number of children in the family was unknown, three child forms and six

parent forms were included.

Normal Comparison Group

Upon ethical approval by the Calgary Public and Catholic school boards, various principals were contacted in each board. The researchers briefly explained the study to each principal and asked to meet with him or her. Each principal received a summary of the research proposal for their perusal (see Appendix K). Eight principals were contacted by the researcher and seven agreed to help with the project. An agreement was then reached between the researcher and the principal concerning the number of questionnaires to be sent out through his or her school. Children within the appropriate grades were given a letter to their parents from the principal investigator indicating the purpose of the study (Appendix A). Attached was an agreement to participate form (Appendix A). Parents were asked to complete and return this form to the school if they were interested in participating, or in receiving more information about the study. This method allowed for the anonymity of the families to be maintained until they returned the form to the school indicating interest in participating. Those parents who returned the form to the school were sent questionnaires in the mail. These packages included 2 copies each of the parent and child consent forms (Appendix L and G), a general information questionnaire (Appendix M), and the appropriate number of parent and child report forms (Appendix I and J).

Results

Group Differences in Social Skills

A total of 92 children completed the MESSY, while 88 mothers and 54 fathers reported on their children's social skills. Table 2 provides the means and standard deviations for the total MESSY score for each of the report sources as well as for the appropriate social skills and inappropriate social skills factors. Also included in the table is the mean and standard deviation for a total negative child factor. This factor represents the sum of all negative social skill factors (factors 2, 3, 4, and 5) as reported by Matson, Rotatori, et al. (1983)

Table 2. MESSY Factor Scores by Group and Report Source

| Factor | | Total | | Inappr | opriate | Appro | priate | Total r | egative |
|--------|------|--------|-----------|--------|---------|----------|-----------|---------|-----------|
| Group | N | M | SD | M | SD | <u>M</u> | <u>SD</u> | M | <u>80</u> |
| Child | 1=32 | 74.56 | 21.96 | 29.38 | 11.60 | 97.72 | 11.26 | 59.28 | 19.33 |
| | 2=16 | 81.12 | 14.64 | 30.38 | 7.08 | 92.31 | 11.49 | 58.44 | 10.91 |
| | 3=49 | 75.08 | 19.97 | 27.61 | 6.95 | 95.31 | 11.63 | 55.39 | 12.68 |
| Mother | 1=29 | 104.34 | 21.71 | 83.38 | 16.80 | 79.03 | 12.86 | N/ | A |
| | 2=15 | 104.47 | 23.13 | 82.10 | 24.63 | 81.07 | 10.59 | | |
| | 3=49 | 101.10 | 28.79 | 85.53 | 20.49 | 81.00 | 10.89 | | |
| Father | 1=14 | 111.00 | 18.40 | 88.14 | 16.71 | 77.14 | 10.00 | N/ | A |
| | 2=6 | 100.17 | 26.20 | 83.83 | 24.56 | 83.67 | 6.62 | | |
| | 3=34 | 107.09 | 27.61 | 89.35 | 24.98 | 82.26 | 10.96 | | |

To examine differences between groups a multivariate analysis of variance (MANOVA) was performed comparing MESSY total scores, and first two factors for the three difference sources. For child self reports no significant differences were found for the total MESSY score ($\mathbf{F}(2,94)=.66$, $\mathbf{p}=.52$), or for the appropriate social skills factor ($\mathbf{F}(2,94)=1.21$, $\mathbf{p}=.30$) and inappropriate social skills factor ($\mathbf{F}(2,94)=.31$, $\mathbf{p}=.73$). Similarly no differences were found on any of these measures on either maternal or parental reports (i.e. mothers' total social skills $\mathbf{F}(2,90)=.19$, $\mathbf{p}=.83$, appropriate skills $\mathbf{F}(2,90)=.30$, $\mathbf{p}=.74$, inappropriate social skills $\mathbf{F}(2,90)=.17$, $\mathbf{p}=.84$; fathers' total scores $\mathbf{F}(2,51)=.38$, $\mathbf{p}=.68$, appropriate skills $\mathbf{F}(2,90)=.14$, $\mathbf{p}=.86$

These tests were repeated using father's occupation and education level as co-variates for the child total scores on the MESSY. With these covariates added in the MANOVA equation no group differences were found in children's self reported social skills ($\mathbf{F}(2,82)=0.472$, $\mathbf{p}=0.76$). The same covariates were then added to a MANOVA which examined group differences between father's MESSY total scores. Again, no group differences were found ($\mathbf{F}(2,49)=0.23$, $\mathbf{p}=0.80$). Group differences according to maternal reports were examined using mother's occupation as a covariate. No group differences were seen on total MESSY scores as reported by mothers ($\mathbf{F}(2,89)=0.17$, $\mathbf{p}=0.84$).

Differences Between Report Sources

As differences were not found between groups the sample was pooled and the remaining analyses investigated differences within the groups and between report sources. The total MESSY score was compared among mothers, fathers, and child reports. A repeated measures analysis of variance was utilized to test the hypothesis that parental reports would differ from children self reports. Comparing child total MESSY scores, mother total MESSY scores, and father total MESSY scores there was found to be a significant difference ($\mathbf{F}(2,46)=35.50$, $\mathbf{p}<0.001$). Univariate tests revealed differences both between child and their mother's reports ($\mathbf{F}(1,47)=65.31$, $\mathbf{p}<0.001$) and child reports as compared to their father's reports ($\mathbf{F}(2,47)=16.71$, $\mathbf{p}<0.001$). In both cases, children tended to under report their own negative social skills, or they over-estimated their positive social skills to give a lowered estimate of their abilities as compared to their parent's.

To compare child factors with parental factor scores it was necessary to first reduce the factors in order to find common questions across the child factors and parental factors. The results of this comparison created 2 new factors (Table 3). Fneg consisted of elements common across parent factor 1 (inappropriate) and child factors 2 (inappropriate assertiveness), 3 (impulsive/recalcitrant), 4 (overconfident), and 5 (jealousy/withdrawal) as determined by Matson, Rotatori, et al. (1983). This factor had a total of 29 questions. The second factor, named Fapp included common question across parent factor 2 (appropriate social skills) and child factor 1 (appropriate social skills) and had a total of 14 questions.

Table 3. Revised Child and Parent MESSY Factors

Appropriate Factor

| - Proposition | |
|---|--|
| Child Question | Parent Question |
| 12 I help a friend who is sad | 10 Helps a friend who is hurt |
| 9 I look at people when I talk to them | 26 Looks at people when they are speaking |
| 23 I walk up to people and start a | 18 Walks up to people and starts a |
| conversation | conversation |
| 24 I say 'thank you' and am happy when | 19 Says 'thank you' and is happy when some |
| someone does something for me | one does something nice for him/her |
| 31 I stick up for my friends | 25 Sticks up for friends |
| 32 I look at people when they are speaking | 26 Looks at people when they are speaking |
| 40 I take care of others' property as | 37 Takes care of others' property |
| if it were my own | as if it were his/her own |
| 42 I call people by their names | 39 Calls people by their names |
| 43 I ask if I can be of help | 40 Asks if he/she can be of help |
| 44 I feel good if I help someone | 41 Feels good if he/she helps others |
| 46 I ask questions when talking with others | 45 Asks questions when talking with others |
| 50 I feel sorry when I hurt someone | 47 Feels sorry when he/she hurts others |
| 52 I join in games with other children | 50 Joins in games with other children |
| 55 I do nice things for people who are | 54 Does nice things for others |
| nice to me | who are nice to him/her |
| | |

Negative Factor

Child Question

2 I threaten people or act like a bully 3 I become angry easily 4 I am bossy (tell people what to do instead of asking 5 I gripe or complain often 6 I speak (break in) when someone else is speaking 7 I take or use things that are not mine without permission 8 I brag about myself 11 I slap or hit when I am angry 14 I give other children dirty looks 15 I feel angry or jealous when someone else does well 17 I pick out other children's faults/mistakes 13 Picks out other children's faults/mistakes 19 I break promises

21 I lie to get something I want

30 I make fun of others

33 I think I know it all

22 I pick on people to make them angry

(I try to make people sad)

29 I hurt others' feeling on purpose

Parent Question

- 2 Threatens people or acts like a bully 3 Becomes angry easily
- 4 Is bossy (tells people what to do instead of asking
- Gripes or complains often
- 6 Speaks (breaks in) when someone else is speaking
- 7 Takes or uses things that are not his/hers without permission
- 8 Brags about himself/herself
- 9 Slaps or hits when angry
- 11 Gives other children dirty looks
- 12 Feels angry or jealous when someone else does well
- 15 Breaks promises
- 16 Lies to get what he/she wants
- 17 Picks on people to make them angry
- 21 Hurts others' feelings on purpose (tries to make people sad)
- 23 Makes fun of others
- 27 Thinks he/she knows it all

- 35 I am stubborn
- 36 I act like I am better than other people
- 38 I think people are picking on me when they are not
- 39 I make sounds that bother others (burping, sniffling)
- 41 I speak too loudly
- 53 I get into fights a lot
- 54 I am jealous of other people
- 57 I stay with others too long (wear out my welcome)
- 58 I explain things more than I need to
- 60 I think that winning is everything
- 61 I hurt others when teasing them
- 62 I want to get even with someone who hurts me

- 29 Is stubborn
- 30 Acts like he/she is better than others
- 32 Thinks people are picking on him/her when they are not
- 33 Makes sounds that bother others (burping, sniffling)
- 38 Speaks too loudly
- 52 Gets into fights a lot
- 53 Is jealous of other people
- 57 Stays with others too long (wears out welcome)
- 58 Explains things more than needs to
- 62 Thinks that winning is everything
- 63 Hurts others when teasing them
- 64 Wants to get even with someone who hurts them

Analyses using these factors were performed to compare child with father's reports, and child with mother's reports. These analyses were performed separately in order to save power due to the number of missing father reports. When mother and child reports were compared across the appropriate social skills factor using a repeated measures ANOVA, a significant difference was found (F (1,88) = 795.45, p < 0.001). It was observed that children reported higher appropriate social skills as compared to their mothers (see Table 4). A similar result was found when children's reports were compared to their fathers' (F (1,50) = 5.98, p = 0.02). Significant differences were not found when negative factor scores were compared across report sources. No differences were seen between child and mother reports of negative social skills (F (1,90) = 1.23, p = .27), nor between child and father scores on the negative social skills factor (F (1,52) = 3.15, p = .08). This indicated that total MESSY scores varied according to report source due to different perceptions of appropriate social skills

between children and their parents.

Table 4. Report Source Differences

| Report Sour | rce | F approp | riate | F negative | |
|-------------|-----|----------|-------|------------|-------|
| | N | <u>M</u> | SD | <u>M</u> | SD |
| Child | 97 | 58.90 | 6.72 | 54.43 | 14.41 |
| Mother | 93 | 54.05 | 7.88 | 55.61 | 14.52 |
| Father | 54 | 54.87 | 6.89 | 60.11 | 16.15 |

To investigate differences between mothers' and fathers' reports, a repeated measures ANOVA was performed. Significant differences were not found when parental reports were compared on negative social skills $\mathbf{E}(1,48) = 2.85$, $\mathbf{p} = 0.10$, appropriate social skills $\mathbf{E}(1,48) = 2.69$, $\mathbf{p} = 0.11$), or in their interaction ($\mathbf{E}(1,48) = 1.11$, $\mathbf{p} = 0.30$). A trend, however, is apparent among these analyses. Fathers tended to report more negative social skills than their children. As well, fathers tended to over report their children's negative social skills as compared to mothers.

Sex Differences

Sex differences were examined for child self reports for the appropriate and inappropriate social skills factors of the MESSY. A multivariate analysis of variance indicated that there were significant differences between genders on the MESSY ($\mathbf{F}(2,94) = 4.22$, $\mathbf{p} = .02$). Univariate tests revealed that scores on Factor 1, children's appropriate social skills, were significantly higher for girls as compared to boys ($\mathbf{F}(1,95)=7.33$, $\mathbf{p}=.01$), indicating that girls reported having more appropriate

social behaviours. No sex differences were found for children's negative social skills (a combined total of factors 2, 3, 4, and 5 as reported by Matson, Rotatori, et al., 1983) ($\mathbf{F}(1,95) = 1.77$, $\mathbf{p}=.19$).

Differences in sex were also investigated according to parental reports. No significant findings were found for mothers' reports on either the appropriate (factor 2 as reported by Matson, Rotatori, et al., 1983) ($\mathbf{F}(1,91) = 0.05$, $\mathbf{p} = 0.83$) or inappropriate factors (factor 1 as reported by Matson, Rotatori, et al., 1983) ($\mathbf{F}(1,91) = 0.53$, $\mathbf{p} = 0.47$), nor on the fathers' reports of appropriate social skills ($\mathbf{F}(1,52) = 0.21$, $\mathbf{p} = 0.66$). However, fathers reported differences between boys and girls on inappropriate social skills ($\mathbf{F}(1,52) = 4.80$, $\mathbf{p} = 0.03$). Specifically boys ($\mathbf{M} = 96.32$, $\mathbf{SD} = 20.47$) were reported to have more inappropriate social skills compared girls ($\mathbf{M} = 83.00$, $\mathbf{SD} = 22.91$) (see Table 5).

Table 5. Sex Differences by Report Source

| Factor | • | Approp | riate | Inappr | opriate | Total n | egative |
|--------|----------|--------|-------|--------|-----------|---------|---------|
| Source | <u>N</u> | M | SD | M | <u>so</u> | M | SD |
| Child | M = | 91.95 | 11.54 | 30.38 | 10.36 | 58.90 | 15.52 |
| 40 | | 98.18 | 10.87 | 27.44 | 7.28 | 54.84 | 14.29 |
| | F = 57 | | | | | | |
| Mother | M = 37 | 80.08 | 10.31 | 84.92 | 16.86 | N/A | |
| : | F = 56 | 80.61 | 12.16 | 81.82 | 21.84 | | |
| Father | M = 22 | 80.32 | 7.20 | 96.32 | 20.47 | N/A | |
| | F = 32 | 81.63 | 12.28 | 83.00 | 22.91 | | |

Age Differences

In order to examine age differences, the sample was split into two age groups. Age group 1 consisted of children less than 13 years and age group 2 were those children 13 years and older. This age split was chosen as it divided the sample into two groups with equal age ranges. As well, it divided the groups between children and adolescents. This split the group approximately evenly in half, with 49 children under 13 and 43 children 13 and over. Age differences in MESSY scores were examined by report source using a multivariate analysis of variance. For the child reports, a significant age effect was demonstrated. On the total MESSY score, older children were found to have higher scores, which indicates fewer social skills, or more inappropriate skills ($\mathbf{E}(1.90) = 5.27$, $\mathbf{p} = 0.02$) (see Table 6). Univariate tests were conducted for the appropriate social skills factor and the negative social skills factor (sum of factors 2 through 5). Results revealed that age differences in children's social skills occurred mainly within the area of negative social skills ($\underline{\mathbf{F}}(1,90) = 3.14$, $\underline{\mathbf{p}} = 0.08$). However, there was also a slight trend for younger children to report having more appropriate social skills than older children ($\mathbf{F}(1.90) = 2.72$, $\mathbf{p} = 0.10$).

No age differences were found for mother or father's total scores on the MESSY or on either of the factors. Maternal reports of total social skills, inappropriate social skills, and appropriate social skills did not demonstrate any differences by age $(\underline{F}(1,86) = 1.03, p = 0.31; \underline{F}(1,86) = 2.25, p = 0.14;$ and $\underline{F}(1,86) = 0.10, p = 0.75$ respectively). Similarly, results revealed that fathers did not indicate any differences by age on the total score or the

two factors (Total MESSY $\underline{F}(1,52) = 0.54$, $\underline{p} = 0.46$, inappropriate $\underline{F}(1,52) = 0.00$, $\underline{p} = 1.00$, and appropriate $\underline{F}(1,52) = 3.29$, $\underline{p} = 0.07$). Means and standard deviations for the child, mother, and father's appropriate and inappropriate social skill factors are presented in Table 6.

Table 6. Age Differences by Report Source

| Factor | | Appro | priate | Inappr | opriate | Total | |
|--------|------------|-------|--------|----------|-----------|----------|---------------|
| Source | * <u>N</u> | M | SD | <u>M</u> | <u>20</u> | <u>M</u> | SD |
| Child | 1 = 43 | 97.86 | 12.10 | 27.47 | 8.68 | 71.12 | 21.09 |
| | 2 = 49 | 97.84 | 11.04 | 29.84 | 8.68 | 80.56 | 17.89 |
| Mother | 1 = 45 | 81.22 | 10.57 | 86.49 | 20.96 | 105.27 | 27.47 |
| | 2 = 43 | 80.44 | 12.30 | 80.07 | 19.13 | 99.63 | 24.4 3 |
| Father | 1 = 24 | 83.83 | 8.49 | 88.42 | 20.91 | 104.50 | 22.59 |
| | 2=30 | 78.83 | 11.43 | 88.43 | 24.45 | 109.60 | 27.16 |

^{*}Where age group 1=younger and 2=older children

Regression Analyses

Finally, to look at which factors may contribute to social skill development for children with CF and their siblings a regression analysis was performed. A simultaneous method of entry was used for the multiple regressions. In the first analysis the predictor variable was the child's total social skill score on the MESSY and dependent variables consisted of SES (father's occupation), parent's rating of disease severity, age at diagnosis, demand of care on families, the number of hours mothers, fathers, and

siblings (sibling group only) spent doing in-home therapy each week, and days away from school each year (CF group only). For the CF children, in the final equation only the severity of CF and the rating of how demanding care was on the families were found to be significant predictors of child's total MESSY score (Table 7). The model accounted for 55.4% of the variance in children's self reports of their social skills (\mathbf{F} (7, 18) = 3.19, \mathbf{p} = .02). Examination of the results indicated that a lower ranking of severity and a higher rating of how demanding care was on the family predicted higher total social skills score, or more inappropriate social skills.

The analysis was subsequently rerun using mother's and father's total MESSY scores as the dependent variable, keeping all predictors the same (Tables 8 and 9 respectively). With mother's total social skill score for the child the predictors accounted for 27.89% of the variance which was not significant (\mathbf{F} (7, 15) = .83, \mathbf{p} = .58). Father's total social skill score for the child on the MESSY accounted for 32.35% of the variance, again a non-significant proportion (\mathbf{F} (7, 5) = .34, \mathbf{p} = .90).

A similar regression was conducted for the siblings (Table 9). Siblings' total social skills score on the MESSY were predicted using father's occupation, the severity of their ill sibling's CF, the parental rating of how demanding care of the child with CF was on the family, the time siblings within the home helped doing therapy with their ill brother or sister, and the time the parents did in-home therapy with the CF child. No significant predictors were found. The model accounted for 35.11% of the variance ($\mathbf{F} = 7$ (6,9)=.81, $\mathbf{p} = .59$).

Table 7. Multiple Regression for Predication of CF Child Total MESSY Scores

| | | | |
|-----------------------------|-------|-------|-------|
| Predictor Variable | Beta | ТТ | Sig T |
| Dad's Occupation | 0.24 | 1.40 | 0.18 |
| CF severity (1-5) | -0.88 | -3.31 | <0.01 |
| Age at CF diagnosis (years) | 0.32 | 1.43 | 0.17 |
| Demand of care of CF (1-5) | 1.30 | 4.26 | <0.01 |
| Mom therapy hrs/week | -0.62 | -0.33 | 0.75 |
| Dad therapy hrs/week | -0.03 | -0.13 | 0.89 |
| Days school miss per year | -0.07 | -0.41 | 0.68 |
| | | | |

Table 8. Multiple Regression for Prediction of CF Mother's Total MESSY Scores

| Predictor Variable | Beta | ТТ | Sig T |
|-----------------------------|-------|-------|-------|
| Dad's Occupation | -0.12 | -0.49 | 0.63 |
| CF severity (1-5) | -0.56 | -1.42 | 0.18 |
| Age at CF diagnosis (years) | -0.15 | -0.49 | 0.63 |
| Demand of care of CF (1-5) | 0.61 | 1.41 | 0.18 |
| Mom therapy hrs/week | 0.00 | 0.00 | 1.00 |
| Dad therapy hrs/week | -0.18 | -0.61 | 0.55 |
| Days school miss per year | 0.11 | 0.47 | 0.64 |
| | | | |

Table 9. Multiple Regression for Prediction of CF Father's Total MESSY Scores

| Predictor Variable | Beta | T | Sig T |
|-----------------------------|-------|-------|-------|
| Dad's Occupation | -0.37 | -0.84 | 0.44 |
| CF severity (1-5) | -0.56 | -0.99 | 0.37 |
| Age at CF diagnosis (years) | 0.42 | 0.70 | 0.51 |
| Demand of care of CF (1-5) | 0.47 | 0.66 | 0.54 |
| Mom therapy hrs/week | -0.13 | 0.25 | 0.82 |
| Dad therapy hrs/week | 0.32 | 0.61 | 0.57 |
| Days school miss per year | 0.22 | 0.51 | 0.63 |
| | | | |

Table 10. Multiple Regression for Prediction of Siblings Total MESSY Scores

| | | | |
|--------------------------|-----------|-------------|--------|
| Predictor Variable | Beta | T | Sig T |
| Dad's Occupation | -0.37 | -1.09 | 0.30 |
| CF severity (1-5) | -0.23 | 0.44 | 0.67 |
| Demand of CF care (1-5) | 0.23 | 0.45 | 0.67 |
| Sibling therapy hrs/week | -0.05 | -0.16 | 0.88 |
| Mom therapy hrs/week | -0.13 | -0.39 | 0.71 |
| Dad therapy hrs/week | -0.067569 | -0.215 | 0.8343 |
| | | | |

Psychometric Properties of the MESSY

The MESSY is a relatively new measure with limited information on its reliability and factor structure. These properties were investigated using our sample for child self reports, as well as both mother's and father's reports of their children's social skills.

Reliability

Internal consistency was tested for the entire scale on child, mother, and father reports. The child self report scale revealed a Cronbach coefficient alpha of 0.80 and a Spearman-Brown split-half reliability of 0.81. These figures are in line with the results reported by Spence and Liddle (1990). Mother's reports resulted in a Cronbach coefficient alpha of 0.85 and Spearman-Brown split-half reliability of 0.76, while fathers' reports had a Cronbach coefficient alpha of 0.91 and Spearman-Brown split-half reliability of 0.86. These results indicate that the MESSY had strong reliability across all report sources.

Factor Analysis

Factor analyses of the MESSY were conducted using the SPSS computer statistical package (Norusis, 1993). A principal components factor analysis with varimax rotation was conducted on the children's, mothers, and fathers reports separately. Factors with eigenvalues greater than 1 were considered. Loadings for each question were required to be greater than .30 to be included in a factor. This method and criteria were used in order to create equivalence with the previous analyses done on the MESSY (Spence & Liddle, 1990).

The factor analysis of the child self report questionnaire extracted 21 initial factors. A scree curve was used to select a factor solution. The eigenvalues for the first five factors were 9.01, 7.09, 3.52, 2.87, and 2.74 respectively. Plotting these values the 'elbow', or significant drop in the curve occurred at approximately the third factor. Using a scree plot suggests that the optimal factor solution is one factor less than the solution corresponding to this elbow (Diekhoff, 1992). Therefore it was decided to retain the first two initial factors. This two-factor solution (Table 11) appeared valid as most of the questions in the MESSY loaded on one of the first two factors. In addition, these two factors evidenced face validity as questions related to appropriate social skills loaded on the other factor.

Combined, the two factors accounted for 26.0% of the variance.

Factor 1 was an inappropriate social skills factor with 31 questions and accounted for 14.5% of the variance. Factor 2 included 23 questions related to appropriate social skills and accounted for 11.4% of the total variance. In this solution seven questions were not included in these two factors. The solution for the child report form resembled the parent factors and is in fact more similar to the parent factors than the child factor solutions reported by Matson, Rotatori, et al. (1983) or Spence & Liddle (1990).

Table 12 compares the means and standard deviations of the factors found in this study to those reported by Spence and Liddle (1990) using Matson, Rotatori, et al.'s (1983) original factor structure. Results indicated that the means of factors reported in the current study are both within one

Table 11. New MESSY Factors: Child Report

| Factor 1: Inappropriate | factor loading |
|---|----------------|
| 2. I threaten people or act like a bully | 0.54462 |
| 3. I become angry easily | 0.35816 |
| 4. I am bossy (tell people what to do instead of asking) | 0.51928 |
| 5. I gripe or complain often | 0.36157 |
| 6. I speak (break in) when someone else is speaking | 0.41886 |
| 7. I take or use things that are not mine without permiss. | |
| 8. I brag about myself | 0.49784 |
| 14. I give other children dirty looks | 0.59921 |
| 15. I feel angry or jealous when someone else does well | 0.45939 |
| 17. I pick out other children's faults/mistakes | 0.42677 |
| 18. I always want to be first | 0.40850 |
| 19. I break promises | 0.60859 |
| 21. I lie to get something I want | 0.58573 |
| 22. I pick on people to make them angry | 0.39908 |
| 29. I hurt others' felling on purpose (I try to make people s | |
| 30. I make fun of others | 0.51873 |
| 33. I think I know it all | 0.40836 |
| 35. I am stubborn | 0.42013 |
| 36. I act like I am better than other people | 0.53102 |
| 38. I think people are picking on me when they are not | 0.42964 |
| 39. I make sounds that bother others (burping, sniffling) | 0.41681 |
| 45. I try to be better than everyone else | 0.49558 |
| 49. I feel lonely | 0.38057 |
| 51. I like to be the leader | 0.33342 |
| 53. I get into fights a lot | 0.47839 |
| 54. I am jealous of other people | 0.44937 |
| 57. I stay with others too long (wear out my welcome) | 0.39270 |
| 58. I explain things more than I need to | 0.40513 |
| 60. I think that winning is everything | 0.44852 |
| 61. I hurt others when teasing them | 0.62515 |
| 62. I want to get even with someone who hurts me | 0.38277 |
| Factor 2: Appropriate | factor loading |
| 1. I make other people laugh | 0.52698 |
| 9. I look at people when I talk tothem | 0.32712 |
| 10. I have many friends | 0.60958 |
| 11. I slap or hit when I am angry | 0.36496 |
| 12. I help a friend who is sad | 0.48001 |
| 13. I cheer up a friend who is sad | 0.44494 |
| 16. I feel happy when someone else does well | 0.33849 |

| 20. I tell people they look nice 23. I walk up to people and start a conversation 24. I say 'thank you' and am happy when someone does | 0.44087 0.56235 |
|--|----------------------------|
| something for me 28. I know how to make friends | 0.45805 0.76486 |
| 31. I stick up for my friends | 0.59449 |
| 32. I look at people when they are speaking 34. I share what I have with others | 0.39383 0.36090 |
| 37. I show my feelings 41. I speak too loudly | 0. 44268 0.31511 |
| 43. I ask if I can be of help 44. I feel good if I help someone | 0.53153 0.46120 |
| 46. I ask questions when talking with others 52. I join in games with other children | 0.42147 0.52947 |
| 55. I do nice things for people who are nice to me | 0.40451 |
| 56. I ask others how they are, what they have been doing, etc 59. I laugh at other people's jokes and funny stories | 0.53054 0.45838 |

Table 12. Population Means for Appropriate and Inappropriate Social Skills

| Factor | Spence & | Spence & Liddle (1990) | | tudy |
|-----------------|----------|------------------------|-------|-------|
| | <u>M</u> | <u>SD</u> | M | SD |
| Appropriate | 81.29 | 17.75 | 90.62 | 11.57 |
| Total negative* | 56.96 | N/A | 58.22 | 15.33 |

^{*} The total negative factor score was obtained by adding 4 negative factor means

standard deviation of those reported in the previous study.

In mothers' reports, 18 factors were extracted accounting for 77% of the variance (Table 13). The eigenvalues for the first five factors were 13.27, 7.03, 3.93, 3.10, and 2.72. Thus the scree plot suggested a two-factor solution. Again, these two factors displayed face validity with questions related to appropriate social skills loading on one factor and those related to inappropriate skills loading on the other factor. Together the two factors accounted for 32% of the variance. The first factor was an inappropriate factor which accounts for 21% of the variance with 37 questions. The second factor accounted for 11% of the variance and could be labelled as appropriate social skills. It contained 18 questions. Nine questions were not included in either of these two factors.

For fathers' reports 18 factors were extracted. The eigenvalues for the first five factors were 13.59, 7.03, 3.93, 3.10, and 2.72. This suggested a two-factor solution (Table 14). This solution also evidenced face validity with questions related to appropriate social skills loading on one factor and those related to inappropriate skills loading on the other factor. In this case the first two factors accounted for 32% of the variance and included all but 5 of the questions. Factor 1 was an inappropriate social skills factor accounting for 21.2% of the variance with a total of 38 questions. Factor 2 was again appropriate social skills, and accounted for 10.8% of the variance. Twenty-one questions loaded on this factor.

For both the mother and father factor analyses the results resembled the initial teacher factor analyses as presented by Matson, Rotatori, et al. (1983). There were, however, some differences between mother and father reports. For example, 2 questions which loaded on the mothers' appropriate social skills factor, ended up loading on fathers' inappropriate social skills factor. These questions were #49 (Likes to be the leader) and #55 (Tries to get others to do what he/she wants). Both of these questions loaded on the inappropriate social skills factor in Matson's analysis. A third question, #52 (Gets into fights a lot) also loaded differently across parental reports. For mothers, in the present study, as well as in Matson's, this question loaded on the inappropriate social skills factor; however, for fathers in this study, this question loaded on the appropriate social skill factor.

Table 13. New MESSY Factors: Mother Report

| Factor 1: Inappropriate social skills | factor loading |
|---|------------------|
| 2. Threatens people or acts like a bully | 0.46506 |
| 3. Becomes angry easily | 0.49043 |
| 4. Is bossy (tells people what to do instead of asking) | 0.52338 |
| 5. Gripes or complains often | 0.38068 |
| 6. Speaks (breaks in) when someone else is speaking | 0.53578 |
| 7. Takes or uses things that are not his/hers without | |
| permission | 0.47817 |
| 8. Brags about himself/herself | 0.38722 |
| 9. Slaps or hits when angry | 0.37918 |
| 11. Gives other children dirty looks | 0.52513 |
| 12. Feels angry or jealous when someone else does well | 0.63771 |
| 13. Picks out other children's faults/mistakes | 0.59738 |
| 14. Always wants to be first | 0. 4679 3 |
| 15. Breaks promises | 0.49381 |
| 16. Lies to get what he/she wants | 0.48560 |
| 17. Picks on people to make them angry | 0.59357 |
| 21. Hurts others' feeling on purpose(tries to make people s | ad) 0.46494 |
| 22. Is a sore loser | 0.47650 |
| 23. Makes fun of others | 0.59044 |
| 24. Blames own problems on others | 0.65837 |
| 27. Think he/she knows it all | 0.44673 |
| 29. Is stubborn | 0.59787 |
| 30. Acts like he/she is better than others | 0.45003 |
| 32. Thinks people are picking on him/her when they are no | ot 0.47014 |
| 36. Brags too much when he/she wins | 0.48548 |
| 38. Speaks too loudly | 0.41328 |
| 43. Always thinks something bad is going to happen | 0.52990 |
| 44. Tries to be better than everyone | 0.36177 |
| 46. Feels lonely | 0.44542 |
| 48. Gets upset when he/she has to wait for things | 0.37580 |
| 52. Gets into fights a lot | 0.59236 |
| 53. Is jealous of other people | 0.56821 |
| 57. Stays with others too long (wears out welcome) | 0.51198 |
| 58. Explains things more than needs to | 0.34272 |
| 60. Hurts others to get what he/she wants | 0.58873 |
| 62. Thinks that winning is everything | 0.41198 |
| 63. Hurts others when teasing them | 0.51840 |
| 64. Wants to get even with someone who hurts him/her | 0.46355 |

| Factor 2: Appropriate Social Skills | factor loading |
|--|----------------|
| 10. Helps a friend who is hurt | 0.39586 |
| 18. Walks up to people and starts a conversation | 0.61787 |
| 19. Says'thank you' and is happy when someone does | |
| something for him/her | 0.48280 |
| 25. Sticks up for friends | 0.44467 |
| 26. Looks at people when they are speaking | 0.46167 |
| 28. Smiles at people he/she knows | 0.65074 |
| 31. Shows feelings | 0.56368 |
| 33. Thinks good things are going to happen | 0.35466 |
| 39. Calls people by their names | 0.37135 |
| 40. Asks if he/she can be of help | 0.39687 |
| 42. Defends self | 0.34774 |
| 45. Asks questions when talking with others | 0.49687 |
| 49. Likes to be the leader | 0.46404 |
| 50. Joins in games with other children | 0.45478 |
| 54. Does nice things for others who are nice to him/her | 0.48074 |
| 55. Tries to get others to do what he/she wants | 0.51784 |
| 56. Asks others how they are, what they have been doing, e | |
| 59. Is friendly to new people he/she meets | 0.57932 |
| | |

Table 14. New MESSY Factors: Father Report

| Factor 1: Inappropriate | factor loading |
|--|----------------|
| 2. Threatens people or acts like a bully | 0.31514 |
| 3. Becomes angry easily | 0.56823 |
| 4. Is bossy (tells people what to do instead of asking) | 0.41389 |
| 5. Gripes or complains often | 0.60221 |
| 6. Speaks (breaks in) when someone else is speaking | 0.70027 |
| 7. Takes or uses things that are not his/hers without | |
| permission | 0.50404 |
| 8. Brags about himself/herself | 0.57518 |
| 9. Slaps or hits when angry | 0.57295 |
| 11. Gives other children dirty looks | 0.43043 |
| 12. Feels angry or jealous when someone else does well | 0.53258 |
| 13. Picks out other children's faults/mistakes | 0.63953 |
| 14. Always wants to be first | 0.60731 |
| 15. Breaks promises | 0.48196 |
| 16. Lies to get what he/she wants | 0.36157 |
| 17. Picks on people to make them angry | 0.63953 |
| 21. Hurts others' feeling on purpose (tries to make people s | ad) 0.69753 |
| 22. Is a sore loser | 0.66212 |
| 23. Makes fun of others | 0.55980 |
| 24. Blames own problems on others | 0.67541 |
| 27. Think he/she knows it all | 0.68390 |
| 29. Is stubborn | 0.57254 |
| 30. Acts like he/she is better than others | 0.67274 |
| 32. Thinks people are picking on him/her when they are no | |
| 35. Make sounds that bother others (burping, sniffling) | 0.49794 |
| 36. Brags too much when he/she wins | 0.75975 |
| 38. Speaks too loudly | 0.64236 |
| 43. Always thinks something bad is going to happen | 0.31816 |
| 44. Tries to be better than everyone | 0.67824 |
| 48. Gets upset when he/she has to wait for things | 0.71343 |
| 49. Likes to be the leader | 0.49708 |
| 53. Is jealous of other people | 0.49708 |
| 55. Tries to get others to do what he/she wants | 0.60909 |
| 57. Stays with others too long (wears out welcome) | 0.61809 |
| 58. Explains things more than needs to | 0.52984 |
| 60. Hurts others to get what he/she wants | 0.66168 |
| 62. Thinks that winning is everything | 0.61378 |
| 63. Hurts others when teasing them | 0.56695 |
| 64. Wants to get even with someone who hurts him/her | 0.60861 |

| Factor 2: Appropriate | factor loading |
|--|----------------|
| 1. Make other people laugh (tells jokes, funny stories, etc) | 0.38929 |
| 10. Helps a friend who is hurt | 0.47676 |
| 18. Walks up to people and starts a conversation | 0.54666 |
| 19. Says'thank you' and is happy when someone does | |
| something for him/her | 0.33983 |
| 25. Sticks up for friends | 0.49016 |
| 28. Smiles at people he/she knows | 0.58104 |
| 31. Shows feelings | 0.30423 |
| 33. Thinks good things are going to happen | 0.46780 |
| 34. Works well on a team | 0.52296 |
| 37. Takes care of others' property as if it were his/her own | 0.37302 |
| 39. Calls people by their names | 0.49789 |
| 41. Feels good if he/she helps others | 0.36108 |
| 42. Defends self | 0.51792 |
| 45. Asks questions when talking with others | 0.64220 |
| 50. Joins in games with other children | 0.77951 |
| 51. Plays by the rules of a game | 0.32622 |
| 52. Gets into fights a lot | 0.33622 |
| 54. Does nice things for others who are nice to him/her | 0.33782 |
| 56. Asks others how they are, what they have been doing, e | |
| 59. Is friendly to new people he/she meets | 0.67740 |
| | |

Discussion

Group Differences

Past research has found that children with a chronic illness and their siblings may be at risk for poor psychosocial adaption (Clark et al., 1989; Ferrari, 1984; La Greca, 1992). It was hypothesized that this risk could be accounted for by lowered social skills. Therefore, the purpose of this study was to examine the social skills of children with CF and their siblings compared to a normal comparison group of healthy peers. Reports of each child's social skills were obtained from at least two sources, the child's self report and at least one of their parent's reports. Three measures of social skills were examined: the total score on the MESSY, an appropriate social skills factor and an inappropriate social skills factor. Results indicated that children with CF and their siblings did not differ from normal comparison children on any of these measures according to their self reports of social skills or according to their parents' reports of their social skills. This suggests that the social skills of children with CF and their siblings were similar to those of healthy children and that they did not display deficits in social skills.

These findings are consistent with current literature that has reported no differences in the overall psychosocial adaptation of children with chronic disease, or their siblings (Drotar et al., 1981; Stewart et al., 1992; Ungerer et al., 1988). Ungerer et al. (1988) concluded that children with a chronic illness do not experience increased risk for adjustment difficulties. In addition, Drotar et al (1981) found that children with CF had

age appropriate adjustment overall. Siblings of children with a chronic illness have also been reported to be, on average, well adjusted (Stewart et al., 1992).

Despite research reporting adequate adjustment for children with chronic illnesses, findings by Drotar et al. (1981) and Spirito et al. (1991) indicated that children with chronic disease, including CF, are more likely to evidence social withdrawal, isolation, and rejection. The findings of this study suggest that this social isolation is not due to a lack of social skills. Instead, children with CF, while armed with equivalent social skills compared to peers, may face rejection, teasing, and peer social difficulties (La Greca, 1990; Spirito et al., 1991) because of other stressors, such as physical disease characteristics or limitations.

Bakwin and Bakwin (1972) stated that the development of children with chronic illnesses may be influenced because the illness interferes with the normal activities of the children. It appears that CF did not significantly interfere with the normal activities of children with CF or their siblings, allowing for the appropriate development of social skills. Perhaps children with a chronic illness who have more physical symptoms and limitations (i.e., muscular dystrophy) which interfere with normal activities would display more difficulties in the area of social skills. This is an area of future research that may show that some chronic illnesses do affect children's social skills.

Bakwin and Bakwin also suggested that a chronic illness in childhood may make the child feel different from his/her peers and in turn

negatively impact his/her self-concept. While children with CF demonstrated that they are aware of socially appropriate behaviours, they may not be successful in social performance. As Cavell (1990) stated, the presence of social skills does not necessarily guarantee effective social performance. While knowing the appropriate social skills, children with CF may have negative self-concept which affects their social performance. Specifically this negative self-concept may result in their choosing poor social goals or lacking incentive to behave appropriately. This hypothesis would account for the findings of previous studies which suggested that children with a chronic illness often suffer from peer rejection and isolation. Specifically, for children with CF, Spirito et al. (1991) reported that these children often withdraw from social situations.

No group differences in social skills were found among the siblings of children with CF and the normal comparison group. This finding is consistent with recent research by Noll et al. (1995) who reported that siblings of children with sickle cell anemia (SCA) did not show greater than average problems with peer relationships. Thus, the findings of these studies suggested that the psychosocial adaptation of siblings of children with a chronic illness was not significantly affected by the presence of their ill sibling. If siblings of a child with a chronic illness were having difficulties adjusting, other factors such as parental coping skills, maternal depression, and family resources may be possible explanations for these difficulties (Ievers & Drotar, 1996; Mullins et al., 1995).

There may be several possible explanations for the current finding.

Most importantly may be the nature of current research and the changes it has experienced over the past two decades. Past research has been criticized for a lack of thorough research techniques. It was therefore questioned whether the results from these studies can be considered valid. It is possible, that the significantly lower adaptation reported for children with chronic illness and their siblings as compared to healthy children in previous studies was a product of poor methodology. The current study used more methodologically sound research techniques than many of the earlier research studies. Criticisms from past research were corrected. Specifically, the present study had multiple report sources, concentrated on one particular disease group (CF), used a normal comparison group, and examined a specific area of adaptation, social skills. As these considerations were taken into account, the results of this study should be considered to be valid.

A second possible reason why no group differences in social skills were found may be because of the changing nature of chronic illness in today's society, particularly CF. Over the past twenty years medical research has had a tremendous impact on how children with CF are perceived and treated. No longer are children with CF expected to die in childhood. Further, they do not face multiple hospitalizations resulting in significant time away from social situations such as school, nor are they told that they cannot participate in any physical activities. Today, children with CF are diagnosed early and are able to manage their disease with minimal impact on their environment. They go to school regularly and are

encouraged to participate in all activities. Thus, the advances in medical technologies have helped parents of children with CF normalize the lives of not only their child(ren) with CF but also the home life for their other children.

It is possible that the lack of significant differences between groups on a measure of social skills was related to the measure used. Differences may have emerged if other, non-questionnaire based reports were employed. Previous studies that have investigated social skills in children have typically used peer nominations, teacher reports, or behavioral observation. The use of a questionnaire format for the study of social skills is in its infancy and hence questions remain as to the validity of using this method to examine children's social skills.

The MESSY is still a relatively new measure. While it was chosen for its strong psychometric properties, it was being used in new capacities in this study. In previous studies when the MESSY was employed with younger children, they were administered the scale verbally with an aide (Matson, Esveldt-Dawson, Kazdin, 1983). In this study, children as young as 8 years old were required to complete the questionnaire independently. In addition, to our knowledge this was only the second time that the report form initially designed for use with teachers was used for parental reporting. Whether this use is valid may be questioned.

Further, the questionnaires were completed in the home. Therefore, parents were completing the forms along side their children. Especially with the younger children, this dynamic may have influenced the results

found on the MESSY reports. For example, children may have completed their questionnaires at the same time as their parents or even worked jointly on them. Children may have wished to impress their parents and responded as they thought their parents saw them, rather than indicating which response best described themselves.

As well, no previous studies have used the MESSY with chronically ill children. In previous studies, the MESSY has been used with children with autism and depression, as well as visually handicapped and hearing impaired children. It is possible, however, that specific topics covered by the MESSY do not cover the social skill areas where children with chronic illnesses are potentially lacking (Matson et al., 1985; Matson et al., 1991). The child form of the MESSY contains only 62 questions, hence cannot cover all aspects of social skills. Children with a chronic illness may experience specific deficits not applicable to their peers, such as how to tell their friends about their illness or how to cope with the chronic nature of the disease.

When using self-reports, social desirability must be considered. Not only would this desire to be seen in a positive light influence children reporting on their own social skills, but it could also influence parental reports. Mothers and fathers of children with CF may have wished to minimize their children's problems and maximize their strengths. This may have resulted in these parents reporting few social skill problems for their children with CF and their siblings. As a result, any differences in social skills among children with CF, their siblings and healthy controls

may have been minimized.

MESSY Predictors

While the social skills of children with CF and their siblings were not found to differ significantly from healthy peers, it was still considered valuable to look at whether any of the sociodemographic variables or disease characteristics associated with CF predicted children's level of social skills. Results indicated that the combination of dependent variables including SES (father's occupation), parent's rating of disease severity, age at diagnosis, demand of care on families, the number of hours mothers and fathers spend doing in-home therapy each week, and days away from school each year significantly predicted the total score on the MESSY as reported by the children with CF themselves. This prediction was related to two significant predictors, disease severity and demand of care on the family. It was found that a lower rating of severity and higher demand of care (as described by parents, usually the mother) contributed to poorer social skills as described by the affected children. While it could be said that the parents did not accurately indicate the severity of their children's disease, this was not supported by the findings of Dewey and Crawford (1996). They reported that maternal and paternal ratings of disease severity were highly correlated with physician's ratings.

There are two possible directions from which this finding could be interpreted. First, children with less severe CF but with a higher demand of care have lower social skills, or, second, children with better social skills and more severe CF, demand less care from their family. Because of the

interaction of these factors, it is difficult to determine causation. However, one explanation is that parents who rated their child's CF as severe had different perceptions of degree of demand. They may have perceived the degree of demand to be lower than parents of children with less severe CF. Specifically, they may have felt that the demands of caring for their child were not that great relative to the severity of the child's disease. Hence, they perceived the degree of care to be lower as compared to parents of children with less severe CF. Also, parents of children with severe CF may have put a great deal of effort into helping their child(ren) adjust and to cope with this illness. This may result in better social skills as reported by the child.

Demand of care may be seen as a measure of the perception of how much the family is affected by having a child with CF. Children whose parents indicated a higher degree of demand of care combined with a lower rating of severity, had children who reported a lower level of social skills. It is possible that parents who had a child with less severe CF were overwhelmed with the care demands. Because they perceive the disease as being not that severe, they may not have been as willing or as able to help their child(ren) adjust to living with his/her illness as parents of children with more severe CF. Thus, this may have resulted in children with less severe CF reporting lower social skills.

The results of the present study suggested that factors specific to CF can indeed have an influence on the development of children's social skills. Future research is needed to investigate further possible mediating factors.

Knowledge of the mediating factors, along with our understanding of how disease characteristics are involved in the development of social skills of children with a chronic illness, will assist us in developing a better understanding of the effect childhood chronic illness has on the child and their family.

Regression analyses were also conducted with the aforementioned variables used to predict both mother's and father's total MESSY scores. These analyses did not account for a significant amount of the variance, nor were any of the predictors found to be significant. These findings suggested that the dynamics discussed above are generally linked to the child's experience and hence their perception of their social skills. Parental perceptions of their children's social skills were not influenced by sociodemographic variables, nor were the disease characteristics found to be significant predictors.

A similar analysis also examined whether any disease or sociodemographic variables predicted sibling social skills. None of the variables used in this analysis were found to be significant. These findings suggested that the social skills of siblings of children with CF were not significantly affected by the presence of a child with CF in the home. It should be noted that this study looked only at the effects of sociodemographic variables and disease characteristics on social skills. There may be several mediating variables that may impact the social skills of siblings of children with CF such as parental adaptation, maternal depression, and family resources (Ievers & Drotar, 1996; Mullins et al.,

Differences Between Report Sources

Differences between children's self reports of their social skills and their parents perception of these skills were investigated in relation to the total social skill score, appropriate social skills factor score and the negative social skills factor score. Consistent with our hypothesis, parents' estimates of their children's social skills were lower as compared to their children's self reports. This difference was seen primarily in the reporting of appropriate social skills, with children's reports higher than their mothers and fathers. No differences were reported among mothers, fathers, and children's reports on the inappropriate factor. However a trend indicated that fathers tended to report more children's negative social skills than mothers. The lack of a significant difference between children and parent reports of inappropriate/negative social skills suggested that children and parents' perception of the children's inappropriate social skills were similar, and that the children had a good understanding of their negative behaviours.

The children in this study clearly understood what appropriate social skills were. However, they reported that they exercised these behaviours more regularly than their parents. This difference could be due to the difference between knowing appropriate social skills and actually using them. While children believed their social skills were appropriate, and that they displayed them, they may not consistently use these skills in effective social performance. This would account for the parental reports that their

children demonstrated less appropriate social skills.

Alternatively, parents may not see their children interacting positively with their peers on a regular basis. Parents are often not aware of their children's social progress as many of these behaviours are exhibited at school or other outside activities. In these cases, often only negative behaviours are brought to the parent's attention. Therefore, parents may not often witness their children's positive social behaviours. Also, when parents are observing their children's social skills, they may judge their behaviours in terms of an 'adult model' of social functioning. In this way they expect their children to behave like little adults, equally socially competent. As this most likely does not occur, parents perceive their children to have less appropriate social skills compared to what they would desire. These factors may result in children's reports of their appropriate social skills being higher than their parents' reports.

These differences in children's and parents' perceptions of children's social skills may lead to possible conflict in the home. If children are being punished for inappropriate behaviour when the child believes he/she was being appropriate this could lead to confusion. In addition, if children are being punished by their parents for not behaving in a socially appropriate manner, the children may respond with an increase in inappropriate behaviour.

The results of this investigation supported previous research studies

(i.e. Schneider & Byrne, 1989) which have found differences between

parental and child descriptions of social competence. Schneider and Byrne,

after indicating that parent ratings of social behaviour did not correspond with child self reports, suggested that parents may lack objectivity when reporting on their children's behaviours. Consistent with the findings in this study it has been generally reported that children's reports of their social competence were higher than parental observations (Adelman et al., 1979). This research contributes to our knowledge of quantitative differences between parents and children's perceptions of children's social skills. This study has identified that children and parents had differing perceptions of social behaviours. Parents and their children perceived inappropriate social skills as being similar, while they appeared to have differing perspectives for appropriate behaviours, with children reporting more appropriate skills than their parents indicated. Future investigations may wish to identify which report sources of children's social skills are correlated with unbiased raters' observations of the children's social behaviours.

In comparing parental reports it was found that mothers and fathers had similar views of their children's social skills. No differences were found on the total MESSY score or the appropriate and inappropriate social skills factors. Previous research had not investigated both mothers' and fathers' perceptions of their children's social skills in the same study. Thus, the results of this study provide us with new information about parental perceptions of their children's social skills. One factor that may have influenced these results is the differing questionnaire return rate for fathers and mothers. While both parents were invited to complete the

questionnaires in every case, only approximately half of the fathers did so, whereas nearly all of the mothers did. This 'self-selection' may have biased the results, with fathers who were more involved with their children choosing to complete the questionnaires. It is possible, that fathers who did not complete the questionnaires were less involved with their children. The fathers who did not complete the questionnaires may have observed their children in fewer social situations; therefore, their perceptions of their children's social skills could be quite different from the mothers' perceptions. This may have resulted in more differences between mothers' and fathers' reports.

Sex Differences

As group differences in social skills were not found, age and sex differences within each of the groups were not investigated. Instead, the groups were pooled into a single sample and age and sex differences in social skills among children ages 8-18 were explored.

Differences between boys and girls in reports of children's social skills were compared. It was found that girls reported having better social skills, with significantly higher scores on the appropriate social skill MESSY factor. No differences were found between boys and girls on the negative social skills factor. This indicates that according to the children's self reports, boys and girls displayed similar amounts of inappropriate behaviours, but girls evidenced more appropriate social skills.

This finding is consistent with results reported by Spence and Liddle (1990). They found that girls reported higher levels of appropriate social

skills and lower levels of inappropriate social skills than boys. In contrast, Matson, Rotatori, et al. (1983) did not find a gender differences for the MESSY total score or the appropriate social skills factor, although gender differences were evident for the total negative social skills factor score. Matson, Rotatori, et al., however, did not indicate in which direction this difference was evidenced.

Sex differences were also investigated according to parental reports. It was found that mothers did not report any differences according to gender on either appropriate or inappropriate social skills. No differences in paternal reports were found between boys and girls in the area of appropriate social skills. However, there were differences between boys and girls on inappropriate social skills. Here boys were reported to have more inappropriate social skills as compared to girls. These findings suggest that mothers perceive boys and girls as having similar negative as well as appropriate social skills. Fathers, on the other hand, appeared to have different opinions of boys' social skills as compared to girls, especially in regard to inappropriate social skills. Specifically fathers reported that boys displayed more inappropriate social skills than girls. This may represent the old adage that boys tend to 'misbehave' more that girls. It may also be that fathers were more likely to be the disciplinarians for their sons and hence paid more attention to their negative behaviours. These results indicated that sex differences must be considered when obtaining both self reports and parental reports of children's social skills. Currently, the MESSY has published norms for the total, appropriate, and inappropriate

factors. It is recommended that this normative sample be divided by gender in order to obtain gender norms as this study supports the fact that sex differences occur in the area of social skills.

Age Differences

The effect of age was not found to be significant in relation to children's social skills according to mothers' and fathers' reports. This suggested that according to parent reports, the social skills of children from 8 to 18 years of age do not differ. If we hypothesize that children's social skills do develop over the age range, the finding that parents did not report any changes suggested that they may not be appropriate to provide information concerning the developmental aspects of children's social skills. An alternative explanation for this result is that parents evaluated their children in relation to age-appropriate norms. Therefore, we would expect children's self-reports to vary with age, but if parents took age appropriate behaviour into consideration when completing the questionnaire we would not expect to see any variation in children's social skills with age.

On child reports a significant age effect was demonstrated. Younger children reported that they had better social skills than their older counterparts. Examination of the two separate factors showed trends for younger children to report both fewer inappropriate social skills and more appropriate social skills. This finding may have reflected younger children abiding by social norms and the 'teenagers' becoming more involved in rebellion and conflicting peer relationships. As parental reports indicated

no differences between age groups, and developmentally one would predict older children to be more socially appropriate, there may be other explanations as to why younger and older children reported differing social skills.

First, younger children may be more susceptible to social desirability factors. They may not have understood that their answers were anonymous. As well, they may have believed that their parents would look at their completed questionnaires. Likewise, younger children would be more likely to be observed by a parent when completing the questionnaire, and hence the child could have felt pressured into 'looking good' and reported more positive behaviours. Second, younger children may not have been aware of the complete range of inappropriate social behaviours. Younger children may still be learning what behaviours are considered to be socially inappropriate. Hence, they may have lower social skills without completely understanding the realm of negative social behaviours. This would lead the younger children to under report their inappropriate social skills as compared to their actual behaviour.

A further explanation may be that although younger children were not as socially competent as older children, they may have over-reported positive social skills. This is the difference between having the social cognitive skills and the ability to translate the cognitions into overt behaviours (the ability to enact the social strategy). Younger children may have indicated that they knew what the appropriate social skills were and believed they act appropriately, but were unable to self-monitor and look for

clues which indicated inappropriate behaviour.

Another reason younger children may have reported better social skills was the means by which they self-reported. Younger children are known for their bluntness as well as viewing things as black or white. This may have resulted in younger children using the extremes on a Likert scale, whereas the older children and parents may have had the tendency to moderate their responses to a greater degree and use the middle points of the scale. This hypothesis was examined through a visual inspection of our data. Younger children were seen to use a greater range on the Likert scale, often using the extremes. Older children's responses were more moderate (a smaller range and less extreme reporting). Thus, this finding supports the idea that the differences seen between age groups in the area of social skills in this study may be due to how children completed questionnaires.

The above findings were consistent with results reported by Matson, Rotatori, et al. (1983). They found age differences on the MESSY, with children aged 10 differing from younger and older peers. Matson, Rotatori, et al., however, did not indicate the direction of the difference. Spence and Liddle (1990) also reported they found that children around the age of 12 reported more negative social skills than younger children. As Spence and Liddle looked at a limited age group of children (grades 3 - 6), they questioned whether the trend for older children to report more negative social skills continued through adolescence. The results of this study indicated that adolescents, in general, tended to report more negative social

behaviours than their younger peers. It still remains unclear whether this difference was indicative of a more negative perception by older children of their social behaviour in relation to younger children, an actual increase in inappropriate social behaviour through adolescence, or an artifact of how children of different ages complete Likert scale questionnaires. Thus, Spence and Liddle's recommendation that age norms be established for the MESSY was supported by the findings of this study.

Factor Analysis

Past research using the MESSY has provided results from factor analyses. In the development of the scale for both children and teacher, Matson, Rotatori, et al. (1983) reported two strong factors for the teacher report form and five factors for the child form. Spence and Liddle (1990) investigated the psychometric properties of the MESSY and conducted the factor analysis of the child report form. They found seven factors slightly different from those reported by Matson, Rotatori, et al. Due to the differing factor structures reported on the child MESSY, a factor analysis was conducted in this study. In addition, the teacher report form had not been analyzed when being used with parents. It was therefore important that such an analysis be conducted.

The present study investigated the factors of the MESSY according to report source. Factor analysis of the MESSY revealed two main factors for each of the child, mother, and father reports. In previous factor analyses of the MESSY child reports, appropriate social skills loaded on one factor, while inappropriate/negative social skills were loaded onto 3 or 4 factors

(Matson, Rotatori, et al., 1983; Spence & Liddle 1990). In this case we did not obtain separate factors for the inappropriate / negative social skills. Instead they combined to fit one factor which consisted of 31 questions and together accounted for 14.5% of the variance (factor 1). The second factor we obtained was similar to the appropriate social skills factor previously reported, and accounted for 11.4% of the variance. Twenty of the 23 questions loading on this factor were included in Matson's original factor structure. Two questions in this analysis changed loadings between the factors found in this study and those designated by Matson and colleagues (1983). These questions were #11 - I slap or hit when I am angry and #41 - I speak too loudly. Both these questions appeared on our appropriate social skills factor, whereas they loaded on the inappropriate social skills by the children in Matson's study.

Both mother and father's reports provided a factor structure very similar to that described by Matson, Rotatori, et al. (1983) for teacher reports. Mother's and father's first factor, inappropriate social skills was nearly identical to that of Matson, Rotatori, et al. Mothers' inappropriate social skills factor was comprised of 38 questions, 34 of which were found on Matson's original factor. In total this factor accounted for 21.0%. Likewise, father's inappropriate social skills factor had 39 questions, 36 of which were found in Matson's original analysis. This factor accounted for 21.2% of total variance. The second factor for both mother and father reports was identified as an appropriate social skills factor. Again, this was consistent with Matson's factor structure. Matson's second factor accounted for 8.25%

of total variance; in this study mother's appropriate social skills factor accounted for 11.0% of the variance and father's appropriate social skills factor accounted for 10.8% of the variance. For mother's appropriate social skills factor, 13 of the 17 questions that loaded onto this factor were repeated from Matson's structure. There were 20 questions that loaded on father's appropriate social skills factor, 17 of which were found on Matson's original factor.

There are 3 questions that were found on Matson's inappropriate social skills factor that were not on our mother's or father's inappropriate social skills factor. These questions were #31 - Shows feelings, #42 - Defends self, and #61 - Talks a lot about problems or worries. These obviously can be interpreted as either positive or negative behaviours depending on the situation and the point of view. Questions 31 and 42 were considered to be appropriate skills by both mothers and fathers in our study, whereas question 61 did not load on either factor.

Differences were also found between the factor analytic structure of mothers' and fathers' reports. As previously indicated, 2 questions (#49 - Likes to be the leader, and 55 - Tries to get others to do what he/she wants) loaded on the appropriate social skills factor for mothers' reports, whereas, for fathers, as well as Matson's factor structure, they were considered inappropriate. In addition one question (#52 - Gets into fights a lot) was considered by mothers, as well as by Matson's original factors, to be an inappropriate social skill; however in father's reports this question loaded on factor 2 (appropriate social skill). These differences suggest that certain

reporting. Fathers indicated that gett in into hights perhaps seeing it as sticking up for your lights, or other hand mothers believed that being a lander what he/she wants' were appropriate social skills them as inappropriate. These findings support the mothers and fathers provide valual a information children and that they often provide slightly a first mothers and fathers had some different concepts and inappropriate social skills entered

In summary, the factor structure as represented those initially describe like control (Matson, Rotatori, et al., 1983). I contine precommended that children's incorriate of combined into one factor, rather control factors for the child reports as 4 control of factors for the child reports as 4 control of factors for the child reports as 4 control of factors for the child reports as 4 control of factors for the child reports as 4 control of factors for the child reports as 4 control of factors for the child reports as 4 control of factors for the factors to give a control of factors to give a control of factors to give a control of factors, the child ports of factors, the child ports of factors, the child ports of factors child and parental reports of factors children and facto

skills were deemed to be somewhat different according to which parent is reporting. Fathers indicated that getting into fights was appropriate, perhaps seeing it as sticking up for your rights, or being 'manly'. On the other hand mothers believed that 'being a leader' and 'getting others to do what he/she wants' were appropriate social skills, whereas, fathers viewed them as inappropriate. These findings support the conclusion that both mothers and fathers provide valuable information concerning their children and that they often provide slightly different perspectives. Also, mothers and fathers had some different conceptions of what appropriate and inappropriate social skills entail.

In summary, the factor structures as reported in this study closely resembled those initially described in the construction of the MESSY (Matson, Rotatori, et al., 1983). Based on the present findings, however, it is recommended that children's inappropriate social skills should be combined into one factor, rather than treating the negative social skills factors for the child reports as 4-6 separate factors as described by Matson and colleagues (1983) and Spence and Liddle (1990). In the present study, as well as past research (Spence & Liddle, 1990), one large factor was obtained by adding the factors to give a negative social skill score. Using only one negative social skills factor would increase the strength of the factor structure and the reliability of the inappropriate factor. In addition, by using only two factors, the child reports would be more similar to the factor structure of the parent reports. This would allow for easier comparison across child and parental reports.

Strengths of Study

Critiques of past research within this field were closely examined and many of their recommendations were implemented in order to strengthen the results of this study. First, only one specific component of social competence was examined, that being social skills. Often results from past studies indicated that children with a chronic illness were at risk for poor adaptation. However, it is difficult to remedy poor adaption if it is not known what specific factors contribute to this increased risk. Therefore by examining one aspect that contributes to social competence, social skills, we can begin to understand specific areas where children with a chronic illness and their siblings may experience deficits. Further, only a single illness group was examined in order to limit the type of chronic illness studies. Using only children with CF allowed the effects of the illness to be kept fairly constant. This allowed for a 'pure' sample of children with an individual illness which simplified results for interpretation. When more than one illness is combined within a study it may be difficult to determine potential effects of the different illnesses. While the results reported in this study may be applicable to children with other chronic diseases, caution should be used in generalizing to these populations, as individual chronic illnesses may have differing effects on the children.

A further strength of this study was the use of multiple reporting sources. In previous research, often only one report source was obtained in order to maximize practicality in research. In this study, up to three reports for each individual child was obtained. This allowed for differing

perceptions of children's social skills to be examined. An understanding of how children, mothers and fathers view social skills was gained. In order to obtain multiple sources reporting on children's social skills a measure was required which could facilitate not only this process but also analyses where reports between children, their mothers and fathers, could be compared.

The use of the questionnaire format also contributed to another strength of this study. This mail out format allowed participants from across western Canada to be recruited for the CF and sibling groups. In this way a larger sample size was obtained which contributed to good power when studying group differences. It also provided a better sample representation of CF families.

Limitations of Study

The current study has a number of limitations. These include using a questionnaire to measure social skills, mailing out the surveys, limited sample sizes, and the effects of social desirability. Using a mail-out questionnaire to obtain a measure of social skills has a number of limitations inherent in this procedure. Particularly in the area of social skills research, the use of a questionnaire to examine social skills is a relatively new practice. While questionnaires are expedient and cost-effective they often provide limited information. Spence and Liddle (1990) indicated the need for self reports of children's social skills to be examined in the presence of information from other sources, including direct behavioral observations and information from significant others. While

parental reports were included in this study, it is necessary in further research to examine the correlations of these reports with direct observation of children's social skills.

Secondly, using a mail out questionnaire allowed the participants to self-select. That is they can choose to participate or not. It is possible that those families in the CF population who did not return the questionnaires had children who were having difficulties in social skills and were reluctant to participate in this study. Also, the response rate from the normal comparison participants was poor. In this case, self selection may have resulted in a biased sample of normal comparison children. First, families who indicated that they were willing to participate may have been more likely to have children without social skills difficulties. Further, these families who took the time to complete the questionnaires may spend more time together and be better adjusted than those who would be found randomly. When the families spend more time together, parents may be more in tune with their children. Therefore, differences between maternal and paternal reports, as well as between children's self reports of social skills may have been minimized. In addition, children that come from well adjusted families may be more likely to report having better social skills. Unfortunately, we do not have any data available on the normal comparison families who did not complete the questionnaires sent to them.

While the CF group was relatively large compared to other studies in this field, the effect size would be larger with more substantial numbers. It was unfortunate that more siblings were not available for participation; however, CF families tended to be smaller in size and obviously some siblings were under 8 years of age and were not included in the study sample.

As previously mentioned, it is possible that social desirability affected the results of this study. Child self reports of their social skills may have been affected to the greatest degree. Children may feel they need to report their skills in a positive light, or respond to the question in what they consider to be the correct way, rather than how they normally act. This effect would have maximized differences between parent and child reports of their social skills. In this case, there may not actually be differences in how parents and children perceive social skills, but the differences found may have been due to social desirability influences on the child self reports. Social desirability may also have affected the finding of age differences in this study. The significant differences between age groups could possibly be accounted for by younger children expressing greater social desirability with their responses of higher social adequacy.

Social desirability may also have been a factor in reducing differences between CF children, their siblings, and the normal comparison group. Children with CF and their siblings, as well as their parents, may have been susceptible to answering in terms of greater social desirability. These families may have felt like they were the subjects of an 'experiment' and therefore wished to minimize any of their problems. If this occurred, any differences existing between the experimental groups (CF and siblings) as compared to the normal comparison group would have been minimized

both in terms of child self reports as well as mother and father's reports.

Implications for Future Research and Clinical Practice

Children with chronic illnesses and their siblings have long been considered to be at increased risk for adjustment difficulties.

Unfortunately, the factors that may contribute to poor psychosocial adaptation have remained unknown. This study supported recent findings that these populations did not significantly differ from normal comparison children in the area of social competence. In particular social skills were found to be similar among children with CF, their siblings, and healthy peers. This suggests that if psychosocial adaptation of children with CF and their siblings is impaired, factors other than social skills may be contributors.

Clinicians need to be aware of the possibility of the psychosocial risks inherent in childhood chronic disease. While social skills did not appear to be particularly affected in children with CF, individuals working with this population must remain in tune with the stressors these families face. If social skills are found to be an area of difficulty for these children, then intervention such as social skills training may be valuable and should be implemented as early as possible. This awareness and intervention by clinicians in the areas influenced by the presence of a chronic illness can help minimize the negative impact on the adaptation for the family as a whole.

The information obtained in this study may be reassuring to parents of children with CF. As a whole, children with CF and their siblings did

not evidence social skill deficits. However, future research should continue to investigate whether the adequate development in social skills in children with CF and their siblings is due to any particular mediating factors. For example, is there a difference between children with CF who are encouraged to participate in social and athletic activities as compared to those who miss school frequently and are limited in their activities? How do family socialization practices as compared to peer influences affect children's social competence? This research could then be extended to children with other types of chronic illnesses.

It will also be necessary to continue evaluating the varying components of social competence. Social skills may not be affected by the presence of a chronic illness but other areas, such as peer relationships and social functioning may be affected. This information would help us to understand not only the impact of dealing with a chronic illness, but would also contribute to our knowledge of psychosocial development in children.

It may be of interest in future research to add a social desirability measure to determine if younger children are indeed more influenced by this factor than older children. The results of this study suggest that age may be of more importance when obtaining child self-reports of social skills and other aspects of their feelings or behaviour.

This study provided initial information on how mothers, fathers, and children differentially perceive children's social skills. This information should be considered as a significant contribution to child research. It also indicated that in clinical research obtaining reports from different sources

may be valuable. Future research should address whether differences seen between children's, mothers', and fathers' reports are limited to the area of social skills or whether they are consistent across all fields of psychosocial adaptation.

Conclusion

The findings from this study did not support the hypothesis that children with CF differ in social skills from their healthy peers. Likewise, the siblings of these children also appeared to display social skills comparable to their peers. It was shown, however, that understanding the dynamics of the disease characteristics of CF helped predict a child's perception of their own social skills. It was found that a lower parental rating of disease severity and a higher rating of degree of care demanded of the family predicted lower child reports of their social skills.

When working with children with a chronic illness we must not operate under the assumption that there will be negative psychological effects for each child. There are many factors in addition to the presense of a chronic illness that may influence a child's psychosocial development. These may include factors such as their family environment, opportunities for peer interaction, personality characteristics, and significant life events (e.g. a death or divorce). Thus, when investigating the psychosocial development of children with a chronic illness we must take into account individual differences within their larger social environment.

Also investigated in this study were differences in how children perceived their social skills as compared to their mothers' and fathers'

perceptions. Using the MESSY, an evaluation of social skills designed for children, it was found that children tended to report higher levels of appropriate social skills as compared to their parents. Age and sex differences in children's social skills were examined. Significant differences between boys and girls, as well as between younger and older children, were found. These differences also varied according to the report source. Girls reported more appropriate social skills than boys. Fathers reported that boys had more negative social behaviours than girls. Overall, younger children reported that they displayed more socially appropriate social skills than the older children (adolescents). These findings support the need to examine children's social skills according to specific gender and age groups. It also indicates the necessity of obtaining multiple report sources when investigating children's social skills. It cannot be determined if any of the possible report sources provide information that would correlate with behavioral observations of social skills; however, this study points to the varying perceptions of each source and the valuable information each may provide.

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APPENDIX A: Letter to Normal Comparison Families

January 1996

Dear Parents:

The principal of the school your child attends has been kind enough to send this to you so that we may invite you to participate in a study that we are conducting through the Alberta Children's Hospital. Since it is the principal who is sending this to you, your privacy is protected since we do not have your name.

Researchers here at Alberta Children's Hospital and the University of Calgary are conducting a study examining the social skills of children with cystic fibrosis and their siblings. Past research has indicated that a chronic illness in the family may affect the psychosocial adaptation of children. No research, however, has examined how a chronic illness may influence the development of social skills.

The researchers are looking for families to be part of the **normal comparison** group to complete questionnaires concerning the social skills of their children.

What would we ask of your family? For the study, each parent will be asked to complete a questionnaire about the social skills of each of their children between the ages of 8 and 18. The children themselves will also be asked to answer some questions about their own social skills.

How much time will it take? Each questionnaire will take about 20 minutes to complete.

Are there any requirements? Normal comparison families who participate in this study must have at least one child between the ages of 8 and 18 years who is still living at home. Families who have a child who as been diagnosed with a chronic illness (e.g. asthma, diabetes) will not be eligible for participation in this study.

If your family is willing to even <u>consider</u> taking part in this study, please complete the enclosed consent form with your address and the number of questionnaires you will require and return the form to you child's school. The researchers will then send you the required number of questionnaires for you and your family to complete. Remember, returning the form is entirely voluntary, and does not obligate you to participate. If you would like any further information concerning this study please do not hesitate to contact either Carrie Oke or Dr. Deborah Dewey at 229-7365.

Thank you for your time and cooperation.

Carrie Oke, B.A.
Clinical Psychology Graduate Student
University of Calgary

Deborah Dewey, Ph.D. Assistant Professor University of Calgary **RESEARCH PROJECT:** Social Skills of Children with Cystic Fibrosis and Their Siblings

INVESTIGATORS: Carrie Oke, B.A., and Deborah Dewey, Ph.D.

University of Calgary and Alberta Children's Hospital

Returning this form does not obligate you to participate in our study, it only indicates interest. Upon receipt of this form we will send you more information about the study including a formal consent form and the required questionnaires. You may then decide whether to participate.

Yes, please send our family the information we require to participate in the above named research project.

| Name | |
|-----------------------------------|---|
| Mailing address | |
| | |
| | |
| Phone number | |
| Number of childre | en in household between the ages of 8 and 18: |
| Number of adults (Please circle): | (i.e. Mom and/or Dad) who will be completing questionnaires |

Thank you in advance for taking the time to help us with this study. Please return this form to your child's school.

APPENDIX B: Matson, Rotatori, et al. (1983) Original Child Factors

Matson, Rotatori, et al. (1983) Child Form MESSY Factors

Factor 1: Appropriate Social Skill, Eigenvalue = 10.59

- 9. I look at people when I talk to them
- 10. I have many friends
- 12. I help a friend who is sad
- 13. I cheer up a friend who is sad
- 16. I feel happy when someone else does well
- 20. I tell people they look nice
- 23. I walk up to people and start a conversation
- 24. I say 'thank you' and am happy when someone does something for me
- 28. I know how to make friends
- 31. I stick up for my friends
- 32. I look at people when they are speaking
- 34. I share what I have with others
- 37. I show my feelings
- 40. I take care of others' property as if it were my own
- 42. I call people by their names
- 43. I ask if I can be of help
- 44. I feel good if I help someone
- 46. I ask questions when talking with others
- 50. I feel sorry when I hurt someone
- 52. I join in games with other children
- 56. I ask others how they are, what they have been doing, etc
- 59. I laugh at other people's jokes and funny stories

Factor 2: Inappropriate Assertiveness, Eigenvalue = 4.23

- 2. I threaten people or act like a bully
- 7. I take or use things that are not mine without permission
- 11. I slap or hit when I am angry
- 14. I give other children dirty looks
- 17. I pick out other children's faults/mistakes
- 19. I break promises
- 21. I lie to get something I want
- 22. I pick on people to make them angry
- 29. I hurt others' felling on purpose (I try to make people sad)
- 30. I make fun of others
- 39. I make sounds that bother others (burping, sniffling)
- 41. I speak too loudly
- 53. I get into fights a lot
- 60. I think that winning is everything
- 61. I hurt others when teasing them
- 62. I want to get even with someone who hurts me

Factor III. Impulsive / Recalcitrant, Eigenvalue = 1.91

- 3. I become angry easily
- 4. I am bossy (tell people what to do instead of asking)
- 5. I gripe or complain often
- 6. I speak (break in) when someone else is speaking
- 35. I am stubborn

Factor IV. Overconfident, Eigenvalue = 1.18

- 8. I brag about myself
- 33. I think I know it all
- 36. I act like I am better than other people
- 57. I stay with others too long (wear out my welcome)
- 58. I explain things more than I need to

Factor V. Jealousy / Withdrawal, Eigenvalue = 1.09

- 15. I feel angry or jealous when someone else does well
- 38. I think people are picking on me when they are not
- 49. I feel lonely
- 54. I am jealous of other people

Miscellaneous Items

- 1. I make other people laugh
- 18. I always want to be first
- 25. I like to be alone
- 26. I am afraid to speak to people
- 27. I keep secrets well
- 45. I try to be better than everyone else
- 51. I like to be the leader

APPENDIX C: Matson, Rotatori, et al. (1983) Original Teacher Factors

Matson, Rotatori, et al. (1983) Teacher Form MESSY Factors

Factor 1: Inappropriate, Assertiveness / Impulsiveness, Eigenvalue = 26.19

- 2. Threatens people or acts like a bully
- 3. Becomes angry easily
- 4. Is bossy (tells people what to do instead of asking)
- 5. Gripes or complains often
- 6. Speaks (breaks in) when someone else is speaking
- 7. Takes or uses things that are not his/hers without permission
- 8. Brags about himself/herself
- 9. Slaps or hits when angry
- 11. Gives other children dirty looks
- 12. Feels angry or jealous when someone else does well
- 13. Picks out other children's faults/mistakes
- 14. Always wants to be first
- 15. Breaks promises
- 16. Lies to get what he/she wants
- 17. Picks on people to make them angry
- 21. Hurts others' feeling on purpose(tries to make people sad)
- 22. Is a sore loser
- 23. Makes fun of others
- 24. Blames own problems on others
- 27. Think he/she knows it all
- 29. Is stubborn
- 30. Acts like he/she is better than others
- 31. Shows feelings
- 32. Thinks people are picking on him/her when they are not
- 36. Brags too much when he/she wins
- 38. Speaks too loudly
- 42. Defends self
- 43. Always thinks something bad is going to happen
- 44. Tries to be better than everyone
- 48. Gets upset when he/she has to wait for things
- 49. Likes to be the leader
- 52. Gets into fights a lot
- 53. Is jealous of other people
- 55. Tries to get others to do what he/she wants
- 57. Stays with others too long (wears out welcome)
- 58. Explains things more than needs to
- 60. Hurts others to get what he/she wants
- 61. Talks a lot about problems of worries
- 62. Thinks that winning is everything
- 63. Hurts others when teasing them
- 64. Wants to get even with someone who hurts him/her

Factor 2: Appropriate Social Skills, Eigenvalue 8.25

- 1. Make other people laugh (tells jokes, funny stories, etc)
- 10. Helps a friend who is hurt
- 18. Walks up to people and starts a conversation
- 19. Says'thank you' and is happy when someone does something for him/her
- 25. Sticks up for friends
- 26. Looks at people when they are speaking
- 28. Smiles at people he/she knows
- 33. Thinks good things are going to happen
- 34. Works well on a team
- 37. Takes care of others' property as if it were his/her own
- 39. Calls people by their names
- 40. Asks if he/she can be of help
- 41. Feels good if he/she helps others
- 45. Asks questions when talking with others
- 50. Joins in games with other children
- 51. Plays by the rules of a game
- 54. Does nice things for others who are nice to him/her
- 56. Asks others how they are, what they have been doing, etc.
- 59. Is friendly to new people he/she meets

Miscellaneous Items

- 20. Is afraid to speak to people
- 46. Feels lonely

APPENDIX D: Study Summary for CF Clinics

October, 1995

Dear Sir or Madam:

Hello, my name is Carrie Oke and I am a graduate student in Clinical Psychology at the University of Calgary. Currently, I am conducting research for my Masters thesis on the topic of Social Skills of Children with Cystic Fibrosis and their Siblings. We have received approval to conduct this study through the Alberta Children's Hospital Cystic Fibrosis Clinic and the Conjoint Medical Research Ethics Board of the University of Calgary and the Calgary Regional Health Authority. We are looking for other clinics that may be interested in participating in this study and Kay Jamieson, the nurse coordinator of the CF clinic at Alberta Children's Hospital suggested we should contact you. For this study we would ask clinics to forward our preliminary information to families that have been seen through your clinic. In this way your families would be ensured anonymity. If they then are interested in participating in the study they could then complete the required forms and return them to us at Alberta Children's Hospital.

In this study a questionnaire will be used to examine the social skills of children with cystic fibrosis, their siblings, as well as a normal control group. Children will be asked to complete a questionnaire about their social skills and parents will complete a questionnaire about the social skills of each of their children. This questionnaire takes about 20 minutes to complete for each person (children complete it according to themselves, parents complete one form for each eligible child). Families who agree to participate will also be asked to complete a general information questionnaire which asks questions about demographic and family variables. To be eligible to participate families must have at least one child with cystic fibrosis between the ages of 8 and 18 who is living at home.

What would we expect from you? We would ask that each CF clinic that is willing to participate identify the number of families it sees with at least one child with cystic fibrosis who is between the ages of 8 and 18. We would then send you the correct number of information packages with pre-paid postage for you to address and send to each of the identified families.

Thank you for your attention. We have enclosed a brief summary of the proposal for your perusal. If you are willing to consider asking the families involved in your clinic to participate in this study, please let us know. We will then send you a copy of the complete research proposal and any further information that you require. If you have any questions please contact either Carrie Oke at (403)283-8689 or Dr. Deborah Dewey at (403)229-7365.

Sincerely,

Carrie Oke, B.A.
Graduate Student
Programme of Clinical Psychology

Deborah Dewey, Ph.D. Assistant Professor University of Calgary

APPENDIX E: Letter to CF Parents

October 1995

Dear Parents:

The Cystic Fibrosis Clinic at the (respective hospital) has been kind enough to mail this to you so that we may invite you to participate in a study that we are conducting though Alberta Children's Hospital. Since it is the clinic who is mailing this to you, your privacy is protected since we do not have your name.

Researchers at Alberta Children's Hospital and the University of Calgary are conducting a study examining the social skills of children with cystic fibrosis and their siblings. Past research has indicated that a chronic illness in the family may affect the psychosocial adaptation of children. No research, however, has examined how a chronic illness may influence the development of social skills.

The researchers are looking for families to be a part of this study who will be willing to complete questionnaires concerning the social skills of their children.

What would we ask of your family? For the study, each parent will be asked to complete a questionnaire related to the social skills of each of their children between the ages of 8 and 18 who are living at home. The children themselves will also be asked to answer some questions about their own social skills.

How much time will it take? Each questionnaire will take about 20 minutes to complete.

If your family is willing to take part in this study, please complete the enclosed consent form, general information questionnaire, and a social skills questionnaire on each of your children. In addition, please ask each of your children to complete the Child Consent Form included so that they are aware of the project and a questionnaire about their social skills. Please return all forms, completed and unused, to the researchers in the self-addressed stamped envelope provided. Remember, participation in this study is entirely voluntary.

Thank you for your time and cooperation.

Carrie Oke, B.A.
Clinical Psychology Graduate Student
University of Calgary

Deborah Dewey, Ph.D. Assistant Professor University of Calgary

APPENDIX F: CF Consent Form

CONSENT FORM

RESEARCH PROJECT: Social Skills of Children with Cystic Fibrosis and Their

Siblings.

INVESTIGATORS: Carrie Oke, B.A., and Deborah Dewey, Ph.D.

University of Calgary and Alberta Children's Hospital

This consent form is only part of the process of informed consent. A copy of this form has been given to you. It should give you the basic idea of what the research project is about and what your taking part will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The main purpose of this project is to investigate the social skills of children with cystic fibrosis, their healthy siblings, and their peers. We will also investigate the differences between parent and child self reports of the child's social skills.

Each child in your family who is between 8 and 18 years of age will be asked to complete a questionnaire about their social skills. Each parent will be asked to complete a questionnaire about the social skills of each of their children. Step-parents are invited to complete the questionnaires. In a single parent family, if the children have regular access to a non-custodial parent, this parent may also wish to complete the questionnaires. However, only one mother and father should complete a questionnaire for each child. Parents completing the forms should be the ones who spends the most time with the child. Responses from only one parent are also encouraged.

For parents, the time to complete these questionnaires will depend on the number of children in your family. For two children it will take approximately 40 minutes of your time. Each parent will be asked to complete one questionnaire concerning each child involved in the study. Each child 8 to 18 years of age will also be asked to complete one questionnaire for themselves. This will take about 20 minutes.

Please encourage your children to ask you for help if they have any difficulty filling out the questionnaire. If your child needs help, please complete your questionnaire first. You may explain to your child how to answers the questions in general. You may also explain any words they do not understand. Please do not coach your child on how to answer individual questions. If your child has difficulty completing the form, or does not wish to complete the questionnaire, please return the blank questionnaires along with any completed forms to the researchers.

We are also asking for your permission to approach your child's doctor in the CF clinic at Alberta Children's Hospital. He/she will be asked to give a rating of the severity of your child's illness.

Your child and family may not personally benefit from taking part in this study. By

serving as participants, you may contribute new information about the social skills of children with cystic fibrosis and their siblings.

All information collected during this study will be completely confidential. Data will be used for research purposes only by the principal investigators. Only these researchers will have access to the data. The results of the research will be reported as group data so that no individual identities will be revealed. Neither your name nor your children's names will be used for publication or publicity purposes. Information obtained from this research will be used for this study only. Information will be kept in a locked filing cabinet and will be destroyed at the end of this project. A summary of the study's results will be mailed to you upon completion of this study.

Your signature of this form indicates that you have understood to your satisfaction the information regarding taking part in this study. You also agree to your taking part as a participant. In no way does this waiver your legal rights. It does not release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardising your child's health care. Your continued participation should be as informed as your initial consent. You should feel free to ask for clarification or new information throughout the project. If you have further questions concerning matters related to this research, please contact Carrie Oke or Dr. Deborah Dewey at (403) 229-7365.

If you have any questions about your child's or your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, The University of Calgary, at 220-7990.

The investigator will, as appropriate, explain to your child the research and his or her involvement, and will seek his or her ongoing cooperation throughout the project.

| (Name of Parent or Legal Guardian) | (Signature of Parent or Legal Guardi | | | | |
|------------------------------------|--------------------------------------|--|--|--|--|
| (Name of Witness) | (Signature of Witness) | | | | |
| (Date) | | | | | |

A copy of this consent form is provided for you. Please keep it for your records and future reference.

APPENDIX G: Child Consent Form

CHILD CONSENT FORM

I have been asked to take part in a study. To do this I will answer some questions, by myself, about what I do when I'm with other people. This will take me about 20 minutes. If I do not understand a question I can ask my parents but I should come up with my own answer. I will try and answer each question as it best describes me. I know that I do not have to take part in this study. This study may not help me but it will help the researchers. I will not receive any reward for answering these questions.

| Child | |
|--------|------|
| Child | |
| Child | |
| | |
| Parent | Date |

A copy of this consent form is provided for you.

APPENDIX H: General Information Questionnaire (CF families)

First we would like to ask you some questions about your family.

| | Sex | Date of Birth | CF has been | ndicate if 1 diagnose |
|---|-------------------------------|--------------------------|---------------------|--------------------------|
| Father | | | | |
| Mother | | | · | |
| Child | | | | |
| Child | | | | |
| Child | | | | |
| Other | | | | |
| 3. If YES, what illness 4. Have any children in reading disability, math 5. If YES, which child | your family been disability)? | identified as having a l | | |
| 6. Have any children in (ie. Attention Deficit H | n your family been | | | |
| 7. If YES, which child | (ren), and type of | problem: | | |
| 8. Has your family or y your child(ren)'s ill | | ved any counselling re | lated to coping Yes | with No |

| development of your o | | | any counselling that may relate to the Yes No |
|------------------------------------|----------------|------------------|---|
| • • | te (optional)_ | | |
| Second we would like | re to ask you | ı some questioi | ns about your child(ren)'s illness. |
| 10. How old was you fibrosis (CF)? | ır child(ren) | when he/she firs | st began to show symptoms of cystic |
| Child's name | | | |
| years | | months | |
| Child's name | | | |
| years | | months | |
| 11. How old was you | r child(ren) v | when he/she firs | t diagnosed as having CF? |
| Child's name | | | |
| years | | months | |
| Child's name | | | |
| years | | months | |
| 12. Has your child(re | n) ever been | hospitalised for | CF?Yes No |
| If YES, approximately year? | | | e hospitalised in the last |
| 13. Since your child(r | | | |
| Child's name | | | |
| a) become worse? | No _ | Yes | Don't know |
| b) stayed the same? | No | Yes _ | Don't knowDon't know |
| c) improved? | _No | Yes | Don't know |
| Child's name | | _ | |
| a) become worse? | No _ | Yes | Don't know |
| b) stayed the same? | No | Yes _ | Don't knowDon't know Don't know |
| c) improved? | No | Yes | Don't know |

| 14. How would you currently rate the severity of your child(ren)'s illness? (Please circle) |
|--|
| Child's name |
| 1 2 3 4 5 Not at all Moderately Extremely severe severe severe |
| Child's name |
| 1 2 3 4 5 Not at all Moderately Extremely severe severe severe |
| 15. How demanding do you find your child(ren)'s care? |
| Child's name |
| Child's name |
| 1 2 3 4 5 Not at all Moderately Extremely demanding demanding |
| 16. Approximately how many hours <u>last week</u> did: |
| a) mother spend doing in-home therapy with your child(ren)?hrs b) father spend doing in-home therapy with your child(ren)?hrs c) did another member of the family (ie. older sibling) spend doing in-home therapy with your child(ren)?hrs |
| 17. Is/Are your child(ren) currently attending school?NoYes |
| If YES, approximately how many days was your child(ren) away from school because of his/her illness over the past |
| Child's name |
| a) monthdays b) yeardays |
| Child's name |
| a) monthdays |

Finally, we have some questions about you, the parents.

| For | Mother: | | | | | |
|------|---------------------------------------|------------------------|-------------------|-------------------------|-------------|----------|
| 18. | What category be | est describes your res | sidence? | | | |
| | Large city | Small city | Town | Rural | | |
| 19. | What is your pres | ent marital status? | | | | |
| | Married | | | | | |
| | Separated | | | | | |
| | Living with s | omeone | h | | | |
| | Never marrie Divorced | d and not living wit | n someone | | | |
| _ | Widowed | | | | | |
| | From the list belowase circle) | w, please indicate th | ne highest level | of education that yo | u complet | ed |
| a) N | No high school | | | | | |
| | Some high school, | didn't graduate | | | | |
| | High school diplon | | | | | |
| | | ary, but no diploma | or degree | | | |
| | | loma (e.g., technica | l diploma) | | | |
| f) (| Iniversity degree | | | | | |
| 21. | What is your occu | ipation? | | | | _ |
| 22. | Have you been dia | agnosed with a chro | nic illness (e.g. | . diabetes, asthma). | Yes N | Ю |
| If Y | ES, please specify | illness and approxi | mate date of di | agnosis: | | |
| | Have you been dia h disability). Y | | ific learning dis | sability (ie. trouble w | vith readin | g, |
| If Y | ES, please specify | type of problem: | | | | |
| | Have you been dia order)? YesNo | • | on difficulties (| Attention Deficit Hy | peractivity | <i>,</i> |
| If Y | ES, please specify | : | | | | |
| | | | | | | |

| For Father: |
|--|
| 25. What category best describes your residence? |
| Large citySmall cityTownRural |
| 26. What is your present marital status? MarriedSeparatedLiving with someoneNever married and not living with someoneDivorcedWidowed |
| 27. From the list below, please indicate the highest level of education that you completed (please circle) |
| a) No high school b) Some high school, didn't graduate c) High school diploma d) Some post-secondary, but no diploma or degree e) Post-secondary diploma (e.g., technical diploma) f) University degree 28. What is your occupation? |
| 29. Have you been diagnosed with a chronic illness (e.g. diabetes, asthma). Yes No |
| If YES, please specify illness and approximate date of diagnosis: |
| 30. Have you been diagnosed with a specific learning disability (ie. trouble with reading, math disability). Yes No |
| If YES, please specify type of problem: |
| 31. Have you been diagnosed with attention difficulties (Attention Deficit Hyperactivity Disorder)? Yes No |
| If VES please specific |

Thank you very much for agreeing to participate in this study and taking time to complete this preliminary questionnaire. Below please provide us with your address if you would like a summary of the findings of this study. Please feel free to add any comments you feel are pertinent:

| NAME & ADDRESS: | | | | |
|-----------------|-------------|--|-------------|--|
| | | | | |
| | | ~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~ | | |
| | | | | |
| | | | | |
| COMMENTS: | | | · | |
| | | | | |
| | | | | |
| | | | | |
| | | | | |

APPENDIX I: Child MESSY

| N | Vame_ | | |
|---|-------|------|------|
| | | | |

Matson Evaluation of Social Skills with Youngsters Child Report Form

Please read the following questions very carefully. Circle the answer that tells us how you act:

circle the 1 if you never do that or it is not true; circle the 5 if it is very true, or you do what the question says a lot; circle the 2, 3, or 4 if it is sort of like how you might act.

If you do not understand a question, ask your Mom or Dad, but try to answer the question by yourself, as it best describes YOU.

| 1. I make other people laugh | not like me l | 2 | sort of like me | 4 | a lot like me 5 |
|--|------------------|---|-----------------|---|--------------------|
| 2. I threaten people or act like a bully | 1 | 2 | 3 | 4 | 5 |
| 3. I become angry easily | 1 | 2 | 3 | 4 | 5 |
| 4. I am bossy (tell people what to do instead of aski | l ing) | 2 | 3 | 4 | 5 |
| 5. I gripe or complain often | 1 | 2 | 3 | 4 | 5 |
| 6. I speak (break in) when someone else is speaking | 1 | 2 | 3 | 4 | 5 |
| 7. I take or use things that are not mine without permission | 1 | 2 | 3 | 4 | 5 |
| 8. I brag about myself | 1 | 2 | 3 | 4 | 5 |
| 9. I look at people when I talk to them | 1 | 2 | 3 | 4 | 5 |
| 10. I have many friends | 1 | 2 | 3 | 4 | 5 |
| 11. I slap or hit when I am angry | 1 | 2 | 3 | 4 | 5 |
| 12. I help a friend who is sad | l | 2 | 3 | 4 | 5 |

| 13. I cheer up a friend who is sad | not like me l | sort 2 | of like me 3 | a lo | t like me 5 |
|---|------------------|-----------|-----------------|------|----------------|
| 14. I give other children dirty looks | 1 | 2 | 3 | 4 | 5 |
| 15. I feel angry or jealous when someone else does well | 1 | 2 | 3 | 4 | 5 |
| 16. I feel happy when someone else does | well 1 | 2 | 3 | 4 | 5 |
| 17. I pick out other children's faults/mista | kes 1 | 2 | 3 | 4 | 5 |
| 18. I always want to be first | 1 | 2 | 3 | 4 | 5 |
| 19. I break promises | I | 2 | 3 | 4 | 5 |
| 20. I tell people they look nice | 1 | 2 | 3 | 4 | 5 |
| 21. I lie to get something I want | 1 | 2 | 3 | 4 | 5 |
| 22. I pick on people to make them angry | 1 | 2 | 3 | 4 | 5 |
| 23. I walk up to people and start a converse | ation 1 | 2 | 3 | 4 | 5 |
| 24. I say 'thank you' and am happy when someone does something for me | 1 | 2 | 3 | 4 | 5 |
| 25. I like to be alone | 1 | 2 | 3 | 4 | 5 |
| 26. I am afraid to speak to people | 1 | 2 | 3 | 4 | 5 |
| 27. I keep secrets well | 1 | 2 | 3 | 4 | 5 |
| 28. I know how to make friends | 1 | 2 | 3 | 4 | 5 |

| | not like me | sort | of like me | a lot li | ke me |
|--|-------------|------|------------|----------|-------|
| 29. I hurt others' felling on purpose (I try to make people sad) | 1 | 2 | 3 | 4 | 5 |
| 30. I make fun of others | 1 | 2 | 3 | 4 | 5 |
| 31. I stick up for my friends | 1 | 2 | 3 | 4 | 5 |
| 32. I look at people when they are speaki | ing 1 | 2 | 3 | 4 | 5 |
| 33. I think I know it all | 1 | 2 | 3 | 4 | 5 |
| 34. I share what I have with others | 1 | 2 | 3 | 4 | 5 |
| 35. I am stubborn | 1 | 2 | 3 | 4 | 5 |
| 36. I act like I am better than other people | 1 | 2 | 3 | 4 | 5 |
| 37. I show my feelings | 1 | 2 | 3 | 4 | 5 |
| 38. I think people are picking on me when they are not | ī | 2 | 3 | 4 | 5 |
| 39. I make sounds that bother others (burping, sniffling) | 1 | 2 | 3 | 4 | 5 |
| 40. I take care of others' property as if it were my own | 1 | 2 | 3 | 4 | 5 |
| 41. I speak too loudly | 1 | 2 | 3 | 4 | 5 |
| 42. I call people by their names | 1 | 2 | 3 | 4 | 5 |
| 43. I ask if I can be of help | 1 | 2 | 3 | 4 | 5 |
| 44. I feel good if I help someone | 1 | 2 | 3 | 4 | 5 |

| | not like me | sort | of like me | a lo | t like me |
|---|-------------|------|------------|------|-----------|
| 45. I try to be better than everyone else | 1 | 2 | 3 | 4 | 5 |
| 46. I ask questions when talking with other | ers I | 2 | 3 | 4 | 5 |
| 47. I see my friends often | 1 | 2 | 3 | 4 | 5 |
| 48. I play alone | 1 | 2 | 3 | 4 | 5 |
| 49. I feel lonely | 1 | 2 | 3 | 4 | 5 |
| 50. I feel sorry when I hurt someone | 1 | 2 | 3 | 4 | 5 |
| 51. I like to be the leader | 1 | 2 | 3 | 4 | 5 |
| 52. I join in games with other children | 1 | 2 | 3 | 4 | 5 |
| 53. I get into fights a lot | 1 | 2 | 3 | 4 | 5 |
| 54. I am jealous of other people | 1 | 2 | 3 | 4 | 5 |
| 55. I do nice things for people who are nice to me | 1 | 2 | 3 | 4 | 5 |
| 56. I ask others how they are, what they have been doing, etc | 1 | 2 | 3 | 4 | 5 |
| 57. I stay with others too long (wear out my welcome) | 1 | 2 | 3 | 4 | 5 |
| 58. I explain things more than I need to | 1 | 2 | 3 | 4 | 5 |
| 59. I laugh at other people's jokes and funny stories | 1 | 2 | 3 | 4 | 5 |

| | not like me | sort | of like me | a lot | like me |
|--|-------------|------|------------|-------|---------|
| 60. I think that winning is everything | 1 | 2 | 3 | 4 | 5 |
| 61. I hurt others when teasing them | 1 | 2 | 3 | 4 | 5 |
| 62. I want to get even with someone who hurts me | 1 | 2 | 3 | 4 | 5 |

APPENDIX J: Parent MESSY

| Parent | |
|-------------------------|--|
| Name of Child concerned | |

Matson Evaluation of Social Skills with Youngsters Parent Report Form

Please answer the following questions as they best describe your child: circle the 1 if the statement does not apply at all to your child; circle the 5 if it very much applies;

circle the 2, 3, or 4 if your child is somewhere in between. Try to answer these questions in terms of how you see your child's behaviour

| Try to answer these questions in terms of | how you se | e your | child's beh | aviou | ır |
|--|------------|--------|-------------|-------|-----------|
| • | not true | sort | of applies | 7 | very true |
| Makes other people laugh (tells jokes, funny stories, etc) | I | 2 | 3 | 4 | 5 |
| 2. Threatens people or acts like a bully | 1 | 2 | 3 | 4 | 5 |
| 3. Becomes angry easily | 1 | 2 | 3 | 4 | 5 |
| 4. Is bossy (tells people what to do instead of asking) | 1 | 2 | 3 | 4 | 5 |
| 5. Gripes or complains often | 1 | 2 | 3 | 4 | 5 |
| Speaks (breaks in) when someone else is speaking | 1 | 2 | 3 | 4 | 5 |
| 7. Takes or uses things that are not his/hers without permission | I | 2 | 3 | 4 | 5 |
| 8. Brags about himself/herself | 1 | 2 | 3 | 4 | 5 |
| 9. Slaps or hits when angry | 1 | 2 | 3 | 4 | 5 |
| 10. Helps a friend who is hurt | 1 | 2 | 3 | 4 | 5 |
| 11. Gives other children dirty looks | 1 | 2 | 3 | 4 | 5 |
| 12. Feels angry or jealous when someone else does well | ī | 2 | 3 | 4 | 5 |

| 13. Picks out other children's faults/mistakes | not true I | 2 | sort of applies | ; 4 | very true 5 |
|--|---------------|---|-----------------|--------|----------------|
| 14. Always wants to be first | 1 | 2 | 3 | 4 | 5 |
| 15. Breaks promises | 1 | 2 | 3 | 4 | 5 |
| 16. Lies to get what he/she wants | 1 | 2 | 3 | 4 | 5 |
| 17. Picks on people to make them angry | 1 | 2 | 3 | 4 | 5 |
| 18. Walks up to people and starts a conversation | 1 | 2 | 3 | 4 | 5 |
| 19. Says'thank you' and is happy when someone does something for him/her | 1 | 2 | 3 | 4 | 5 |
| 20. Is afraid to speak to people | 1 | 2 | 3 | 4 | 5 |
| 21. Hurt others' feeling on purpose (tries to make people sad) | 1 | 2 | 3 | 4 | 5 |
| 22. Is a sore loser | 1 | 2 | 3 | 4 | 5 |
| 23. Makes fun of others | 1 | 2 | 3 | 4 | 5 |
| 24. Blames own problems on others | 1 | 2 | 3 | 4 | 5 |
| 25. Sticks up for friends | 1 | 2 | 3 | 4 | 5 |
| 26. Looks at people when they are speaking | 1 | 2 | 3 | 4 | 5 |
| 27. Think he/she knows it all | 1 | 2 | 3 | 4 | 5 |
| 28. Smiles at people he/she knows | 1 | 2 | 3 | 4 | 5 |

| | not true | sor | t of applies | ver | y true |
|--|----------|-----|--------------|-----|--------|
| 29. Is stubborn | 1 | 2 | 3 | 4 | 5 |
| 30. Acts like he/she is better than others | 1 | 2 | 3 | 4 | 5 |
| 31. Shows feelings | 1 | 2 | 3 | 4 | 5 |
| 32. Thinks people are picking on him/her when they are not | 1 | 2 | 3 | 4 | 5 |
| 33. Thinks good things are going to happen | 1 | 2 | 3 | 4 | 5 |
| 34. Works well on a team | 1 | 2 | 3 | 4 | 5 |
| 35. Make sounds that bother others (burping, sniffling) | I | 2 | 3 | 4 | 5 |
| 36. Brags too much when he/she wins | 1 | 2 | 3 | 4 | 5 |
| 37. Takes care of others' property as if it were his/her own | 1 | 2 | 3 | 4 | 5 |
| 38. Speaks too loudly | 1 | 2 | 3 | 4 | 5 |
| 39. Calls people by their names | 1 | 2 | 3 | 4 | 5 |
| 40. Asks if he/she can be of help | 1 | 2 | 3 | 4 | 5 |
| 41. Feels good if he/she helps others | 1 | 2 | 3 | 4 | 5 |
| 42. Defends self | 1 | 2 | 3 | 4 | 5 |
| 43. Always thinks something bad is going to happen | 1 | 2 | 3 | 4 | 5 |

| | not true | sort | of applies | very | true |
|--|----------|------|------------|------|------|
| 44. Tries to be better than everyone | 1 | 2 | 3 | 4 | 5 |
| 45. Asks questions when talking with others | 1 | 2 | 3 | 4 | 5 |
| 46. Feels lonely | 1 | 2 | 3 | 4 | 5 |
| 47. Feels sorry when he/she hurts others | 1 | 2 | 3 | 4 | 5 |
| 48. Gets upset when he/she has to wait for things | I | 2 | 3 | 4 | 5 |
| 49. Likes to be the leader | 1 | 2 | 3 | 4 | 5 |
| 50. Joins in games with other children | 1 | 2 | 3 | 4 | 5 |
| 51. Plays by the rules of a game | 1 | 2 | 3 | 4 | 5 |
| 52. Gets into fights a lot | 1 | 2 | 3 | 4 | 5 |
| 53. Is jealous of other people | 1 | 2 | 3 | 4 | 5 |
| 54. Does nice things for others who are nice to him/her | 1 | 2 | 3 | 4 | 5 |
| 55. Tries to get others to do what he/she wants | 1 | 2 | 3 | 4 | 5 |
| 56. Asks others how they are, what they have been doing, etc | 1 | 2 | 3 | 4 | 5 |
| 57. Stays with others too long (wears out welcome) | 1 | 2 | 3 | 4 | 5 |
| 58. Explains things more than needs to | 1 | 2 | 3 | 4 | 5 |

| | not true | sor | t of applies | ver | ry true |
|--|----------------|-----|--------------|-----------|----------|
| 59. Is friendly to new people he/she mee | ts 1 | 2 | 3 | 4 | 5 |
| 60. Hurts others to get what he/she wants | s 1 | 2 | 3 | 4 | 5 |
| 61. Talks a lot about problems or worries | s 1 | 2 | 3 | 4 | 5 |
| 62. Thinks that winning is everything | 1 | 2 | 3 | 4 | 5 |
| 63. Hurts others when teasing them | 1 | 2 | 3 | 4 | 5 |
| 64. Wants to get even with someone who hurts him/her | 1 | 2 | 3 | 4 | 5 |
| | No help at all | SO | me help | a lot o | of help |
| 65. How much help did you provide your child in filling out their questionnaire? | | 30. | - | ~ ~ ~ ~ ~ | e |
| Name of child | . 1 2 | 3 | 3 4 | 5 | |

APPENDIX K: Study Summary for Principals

RESEARCH PROJECT: Social Skills of Children with Cystic Fibrosis and their Siblings

INVESTIGATORS: Carrie Oke, B.A., and Deborah Dewey, Ph.D. University of Calgary and Alberta Children's Hospital

The following is a short summary of the above named research project currently being conducted through the Programme of Clinical Psychology at the University of Calgary. It is in partial fulfilment of a Masters thesis. This summary is designed to give you a brief overview of some of the current work in the area of interest, the design of the study, and what you could expect if you agree help the researchers find an appropriate control group. A complete proposal of the project is available upon request.

Pediatric chronic illness is a term used to designate illnesses that can be progressive and fatal, or associated with a relatively normal life span, but are usually accompanied by impaired physical or mental functioning. Unfortunately there are many aspects of the effects of chronic illness on children that are not understood. There is a large amount of literature concentrating on the effects of a pediatric chronic or life-threatening illness on the child's psychosocial adaptation and on the family environment in general. It has been suggested that social adjustment is an area of special vulnerability for children with chronic or life threatening pediatric conditions. Certain aspects of having a chronic illness, such as prolonged absences from school and perceptions and attitudes of peers towards a child with a chronic illness may be detrimental to the development of social skills. Similarly, there may also be conditions associated with chronic illness that positively affect social skills, such as increased involvement with adults. Social skills are an important aspect of overall psychosocial adaptation as these skills are necessary to adapt to a social environment and to build interpersonal relationships. Whether social skills are a particular area of vulnerability for children with a chronic illness has yet to be determined as it is an area of adaptation that has often been excluded from the study of adjustment. This research will use a measurement of social skills in order to determine whether social skills are affected in children with a specific chronic illness, namely cystic fibrosis. The social skills of their siblings will also be examined. Social skills will be measured through a self-report questionnaire completed by the children themselves as well as a questionnaire to be completed by one or both parents concerning the social skills of their children.

There is no risk for any of the participants involved in this study. There is no deception involved in this project. Informed consent will be gained from both parents and children before they are sent the questionnaires. All information collected during this study will be completely confidential. Names will not be

used to identify participants during the analysis of the data. We are interested in group data only. Data will be used for research purposes only by the principal investigators. This data will be used for the purposes of this project only. All data will be stored in a locked filing cabinet with access provided to only the researchers. Upon completion of the study, or after 3 years, all material pertaining to this study will be destroyed. Interested parents will be sent a summary of the study's findings at the conclusion of the project. This summary will also be available to participating schools, if desired.

Subject groups for this study have been recruited through cystic fibrosis clinics across Western Canada. We are asking principals within the Calgary area to help us recruit our <u>normal comparison</u> group. Families participating in this study must have at least one child between the ages of 8 and 18. We also ask that these children are in normal classrooms at school. It is asked that a predetermined number of students at your school, agreed upon between yourself and the researcher, be given a letter to be taken home to his/her parents. Attached to this letter will be an informal consent form which can be returned to the school by families who are interested in participating in the study, and picked up by the researchers. On this form we ask the address of the family and the number of eligible children within the family. From this information the researchers will then send the complete package of questionnaires directly to the family.

APPENDIX L: Consent Form (Normal Comparison Families)

CONSENT FORM

RESEARCH PROJECT: Social Skills of Children with Cystic Fibrosis and Their

Siblings

INVESTIGATORS: Carrie Oke, B.A., and Deborah Dewey, Ph.D.

University of Calgary and Alberta Children's Hospital

This consent form is only part of the process of informed consent. A copy of this form has been given to you. It should give you the basic idea of what the research project is about and what your taking part will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The main purpose of this project is to investigate the social skills of children with cystic fibrosis, their healthy siblings, and their peers. We will also investigate the differences between parent and child self reports of the child's social skills. Your family will be part of our **normal comparison group**.

Each child in your family who is between 8 and 18 years of age will be asked to complete a questionnaire about their social skills. Each parent will be asked to complete a questionnaire about the social skills of each of their children. Step-parents are invited to complete the questionnaires. In a single parent family, if the children have regular access to a non-custodial parent, this parent may also wish to complete the questionnaires. However, only one mother and father should complete a questionnaire for each child. Parents completing the forms should be the ones who spends the most time with the child. Responses from only one parent are also encouraged.

For parents, the time to complete these questionnaires will depend on the number of children in your family. For two children it will take approximately 40 minutes of your time. Each parent will be asked to complete one questionnaire concerning each child involved in the study. Each child 8 to 18 years of age will also be asked to complete one questionnaire for themselves. This will take about 20 minutes.

Please encourage your children to ask you for help if they have any difficulty filling out the questionnaire. If your child needs help, please complete your questionnaire first. You may explain to your child how to answer the questions in general. You may also explain any words they do not understand. Please do not coach your child on how to answer individual questions. If your child has difficulty completing the form, or does not wish to complete the questionnaire, please return the blank questionnaires along with any completed forms to the researchers.

Your child and family may not personally benefit from taking part in this study. By serving as participants, you may contribute new information about the social skills of children with cystic fibrosis and their siblings.

All information collected during this study will be completely confidential. Data will be used for research purposes only by the principal investigators. Only these researchers will have access to the data. The results of the research will be reported as group data so that no individual identities will be revealed. Neither your name nor your children's names will be used for publication or publicity purposes. Information obtained from this research will be used for this study only. Information will be kept in a locked filing cabinet and will be destroyed at the end of this project. A summary of the study's results will be mailed to you upon completion of this study.

Your signature of this form indicates that you have understood to your satisfaction the information regarding taking part in this study. You also agree to your taking part as a participant. In no way does this waiver your legal rights. It does not release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardising your child's health care. Your continued participation should be as informed as your initial consent. You should feel free to ask for clarification or new information throughout the project. If you have further questions concerning matters related to this research, please contact Carrie Oke or Dr. Deborah Dewey at (403) 229-7365.

If you have any questions about your child's or your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, The University of Calgary, at 220-7990.

The investigator will, as appropriate, explain to your child the research and his or her involvement, and will seek his or her ongoing cooperation throughout the project.

| (Name of Parent or Legal Guardian) | (Signature of Parent or Legal Guardian) |
|------------------------------------|---|
| (Name of Witness) | (Signature of Witness) |
| (Date) | |

A copy of this consent form is provided for you. Please keep it for your records and future reference.

APPENDIX M: General Information Questionnaire (Normal Comparison Families)

First we would like to ask you some questions about your family.

| 1. | Please complete the following information about all family members currently | living in | your |
|----|--|-----------|------|
| ho | me. | | |

| | Name | Sex | Date of Bi | rth |
|---|---|---------------------------------|-----------------------------------|-----------|
| Father | | | | |
| Mother | | | | |
| Child | | | | |
| Child | | | | |
| Child | | | | |
| Other | | | | |
| | lren in your family be a, diabetes)? | een diagnosed with a c | hronic illness Yes | No |
| 3. If YES, who, v | • • | roximate date of diagn | | |
| disability, math dis | ability). child(ren), and type | Yes | | g. readin |
| 6. Have any child Deficit Hyperactiv | | en identified with atter Yes | ntional difficulties (ie. A No | ttention |
| 7. If YES, which | child(ren), and type | • | | - |
| levelopment of yo | ur children's social sl | kills? | elling that may relate to Yes | the No |
| ir yes, pies | ise elaborate (optiona | ıl) | | |

Finally, we have some questions about you, the parents.

| For Mother: | |
|--|----|
| 9. What category best describes your residence? | |
| Large citySmall cityTownRural | |
| 10. What is your present marital status? MarriedSeparatedLiving with someoneNever married and not living with someoneDivorcedWidowed | |
| 11. From the list below, please indicate the highest level of education that you completed (please circle) | |
| a) No high school b) Some high school, didn't graduate c) High school diploma d) Some post-secondary, but no diploma or degree e) Post-secondary diploma (e.g., technical diploma) f) University degree | |
| 12. What is your occupation? | |
| 13. Have you been diagnosed with a chronic illness (e.g. diabetes, asthma). Yes N | 0 |
| If YES, please specify illness and approximate date of diagnosis: | |
| 14. Have you been diagnosed with a specific learning disability (ie. trouble with reading, math disability). Yes No | |
| If YES, please specify type of problem: | |
| 15. Have you been diagnosed with attention difficulties (Attention Deficit Hyperactivity Disorder)? Yes | Ιο |
| If YES, please specify: | |

| For | Father: |
|--------------|--|
| 16. | What category best describes your residence? |
| | Large citySmall cityTownRural |
| 17. | What is your present marital status? MarriedSeparatedLiving with someoneNever married and not living with someoneDivorcedWidowed |
| 18. 1 | From the list below, please indicate the highest level of education that you completed (please circle) a) No high school b) Some high school, didn't graduate c) High school diploma d) Some post-secondary, but no diploma or degree |
| | e) Post-secondary diploma (e.g., technical diploma) f) University degree |
| 19. | What is your occupation? |
| 20. F | Fave you been diagnosed with a chronic illness (e.g. diabetes, asthma). Yes No |
| | If YES, please specify illness and approximate date of diagnosis: |
| 21. 1 | Have you been diagnosed with a specific learning disability (ie. trouble with reading, math disability). Yes No |
| | If YES, please specify type of problem: |
| 22. I | Have you been diagnosed with attention difficulties (Attention Deficit Hyperactivity Disorder)? Yes No |
| | If YES, please specify: |
| | |

| Thank you very much for agreeing to participate in this study and taking time to complete this preliminary questionnaire. Below please provide us with the address where we should send the questionnaires and final summary of findings of this study. Please feel free to add any comments you feel are pertinent: | |
|--|--|
| NAME & ADDRESS: | |
| | |
| | |
| COMMENTS: | |
| | |