RELATIONSHIP BETWEEN FAMILY USE OF NORMALIZATION AND PSYCHOSOCIAL ADJUSTMENT IN CHILDREN WITH CHRONIC PHYSICAL DISORDERS

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Relationship between Normalization and Adjustment in Ill Children

Abstract

The purpose of this study was to examine the relationship between a family's use of normalization and the psychosocial adjustment (personal adjustment, role skills, and perceived competence) of children with chronic physical disorders (CPD). Seventy-six mothers and their CPD children participated in the study. Families' use of normalization was related to CPD child's psychosocial adjustment. Specifically, mothers' perceptions that their families and other people viewed their family and CPD child as normal were strongly related to overall [illegible] personal adjustment, better peer relationships, and better productivity in the CPD child, as well as less reported anxiety and depression, less dependence, less withdrawal, and less hostility. However, a family's use of normalization was not related to the CPD child's perception of self-competence in this study.

Résumé

Cette étude a pour but d'examiner le rapport entre l'emploi de la normalisation par une famille et l'adaptation psychosociale (l'adaptation personnelle, les aptitudes de rôle, et la compétence perçue) des enfants atteints d'un problème physique chronique (PPC). L'échantillon comprenait 76 mères et leurs enfants atteints d'un PPC. L'emploi de la normalisation par une famille était relié à l'adaptation psychosociale des enfants atteints d'un PPC. De façon plus précise, les mères qui percevaient que leur famille et que les gens en général considéraient leur famille et leur enfant comme normal étaient celles dont les enfants avaient une bonne adaptation psychosociale, avaient l'impression d'être mieux acceptées par leurs pairs et étaient plus productifs. Les mères de ces enfants considéraient également que leur enfant était moins sensible à l'anxiété et à la dépression, moins dépendant, moins renfermé, et moins hostile. Néanmoins, dans cette étude, l'emploi de la normalisation par une famille n'était pas relié à une meilleure perception de compétence perçue par l'enfant lui-même.

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Literature Review

According to several epidemiological surveys, 10 to 30 percent of children under 18 years of age have a chronic physical disorder (CPD) (Cadman, Boyle, Szatmari, & Offord, 1987; Newacheck & Taylor, 1992; Pless & Nolan, 1991). CPD is defined as a condition of long-term duration, not curable, and/or having some residual features that limit an individual's functional capabilities (Diamond & Jones, 1983).

The majority of CPD children are well adjusted. However, children with CPD are known to have 2.4 times more psychosocial adjustment problems than do physically healthy children (Cadman et al., 1987). The factors differentiating adjusted CPD children and maladjusted CPD children are not yet clear. Disease, child, and family characteristics are factors that have been examined in terms of their impact on a child's psychosocial adjustment.

Disease characteristics, such as type of disease, and child characteristics, such as age, have not been found to have a consistent impact on a child's psychosocial well-being (Pless & Nolan, 1991). However, family factors consistently have been found to be related to child adjustment outcomes. How the family manages the child's condition may have an impact on the child's adjustment Normalization is a management style that has been linked to CPD children's adjustment (Mattson & Gross, 1966). The purpose of this study was to explore the relationship between the family management style of normalization and CPD children's psychosocial adjustment.

Psychosocial Adjustment in CPD Children

Children with chronic physical disorders (CPD) appear to be at risk for psychosocial adjustment problems when compared to children of similar age who do not have a CPD. CPD children have significantly more behavioural, emotional, and social problems (Cadman et al., 1986; Cadman et al., 1987) Behavioural problems, self-concept or self-esteem, personality, functioning, and psychiatric pathology are general areas assessed in the literature.

Child behavioural problems. Child behavioural problems (CBP) are the most commonly used indicators of CPD children's psychosocial adjustment Children with CPD have more CBP than are found in a comparative group of healthy children (Cadman et al., 1987; Wallander, Varni, Babani, Banis, & Wilcox, 1988). However, no particular pattern of CBP are more or less common in CPD children; internalizing (e.g., depressed; schizoid) and externalizing (e.g., delinquent, cruel, aggressive) CBP as determined by Achenbach and Edelbrock's (1983) Child Behaviour Checklist are distributed in the same proportion in both CPD and the well groups of children (Wallander et al , 1988, 1989; Wallander, Feldman, & Varni, 1989).

Self-concept. Self-concept is another freauently used indicator of psychosocial adjustment. Self-concept (also known as self-worth or self-perception) is an individual's own perception of his or her personality, character, inner resources, and emotional tendencies. The majority of studies have found that CPD children have a self-concept that is well within the limits of the norms of the population in all age groups (Gayton, Friedman, Tavormina, & Tucker, 1977; Hurtig & White, 1986; Kashani, Barbero, Wilfley, Morris, & Shepperd, 1988; Simmons et al., 1985; Tavormina, Kastner, Slater, & Watt, 1976) and that within the CPD group a broad range of scores are found, just as within the normal population (Ungerer, Horgan, Chaitow, & Champion, 1988). However, several studies of children with sickle cell anemia concluded that children with this disease had lower self-concept than normal children (Conyard, Krishnamurthy & Dosik, 1980; Kumar, Powars, Allen & Haywood, 1976). In contrast, Lemanek and her colleagues (1986) found the self-concept of their sample of children with sickle cell anemia to be normal. Lemanek's group suggested that maladjustment in children with sickle cell anemia may be more a result of a poor choice of comparison groups which may not accurately reflect the low socioeconomic status of samples of black children with sickle cell anemia.

General functioning. CPD children's general functioning is another aspect of psychosocial adjustment measured. Peer relationships, participation in leisure activities, school attendance and performance, mood, and family activities are commonly used as indicators of functioning. Children with CPD tend to have difficulty in the area of social functioning. Lower social competence (Breitmayer, Gallo, Knafl, & Zoeller, 1992; Wallander et al., 1988), less time in social and other activities (Morgan & Jackson, 1986), fewer friends and fewer family activities (Timko, Stovel, Moos, & Miller, 1992) have been found in CPD children.

Within the CPD population, children who were rated as overall well adjusted had significantly better peer relationships than poorly adjusted children (Grey, Genel, & Tamborlane, 1980). For CPD adolescents, overall high self-concept was associated with better general functioning (e.g., number of friends, number of contacts with friends) as well as plans to continue in school (Ungerer et al., 1988).

One epidemiology study (Pless, Cripps, Davies, & Wadsworth, 1989) explored how childhood CPD affected social functioning in adolescence and into adult life. Of a cohort of all births in Great Britain in one week of March 1946, 467 (10.6%) of the 5362 children had a chronic physical condition. When tested at age 15, both males and females who had a CPD during childhood tended to have lower educational achievement test scores than non ill children. This finding could not be accounted for by school absence. However, the CPD children did finally complete as much schooling as the others in the cohort CPD children from lower socio-economic circumstances were more likely to be unemployed in adulthood than were well children. Adults who had been ill as children and were still ill as adults were significantly less likely to be married. At age 36, social activities were as common for the group that had been ill as for the group that had been well as children. Overall, the prognosis for social functioning for children with chronic disorders was quite good. This longitudinal study provided reliable and valuable information on the impact of CPD on affected individuals.

Personality. Personality has also been explored as a function of childhood adjustment to CPD CPD children were not found to have personality difficulties (e.g., introversion, nonconformity) when compared to other children (Gayton et al., 1977; Steinhausen, 1976; Tavormina et al., 1976).

Psychiatric disorder. Overall, children with physical disabilities are more at risk for psychiatric disturbance (Breslau, 1985). Chronic conditions that affect the brain are associated with greater psychopathology than conditions without brain involvement (Breslau, 1985; Howe, Feinstein, Reiss, Molock, & Berger, 1993; Pless & Nolan, 1991). In the Ontario Child Health Study, children with CPD were found to be between two and three times more at risk of having one or more psychiatric disorders than were healthy children (Cadman et al., 1987).

Researchers have tended to find similar types of diagnoses as more prevalent in CPD children. Anxiety - related disorders were frequent (Breslau, 1985; Spock & Stedman, 1966; Swift, Seidman, & Stein, 1967; Thompson, Hodges, & Hamlett, 1990). Internalizing type disorders were more common than externalizing disorders (Breslau, 1985; Kashani et al., 1988; Thompson et al., 1990). Depression was diagnosed less often according to some authors (Breslau, 1985; Thompson et al , 1990) but more frequently by others (Morgan & Jackson, 1986). Differences in disease populations may account for some of these discrepancies.

In summary, certain aspects of psychosocial adjustment are more problematic for children with CPD than for well children. Behaviour problems and psychiatric disorders are more common in CPD children No significant differences are found in the self-concept and social functioning of CPD children when compared to well children.

Psychosocial Adjustment within the CPD Population

While studies have found differences in psychosocial adjustment when comparing CPD children to physically healthy children, few studies have examined the differences of psychosocial adjustment within the CPD population. Yet there is wide variability of degree of psychosocial adjustment within the CPD population. Twenty percent of CPD children are maladjusted while eighty percent are adjusted (Wallander et al., 1988). What factors differ between the well adjusted CPD children and the twenty percent of CPD children who are poorly adjusted? Rather than focusing on further comparisons between CPD children and physically healthy children, there is a need to understand why the variability exists within the CPD population. It is important to identify the factors that differentiate the well adjusted and poorly adjusted groups of CPD children in order to guide nurses in their assessments and interventions.

Factors Affecting CPD Children's Adjustment

Disease, child, and family characteristics are factors that have been identified as potentially affecting psychosocial adjustment in CPD children. The specific determinants of risk of maladjustment have not yet been identified but are important in order to develop effective health care services for this population (Pless & Nolan, 1991).

Disease factors. Disease factors that have been explored as potentially influencing adjustment include actual diagnosis and severity of disease. Most studies indicate that specific diagnoses are not linked to specific psychosocial outcomes (Pless & Nolan, 1991; Stein & Jessop, 1982). As noted earlier though, disorders with brain involvement do increase the risk of emotional problems (Breslau, 1985; Pless & Nolan, 1991). Most studies have found that the more severe the degree of the chronic disease, the greater the problem of maladjustment (Billings, Moos, Miller, & Gottlieb, 1987; Timko et al, 1992). One study found that children with the least disease severity were more maladjusted (McAnarney, Pless, Satterwhite, & Friedman, 1974) whereas other studies have failed to find a relationship between these two variables (Hurtig, Koepke, & Park, 1989, Wallander et al, 1989). Unstandardized measures of disease severity, small sample sizes, and different measures of psychosocial adjustment could account for the conflicting results. Overall, disease factors do not appear to identify which CPD children will be well adjusted and which will have adjustment problems.

Child factors Child factors such as gender, age, and coping behaviour have also been examined as possible links with psychosocial adjustment. In one large study, 23 year old males with childhood CPD were found to have more psychosocial sequelae (anxiety and depression, need of psychological care, poor education, and unemployment) than were a similar groups of females (Pless, Power, & Peckham, 1993). Older children with CPD have also been found to have higher risk of maladjustment (Band & Weisz, 1990; Grey, Cameron, & Thurber, 1991; Ungerer et al., 1988) In a study of children between 8 and 18 years old with diabetes, the preadolescents were less depressed, less anxious and had fewer adjustment problems than their adolescent counterparts (Grey et al., 1991). Older children tended to use more avoidance type coping (e.g., drinking; staying away from home); avoidance type coping was associated with more psychosocial adjustment problems (Grey et al., 1991). The relationship between coping style and adjustment may primarily be a relationship between coping style and age. However, because in the general population, the older the child, the greater the incidence of emotional problems (Rutter, Tizard, & Whitmore, 1970), the CPD population follows the trend of the general population

Family factors. The family provides the young child with the environment in which he or she will spend the most time and has the single most influence on his or her well-being. Therefore, the relationship of family characteristics and psychosocial adjustment in CPD children also has received attention. Poor family functioning (e.g., communication) (Lewis & Khaw, 1982), environment (e.g , highly conflictual) (Wertlieb, Hauser, & Jacobson, 1986), poor psychological resources (e.g., low cohesion) (Wallander et al., 1989), parental psychological status (e g., depression) (Daniels, Moos, Billings & Miller, 1987), and more life stress for the CPD child (Bedell, Giordani, Amour, Tavormina, & Boll, 1977) have all been related to poor psychosocial adjustment of the CPD child Therefore, family variables have been determined to affect CPD children's psychosocial adjustment.

Another family factor that may influence a child's psychosocial adjustment is how the family manages the child's condition. Overprotection of CPD children has been linked to increased psychosocial adjustment problems (Cappelli, McGrath, MacDonald, Katsanis, & Lascelles, 1989; Mattson & Gross, 1966; Parker, 1983) On the other hand, clinical observations indicated that families who encouraged the CPD child to live as normally as possible often had well adjusted children (Bossert, Holaday, Harkins, & Turner-Henson, 1990; Knafl & Deatrick, 1986; Mattson & Gross, 1966). This style of managing a child's condition is called normalization. Normalization has been found to be a strongly preferred parenting style for many families with a child with a chronic disorder (Darling & Darling, 1982; Knafl & Deatrick, 1986; Scharer & Dixon, 1989). Saylor (1990) theorized that having a CPD often stigmatizes an individual which then affects self-esteem / self-worth. She noted that redefining the condition in order to represent it as normal (i.e., normalizing it) is one way of managing the illness' potential effect on self-esteem.

In one longitudinal study of 35 hemophiliac boys in 22 families, the clinic psychiatrist used in-depth interviews and observations of the boys and their families for a minimum of two years; the boys and their families were interviewed and observed during some clinic visits and daily when a child was hospitalized. The majority of the boys were well adjusted. In all three age groups examined: infancy to school-aged, school-aged, and adolescence, parents who raised their children as normally as possible had well adjusted children, while parents who overprotected their boys had poorly adjusted children (Mattson & Gross, 1966).

In a sample of 65 chronically ill children in 63 families, Knafl and colleagues (1992) found that children whose mothers and fathers both viewed them as "not normal" were children with a significantly lower sense of self worth However, Anderson (1981) observed that parents employing a normalization strategy might be communicating a double-bind message to their children - in effect telling them that they are normal but simultaneously communicating to them that they are not (e.g., by the restrictions imposed on them that are labeled as normal accommodations but are in fact not normal for "normal" children). She wondered what the effect this double-bind message would have on these children - perhaps then questioning the assumption by many authors that use of normalizing tactics is linked to good psychosocial adjustment for the children.

Normalization

Normalization is a continual process by parents of a CPD child of adjusting the environment to provide normal life experiences that will meet the child's evolving social, physical, intellectual, and emotional needs (Bossert et al , 1990). Knafl and Deatrick (1990) developed the term "family management style" to describe how families respond to CPD in a family member. Management refers to active behavioural responses of the family in reaction to the child's condition. Style implies consistency and pattern of response.

In response to a diagnosis of a CPD in the child, the family appraises their situation in order to cope (Knafl & Deatrick, 1990). Their appraisal includes defining the situation and may include such beliefs as: (1) denial or acknowledgment that the diagnosed impairment actually exists; (2) family life is or is not basically normal, (3) the differences to the child and family caused by the condition do or do not affect their relationships with society. A mixture of these elements determines the family's definition of their situation. One family unit may have members with conflicting definitions of their appraisal of the situation for their family (Knafl & Deatrick, 1990).

The family plans goals based on its definition of the situation. The goals help to direct family efforts in managing the child's condition. The family's management behaviours result from their definitions and goals. Together, this describes family management style.

Normalization Compared to Other Family Management Styles

Normalization is one of the common family management styles and has been studied in a variety of populations- particularly with families who have children who are mentally retarded (Birenbaum, 1970); have visible birth defects (Darling, 1979, Roskies, 1972)), polio (Davis, 1963), osteogenesis imperfecta (Deatrick, Knafl, & Walsh, 1988), chronic life-threatening conditions (Krulik, 1980), or have diabetes (Quint, 1969). Other family management styles, such as overprotection and denial, have also been identified.

Overprotection has been extensively studied (Agle, 1975, Cappelli et al., 1988; Parker, 1983). Denial of the presence of CPD in a diagnosed child has similar features as a management style to normalization except that the impairment is totally denied (Knafl & Deatrick, 1986) The Darlings (1982) believed that all families would employ normalization if adequate services were available for their child's needs; otherwise they would use a "crusadership-style" to seek services, an "altruistic style" if involved in parents' groups or a "resignation style" if services could not be obtained.

Davis (1963) noted that families of a child with residual functional disability following polio responded to the child's disability using normalization, disassociation, and "passing'. Normalization was defined as minimizing, rationalizing, and denying the aspects that distinguish the child or cause the child to be viewed as different than "normal" in order to communicate to others that the handicapped person thinks of himself or herself as normal as do others "Disassociation" was the strategy of significant relinquishing of the normal standard; in other words, the child and the family did not expect to be treated as normal by other people. "Passing" meant being able to hide the disability in a way that others were not aware that the child had polio

Normalization was the strategy used most often by these families Although, at some point in time, all families used both disassociation and normalization in response to the child's condition, Davis rated whether families were predominantly normalizers or disassociaters based on several behavioural (i.e., child's peer relationships and participation in activities; degree and type of special treatment of child by parents) and attitudinal (i.e., family's expressed attitudes toward social meaning of handicap; stigma) criteria.

Davis found that certain situational and structural factors influenced whether normalization or disassociation was the predominant strategy used by these lower middle class, Caucasian families. Normalization predominated where the child was moderately disabled by the polio, five to eight years of age at the time of discharge from the initial hospitalization, had a sibling who was less than five years older or younger, and who came from a family where sex roles were fairly flexible and egalitarian. The families who used disassociation were more likely to have a child seriously disabled by the polio, between nine and 12 years old at discharge from hospital, who was an only child or whose sibling was over five years older or younger, and whose family style was traditional in terms of sex roles, mother being a housewife, and the child living in a nuclear family constellation.

More recently, 63 families with a child or children between the ages of seven and 14 with a chronic physical condition were interviewed to explore family management of the condition (Knafl, Gallo, Breitmayer, Zoeller & Ayres, 1992). The children had a variety of diagnoses. Most parents (66% of mothers and 82% of fathers) perceived their child as normal. Some parents viewed their child as a "tragic figure" - with a compromised life as a result of the condition. Other parents saw their child as a "problem child" - a child difficult to parent due to a combination of condition and other problems. Mothers and fathers tended to have concordant views of their child. There was no relationship between the child's diagnosis and the view held by the parents of their child

When parents described their beliefs about their child's condition (both the medical facts and their experience in living with the condition), most perceived the condition as a "manageable condition" which could be accommodated without the child becoming the center of family life One-third of parents described the condition as an "ominous situation" in which the seriousness of the condition and the fear of future complications were predominant worries Five percent of parents believed the condition to be a "hateful restriction" that significantly decreased the quality of the child's or the family's life Approximately one-quarter of couples had discordant beliefs about the child's condition

"Accommodative" parenting emphasized the importance of a normal childhood for the child and encouraged participation in school and extracurricular activities. Parents organized where necessary so these activities could occur This style was espoused by almost three-quarter of parents Parents who used normalization tended to have an accommodative parenting philosophy Some parents described a "restrictive" parenting philosophy where protecting the child from potential harm was of priority. A few parents "minimized" the necessity of making any accommodations due to the child's condition Several parents had a "shifting" parenting philosophy, describing conflicting descriptions of their parenting. One-third of couples did not share the same parenting philosophy

In terms of actual condition management, Knafl and colleagues (1992) found that most parents felt confident in their ability to manage the child's condition and described how condition management had become routine for the family. Thirty-six percent of mothers and 9% of fathers felt managing the condition was difficult and a "burden". In these families, treatment had not become part of the family's routine. One-quarter of the fathers and 4% of mothers described condition management as "not my job".

Overall, when parents viewed the child as normal: they also viewed the condition as manageable; they held an accommodative parenting philosophy; and they viewed the condition management as a routine part of the family's life style. If parents disagreed on whether the child was normal, they tended to disagree on other areas of assessment.

Strategies Used by Parents to Normalize

Families' responses to CPD are shaped by their definition of the meaning of their situation Normality, as defined by the family with a CPD child, usually differs from the social reality of "well" children (Anderson, 1981). Normalization is often more of a philosophical approach rather than a situational reality (Scharer & Dixon, 1989). Parents selectively attend to "normal" and ignore abnormal situations (Anderson, 1981, Deatrick et al., 1988; Robinson, 1993) and expect others to do likewise (Roskies, 1972). Robinson labeled this behaviour as "constructing the story of life as normal" (Robinson, 1993, p.9). However, condition-related restrictions are often imposed on the CPD child.

Families might describe normalization as stating that "everyday life continued on pretty much as usual" (Thorne, 1985, p.287) even though certain difficulties existed. The actual management behaviours of families employing a normalization style vary greatly. The strategies used may change over time, may differ between families, and may be discovered through trial and error (Deatrick et al., 1988). The ability to normalize may be due to a "conscious leap of faith based on firmly held beliefs" (Robinson, 1993, p. 10), to new information (e.g , examples of normality by the CPD child such as attending school), or to an ability to reframe one's focus or perspective (Robinson, 1993). Engaging in "usual" parenting activities was cited by many researchers as a normalization behaviour (Deatrick et al., 1988; Eiser, Eiser, Town, & Tripp, 1991; Mattson, 1972, Mattson & Gross, 1966; Robinson, 1993; Roskies, 1972). Pushing the child to "keep up" with others, pacing activities to deal with a lack of energy, and controlling information helped families to cover up differences between the CPD child and "normal" children. Participating in normal activities by maintaining a routine, allowing the children to experience normal activities without parental protection, filling in if necessary so a child could complete some of an activity, desensitization by making jokes or getting people "used to " visible difference, and making tradeoffs were other strategies used by parents to foster normalization (Robinson, 1993).

Krulik (1980) explored the parenting tactics of mothers of 20 children with life-threatening CPD and used a comparison group of mothers of 20 healthy children. Mothers of CPD children used parenting strategies that were focused on strengthening the resources and coping of the child and on changing the social environment so it compensated for and accepted the child. The medical regimen management, changes in the child's body, and the child's role performance were the areas where behavioural strategies were concentrated. Strategies included (a) preparation of the child and the environment for anticipated changes, (b) participation of the child in decisions and treatment regimens, (c) the family sharing in the treatment regimen - not singling out the child, (d) the social environment sharing in the regimen - not kept secret, and (e) taking control where possible. Krulik identified areas that parents of CPD children shared as strategies to normalize their situation but did not compare them to the parenting in the comparison group.

The goal of this normalization style is to allow the ill child to be integrated into the family rather than to be the central focus of the family (Deatrick et al., 1988). It is aimed at decreasing the child's vulnerability (Holaday, 1984) and stigma (Saylor, 1990) of being different. Maximizing the child's competencies and developing the child's independence and positive self-perception are outcome goals of this style (Holaday, 1984, Robinson, 1993). The child is guided to develop into a functioning member of the family and society (Holaday, 1984). In other words, the goal of the normalization style is to produce well adjusted children.

Families using normalization are usually not actively involved with groups for handicapped children (Birenbaum, 1970; Darling, 1979; Roskies, 1972). In the period after diagnosis, parents may make friends with other parents of handicapped children as they try to find information and resources. However, parents tend to perceive their child as unique -usually as "less affected" than most children with the particular disorder- and therefore, do not identify with these groups (Darling, 1979; Roskies, 1972). Often, once parents have the information and the necessary medical, social, and educational services, the family becomes able to establish a routine and there is less contact (or less social contact) over time with the parents' groups (Darling, 1979).

In summary, normalization is a parenting style employed by many parents in response to their child's CPD. Employing this style does not necessarily mean that the child's life is in fact "normal". The goal of the style is to promote a well adjusted child who can function within the family and society. Presently, there are very little data linking family use of normalization to a better psychosocial adjustment of the CPD child.

Extraneous Variables

When a child becomes ill with a CPD, the family responds in a certain way to adjust to the situation. Certain variables may influence how the family perceives the child's diagnosis or may affect family circumstances as well as possibly affecting the child's psychosocial adjustment. The age of the child, the time since diagnosis, information and resources available, the nature of the condition, and cultural factors are variables that have been related to the use of normalization.

Child's age. The age of the CPD child may affect the family's ability to use normalization. With increasing age, normalization becomes more difficult (Birenbaum, 1970; Darling, 1979; Davis, 1963; Knafl & Deatrick, 1986; Roskies, 1972) Adolescence tends to be a time where conformity to peer group standards is important and therefore ill adolescents may be less accepted by their peers. At the same time, the ill teens themselves may be more aware of their condition and its impact.

Time since diagnosis. Time since diagnosis often affects the family's ability to normalize. After diagnosis, some time may be needed before the family is familiar enough with the child (if the diagnosis occurs at birth or in infancy), the condition, and available resources to be able to normalize the family routine (Darling, 1979; Roskies, 1972). It usually takes approximately one year from the time of diagnosis for the family to regain a sense of organization in the family and of positive emotions (Venters, 1981).

Information and knowledge. Availability of information about the condition and knowledge level allow parents to normalize the child's medical treatment routine (Darling, 1979; Knafl et al., 1992; Voysey, 1972; Voysey, 1975). Knowledge about the condition provides parents with a sense of competence which then permits the parents greater ability to control situations and develop a sense of routine (Voysey, 1972). Availability of services - educational and treatment programs (Darling, 1979; Darling & Darling, 1982; Roskies, 1972; Voysey, 1972; Voysey, 1975) has also been associated with ability to use normalization although too much use of special services may accentuate for the parents that they are the parents of a "special" child at the expense of having an identity in normal world (Birenbaum, 1970). Knowledge about the condition and availability of services may be related to time since diagnosis because a family may have had the opportunity and personal experiences to learn about the condition and services over time.

Nature of child's condition. The nature of the child's condition may also affect the family's ability to normalize (Davis, 1963; Knafl & Deatrick, 1986). Although the actual diagnosis may not be important (Knafl et al , 1992), most researchers have found that the severity may affect the family's ability to normalize. Severity affects the family's ability to see progress over time - less likely with a more severe condition (Darling, 1979; Roskies, 1972). The nature of the child's condition is also important because less resources are available for children with more severe or rarer conditions (Darling, 1979).

Visibility of the condition may also affect a family's ability to normalize Less visible conditions may allow the child and family to "pass" as normal in more situations than those conditions that are readily apparent to all who meet the child. Less visible conditions may facilitate the family's task of conveying the desired impression (Voysey, 1972).

Cultural factors. Cultural factors may also affect whether or not a family uses normalization (Knafl & Deatrick, 1990). The impact of a child's CPD on a family is partly influenced by the family's cultural background. In one study, Euro-Canadian families perceived CPD as affecting only particular aspects of the child's life, while the child as a whole was perceived as normal. Chinese families who had immigrated to Canada, frequently described CPD as having widespread damaging effects on the child's present and future life (Elfert, Anderson, & Lai, 1991). Both cultural differences and the event of immigration could have influenced the Chinese-Canadians' view of their ill children. Another study also portrayed the effect that cultural beliefs and values can have on family management style While Euro-Canadian mothers with a child with thalidomide tended to use normalization regardless of the severity of the physical abnormalities, Greek-Canadian mothers were unable to perceive their affected children as normal even when the abnormality was minor (Roskies, 1972).

Conceptual Framework

The conceptual model guiding this study includes family management style (FMS) (Knafl & Deatrick, 1990) and links the FMS of normalization (Knafl & Deatrick, 1986) to psychosocial adjustment of the child (see Figure 1). FMS is a conceptual model describing the factors related to family response to CPD. In response to CPD in the child, the family appraises their situation. Their appraisal includes (1) denial or acknowledgment that the diagnosed impairment actually

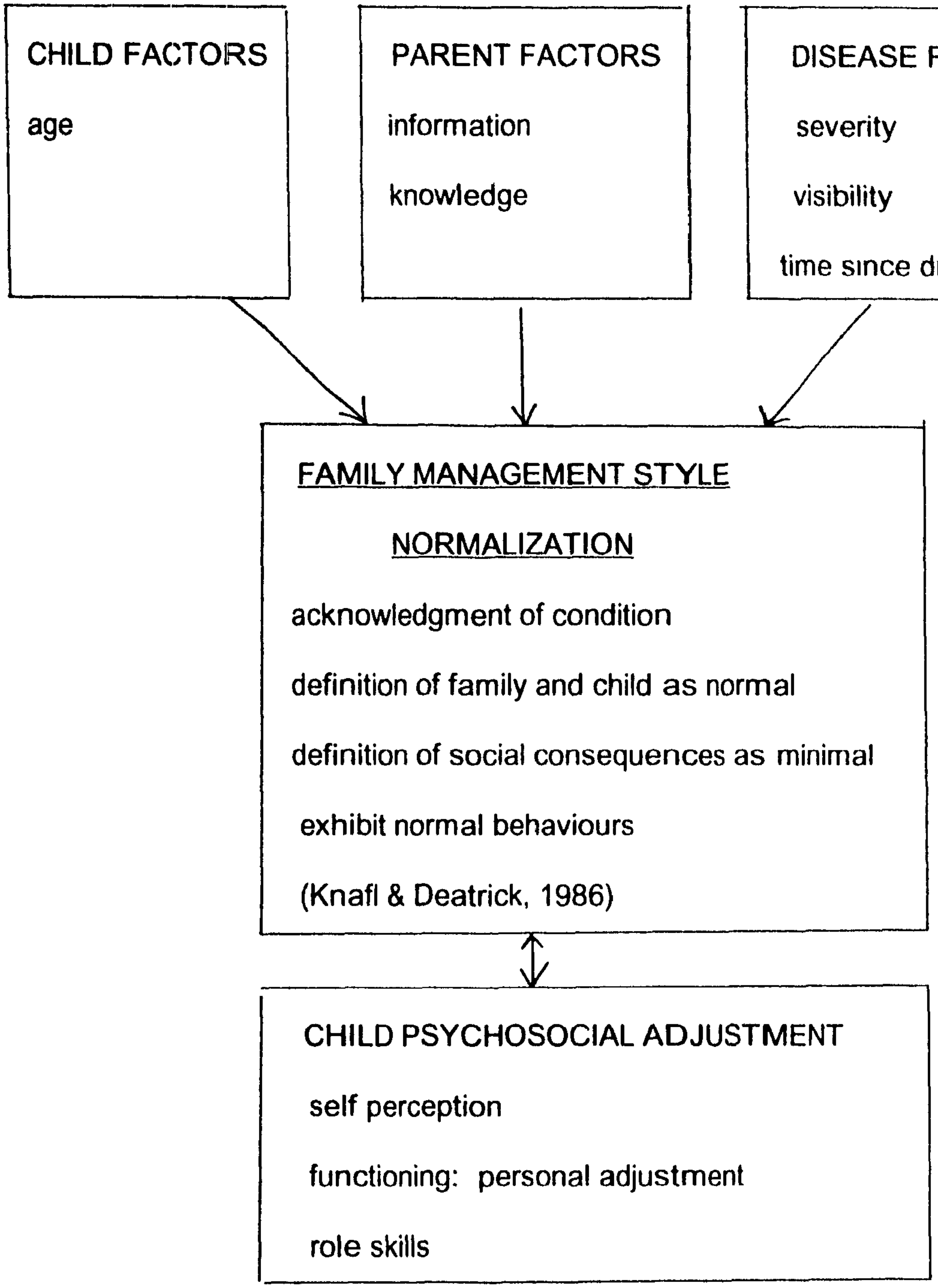

Figure 1 . Conceptual Framework Linking the Family Management Style of Normalization to Child Psychosocial Adjustment.

exists; (2) belief that family life is or is not basically normal; (3) perception that the child's differences do or do not affect their relationships with society. A mixture of these elements determines the family's definition. The family plan goals based on their definition of the situation. The goals help to direct family efforts in managing the child's condition. The family's management behaviours result from their definitions and goals and demonstrate their definition of their situation to others. Together, the appraisal, definition, goals, and behaviours describe FMS (Knafl & Deatrick, 1990). The goal of normalization as a FMS is to increase child competence and self-esteem (Holaday, 1984).

Age of the child, time since diagnosis, information and resources available, nature of the chronic condition, and sociocultural context are variables that may affect a family's definition of the situation. Because the family's definition affects how the family behaves, these factors may affect FMS. Lastly, FMS has been linked to psychosocial adjustment in the child (Cappelli et al, 1989; Knafl et al, 1992; Mattson & Gross, 1966). According to the conceptual framework, if the family uses normalization, the CPD child should demonstrate high psychosocial adjustment.

Summary and Research Question

Although most CPD children do adapt in a healthy manner, a significant proportion are maladjusted. Recently, researchers have gone beyond simply examining differences in psychosocial adjustment between CPD and well children. They have begun to examine the factors within the child and family that account for the variability of psychosocial adjustment among the CPD population. How a family manages a child's CPD is one factor that may account for this variability If a family views themselves and the child as normal, this may affect how the child adjusts. However, presently there is little evidence linking family use of normalization to good psychosocial adjustment in the CPD child.

Therefore, this research addressed the following question:

(1) What is the relationship between a family's use of normalization and the CPD child's psychosocial adjustment?

Methods

Purpose, Design and Hypotheses

The purpose of this study was to examine the relationship between a family's use of normalization and the CPD child's psychosocial adjustment. A correlational design was used to test the following hypotheses:

(1) Families who use high levels of normalization will have CPD children with high personal adjustment and role skills.

(2) Families who use high levels of normalization will have CPD children with a high sense of self-competence.

Sample

The sample was a non-probability sample consisting of 76 mothers and their CPD children. Because disease characteristics, such as type of disease, have not been found to have a consistent impact on a child's psychosocial well-being (Pless & Nolan, 1991), the sample included children with a range of medical diagnoses. The sample was recruited from the diabetic, rheumatology, gastroenterology, nephrology, urology, and cystic fibrosis clinics at a large metropolitan pediatric hospital.

All families who met the inclusion criteria and who attended their scheduled clinic visits during the seven week data collection period, were invited to participate in the study. Inclusion criteria were: (a) The child was between eight and twelve years old. This age group was selected because it is the age at which normalization is most likely to occur (Birenbaum, 1970; Darling, 1979; Davis, 1963; Knafl & Deatrick, 1986; Roskies, 1972). (b) The child had a non-visible (e.g., not cleft lip) CPD because visibility may affect the ability of the family to normalize (Voysey, 1972). (c) The child's CPD required active management by family members to minimize symptoms or consequences. The child had to be receiving some daily medical treatment (e.g., medication, diet, or physiotherapy). (d) The child's CPD had been diagnosed for at least one year. The first year after diagnosis of CPD in a child is a period of disorganization and many negative emotions for most families (Venters, 1981). By the end of the first year, most families perceive that negative emotions no longer predominate and that some degree of organization has been reestablished; families will have had an opportunity to become more informed about the condition and available resources (e) The family was either a single or two parent family. (f) The mother and child could speak and read English or French (g) If more than one child between the ages of eight and twelve in a family had a CPD, the child who was first diagnosed was recruited for the study. (h) The family lived within a 100 km radius of Montreal.

A child was excluded from the sample if he/she had been diagnosed with mental retardation or epilepsy. Chronic conditions that affect the brain are associated with greater psychopathology than conditions without brain involvement (Breslau, 1985, Pless & Nolan, 1991), therefore, this potential intervening variable was controlled. This criterion was assessed by the clinic nurse or by chart review.

Before each clinic visit, mothers and children meeting the inclusion and exclusion criteria for sample selection were identified by the clinic nurse. (In one clinic without a clinic nurse, the use of the child's clinic chart was used). Initially, 10 subjects were recruited for the pilot testing of the Normalization Scale. Subsequently, of 102 eligible families, 101 families agreed to learn more about the study. Eighty one of the 101 families consented to participate. Of the 81, 76 completed the questionnaires (five mothers initially agreed to participate but then changed their minds prior to the home visit). The other 21 eligible families who refused to participate, did so for the following reasons: husband terminally ill (1 mother); too busy (2 mothers), child refused (5 children); not interested (13 mothers).

A sample size of 84 was indicated in order to assure a power of .80 for detecting a moderate effect size at the 05 level of confidence for a correlational study (Cohen, 1992). However, preliminary analysis conducted after 76 mothers and children completed the research project, showed significant results; therefore, no further recruitment was carried out. The final sample, therefore, consisted of 76 mother - child dyads

Sample characteristics. Table 1 summarizes the major characteristics of the families who participated in the study Parents had, on average, a CEGEP (college) education. The majority of the sample were two parent families. More than one third of mothers were housewives and more than one third of families

Table 1

Family Characteristics

	Mean	SD	Range
Age			
mother	39 years	5.8	24-65 years
father	42 years	6.2	31-70 years
Education			
mother	13 years	2.6	6-19 years
father	13 years	3.9	4-20 years
Years Together	14 years	6.7	0-28 years
	n	%	
Marital Status			
married	63	83	
not married	13	17	
Mother's Work			
outside home	48	63	
housewife	28	37	
Language at Home			
French	40	52	
English	22	29	
both	9	12	
other	5	7	
Life Events			
yes	27	36	
no	49	64	

Table 2

Child Characteristics

	Mean	SD	Range
Age	10.4 yrs	17.7 mo	8-12 yrs
Grade	4	1.6	1-7
No of Siblings	1.3	1	0-5
Severity of CPD	68	23	2-100

	n	%
Gender		
male	40	53
female	36	47
Birth Order		
first	38	50
second	27	36
third	7	9
Sibling has CPD	14	18

Note: severity of CPD = higher scores indicate lower perceived severity

Table 2 continues

Table 2 continued

	n	%
Type of Condition		
diabetes	33	43
cystic fibrosis	17	22
renal / urological	11	15
arthritis	9	12
gastrointestinal	6	8
Time since Diagnosis		
12-23 months	14	18
2 -5 years	22	29
over 5 years	40	53
Concurrent Illness		
yes	14	18
no	62	82

described that their families were undergoing "significant life events" (e.g., recent change in family composition; move; etc.).

Children were, on average, 10.4 years old and in grade four (Table 2). Fifty three percent of the CPD children were male. The majority of the CPD children were firstborns and had one sibling. Eighteen percent of the CPD children had siblings with a CPD and four of these siblings had the same illness as the CPD child. Most of the children had been diagnosed for over five years. When mothers were asked to compare the severity of their child's CPD to that of other children with the same condition, the majority of mothers rated their child's CPD as of the same severity as that of other children.

Constructs and Measures

For the purpose of this study, child psychosocial adjustment was measured in terms of self-concept and general functioning. Self-concept was measured using the Self-Perception Profile for Children (Harter, 1985). Behavioural attributes of the child's roles and general functioning were measured by the Personal Adjustment and Role Skills Scale (PARS 111) (Stein & Jessop, 1990; Walker et al., 1990).

Normalization was measured with the Normalization Scale (Murphy & Gottlieb, 1992), a scale developed specifically for this study. Demographic variables and information about extraneous variables were also obtained using a questionnaire.

Self-Perception Profile for Children. (The Harter) (Harter, 1985) The Harter is a questionnaire completed by the child devised to tap children's domain-specific judgments of their competence and adequacy, as well as their global perception of their self-esteem (Appendix A). This 36 item scale is divided evenly among six domains of self-concept: Scholastic Competence (e.g., "Some kids often forget what they learn but other kids can remember things easily."), Athletic Competence (e.g., "Some kids do very well at all kinds of sports but others don't feel that they are very good when it comes to sports."), Social Acceptance (e.g., "Some kids find it hard to make friends but for other kids it's pretty easy."), Physical Appearance (e.g., "Some kids are happy with the way they look but other kids are not happy with the way they look."), Behavioural Conduct (e.g., "Some kids usually do the right thing but other kids often don't do the right thing"), and General Self-Worth (e.g , "Some kids like the kind of person they are but other kids often wish they were someone else").

The format uses a structure alternative approach. This approach offsets the tendency toward socially desirable responses. For each item, the child was asked to choose which of two opposite statements best described him/herself and then, to rate on a four point scale whether the chosen statement was "really true for me" or "sort of true for me". Each item was scored from 1 to 4, 1 indicated least adequate self-judgement and 4 indicated most adequate self-judgement. Scores were summed for each subscale and then averaged to provide six separate mean subscale scores. The scale took approximately twenty minutes to complete.

Validity and reliability. The Harter has undergone extensive psychometric testing. Construct validity has been tested using several samples of third to eighth grade children (n = 1543) (Harter, 1985). General self-worth was not assumed to be an aggregate of the five other domains and factor analysis confirmed that the six subscales were distinct constructs.

Discriminant validity was established in the original scale in the cognitive domain when a study showed that learning disabled children rated their cognitive competence lower than normal peers (Harter, 1982). In a school valuing athletic achievement, children on sports teams rated their physical and social competence higher than non-athletic children (Harter, 1982).

Convergent validity was established in three domains. Students' cognitive subscale scores were moderately correlated (r (744) > .40) with teacher ratings and with achievement test results. The child's social subscale score was correlated with a sociometric standing scale (r (83) = .59). The gym teachers' ratings were correlated with the physical subscale scores (r (207) = .62).

Internal consistency for the six subscales, using Cronbach's alpha coefficient, ranged between .71 and .86 (Harter, 1985). Test-retest reliability over three month and nine month periods (n = 208 & 810 respectively) using two samples found correlations of at least .69 for each sample on all subscales of the original scale (Harter, 1982).

Personal Adjustment and Role Skills Scale: PARS 111. (Stein & Jessop, 1990; Walker et al., 1990). The PARS 111 scale was used to assess behavioural attributes of the child's roles and general functioning of the CPD children (Appendix B). The PARS 111 was shortened from Ellsworth's (1978) 55 item scale to 28 items by Stein and colleagues. This instrument measures psychosocial functioning in children with chronic physical conditions with no cognitive impairment. In PARS 111, 28 items measure psychosocial functioning in six areas: (1) Peer Relations (4 items, e.g., spent time with friends), (2) Dependency (4 items, e.g., been unable to decide things for self), (3) Hostility (6 items, e.g., told lies), (4) Productivity (4 items, e.g , made full use of abilities), (5) Anxiety - Depression (6 items, e.g , seemed sad), and (6) Withdrawal (4 items, e.g., sat and stared without doing anything).

Mothers rated each item on a four-point interval scale ranging from never (1) to always (4). Theoretical scores ranged from 4 to 16 on the four-item subscales (peer relations, dependency, productivity, withdrawal) , 6 to 24 on the six-item subscales (anxiety/depression, hostility) , and 28 to 112 for the total score. Subscale scores were derived by summing the items. Higher scores indicated higher functioning; therefore, a higher score would indicate higher peer relationships and productivity but lower dependency, hostility, anxiety - depression, or withdrawal. The instrument was completed in less than 10 minutes.

Validity and reliability. The PARS 111 was tested in four different studies with a total sample of 450 CPD children between the ages of 5 and 18 years with no cognitive impairment (Walker et al., 1990). The samples from the four studies were compared and found to be similar. The data were pooled.

Across all age groups, girls had slightly higher scores on total score and on the subscales of peer relations, dependency, hostility, and productivity than boys. Boys scored higher on the subscales of anxiety - depression and withdrawal than girls.

Validity was established by generating the PARS 111 from the PARS 11 which had been able to differentiate between a sample of 147 children referred for mental health services and 115 non-referred children. Based on clinical judgement, the pediatrician-researchers selected 28 items from the 55 original items. Factor analysis then confirmed that the items factored in the a priori six factors of PARS 11. Construct validity was supported by using factor analysis on the sample from the four studies Using varimax rotation, 16.7% of the variance was explained and the six factors were the same as in PARS 11. All the factor loadings were above 0.50 and the majority were above 0.70.

Concurrent validity was supported by comparing three studies using the PARS 111 total and subscores to Achenbach and Edelbrock's (1983) CBCL scores and with the Health Resources Inventory (Gesten, 1976) which measures school-related personal and social competencies in primary school children. With a sample of healthy children and two samples of CPD children high correlations were found between PARS 111 total scores and the CBCL scores (0 74,0.80, 0.80 respectively) and between the PARS 111 total scores and the Health Resources Inventory scores (0.76, 0.79, 0.80). The same pattern of results was found for the subscales.

The total sample internal consistency (using coefficient alpha) was .88. Reliability estimates for subscale scores ranged between .70 to .80 (Walker et al., 1990). Test- retest reliability has not been reported

Normalization

The concept of normalization was assessed by the Normalization Scale. This scale was developed for this study.

Normalization scale. (Murphy & Gottlieb, 1992). Items for the Normalization Scale were derived primarily from the work on normalization of Knafl and Deatrick (Deatrick & Knafl, 1990, Deatrick et al, 1988, Knafl & Deatrick, 1986, 1990; Knafl et al., 1992). A study of Knafl and colleagues (1992) interviewing 63 families with a child with a CPD provided many of the items as did the researcher's review of the literature. Knafl and Deatrick, through the use of concept analysis, identified four domains of normalization, namely: (1) acknowledgement of the existence of the impairment - parents confirm that their child does have a physical chronic condition (1 item was developed for the scale), (2) definition of family life as normal - parents perceive and define their child and their family as similar to other families without a CPD child; the child's medical treatment is integrated into family life; the child and the CPD are not the central focus of the family (9 items), (3) definition of the social consequences of their situation as minimal - parents perceive that other people validate their definition of their child's and their family's basic normality; and other people treat their family like a normal family and their child like a normal child (12 items); and (4) engaging in behaviours to demonstrate the family's normality - family behaviours and activities are carried out that illustrate to other people that their family behaves and is like other families who do not have a CPD child (7 items).

A visual analog format was used to rate each item of the scale. The visual analog scale (VAS) was selected as the rating method because it has been found to be potentially very sensitive (Mayer in DeVellis, 1991) and has been used to measure subjective experiences (Polit & Hungler, 1991). The VAS format has also been found to reduce bias (Ramsay, 1973).

Mothers were asked to slash a 10 cm line between two extremes labeled A LOT and A LITTLE. For the purpose of scoring, the distance in centimeters along the line where the line was slashed was taken as the score on the item, giving a theoretical range from 0 to 10. Distances were rounded to the nearest centimeter. Higher scores indicated greater use of normalization. The questionnaire took 10 minutes to complete.

During scale development, ten experts including nurses with clinical and research experience and three mothers of CPD children reviewed the initial list of items for clarity and exhaustiveness. Further testing was conducted with ten mothers (five English and five French) attending the diabetic clinic with their children. Consenting mothers were told that the purpose of their participation was to learn whether the questionnaire actually measured how the family managed chronic conditions. All the mothers asked to participate in the pilot testing consented and they filled out the Normalization Scale in clinic. After completing the questionnaire, mothers were asked to comment on the clarity of each item by stating what they thought the item meant. None of the mothers described any difficulty answering the items but three mothers stated that several items were similar in content (e.g., that an item asking how much they saw their family to be like other families and another asking how much other people saw their family to be like other families were perceived as repetitive).

Given the high population of Francophones in the hospital population, a French version of the questionnaire was needed (Appendix C) The original scale was constructed in English (Appendix D). The backward-forward method of translation was used to translate the scale into French, that is, one translator translated the scale items into French and then a second translator translated the French items back into English. The two versions were then compared. One question ("How much leeway in terms of your child's behaviour do you permit your child because of his/her condition?) was deleted from the final analysis because the meaning of the question was different in English and French Because this is a new scale, psychometric properties, namely, construct validity and internal consistency, will be reported in the results section.

Demographic and Extraneous Variables

Descriptive socio-demographic information was collected (e. g., age, gender, birth order, grade level, socioeconomic status, and family composition) (Appendix E). Information specific to the child's illness (e.g., "What is your child's diagnosis?") was also collected (Appendix E).

Perceived severity of condition. Severity of the child's condition was measured by asking the mother to slash a visual analog line to rate her perception of the severity of her child's condition compared to other children with the same condition. Many studies have shown that the greater the severity of the CPD, the greater the problem of maladjustment (Billings et al , 1987; Timko et al., 1992). Two further questions were asked about the effect of the child's condition on school attendance and on activity participation (Appendix E).

Other extraneous variables Since parental knowledge about the condition has been shown to be related to a family's use of normalization (Darling, 1979; Knafl et al., 1992; Voysey, 1972; Voysey, 1975) and major life events may affect a child's psychosocial adjustment (Bedell et al., 1977), information on these variables was also measured. Parental perception of knowledge about their child's health condition and major recent life events or changes of family members were measured using a visual analog line (Appendix E)

Procedure

After receiving scientific and ethical approval from the McGill University School of Nursing Scientific and Ethical Committee, the research proposal was submitted to the hospital's Institutional Review Board and was accepted as meeting scientific and ethical standards. Specialty clinic directors were then asked by the researcher for permission to recruit subjects during clinic visits

Prior to each clinic, the nurse identified (based on inclusion and exclusion criteria) all eligible families expected that day. During the clinic hours, the nurse, nursing assistant, or secretary identified each potential family for the researcher The researcher then introduced herself to the family and asked permission to explain the study. If the mother and child were interested, they were then told that the researcher was a nurse who had worked at the hospital and was now a Master's student interested in learning more about how families manage chronic conditions in their child and how children behave and develop (Appendix G) Eligibility was reconfirmed. If mothers expressed interest, they were informed that the study involved filling out three questionnaires. They were told that the study would take about thirty minutes. Children were informed that their questionnaire would take 10 to 20 minutes to fill out and could probably be completed before their visit with the doctor if they so wished. Written consent was obtained from both mother and child at the clinic visit (Appendix F)

Fifty mothers answered the questionnaires during a home visit. Twenty six mothers asked to complete the questionnaires in clinic while waiting for their appointments and permission was granted. All but six children completed their questionnaires while in clinic. In both settings, mothers were requested to complete the PARS 111, the Normalization Scale, and a demographic sheet in that order.

Results

The purpose of the study was to examine the relationship between a family's use of normalization and the CPD child's psychosocial adjustment Before presenting the analysis of the relationship between a family's use of normalization and the CPD child's psychosocial adjustment, the psychometric properties of the 25 item Normalization Scale will be described

Psychometric Properties of the Normalization Scale

The psychometric properties of construct validity and internal consistency of the Normalization Scale were examined To assess the scale's construct validity, principal components analysis (PCA) was done on the original 28 items to examine to what extent the theoretical domains of normalization as determined by Knafl and Deatrick (1986), and which guided the generation of the original set of items, corresponded to the statistical factors determined by PCA Internal consistency of the scale was assessed using Cronbach's alpha

Construct validity PCA with varimax rotation was used to identify the underlying statistical structure of the scale and to reduce the number of items to a smaller set of components. PCA permitted a comparison of the theoretical domains with the statistically generated domains

Orthogonal rotation was used because of ease of interpretation Criteria for accepting a factor included: the factor had an eigenvalue greater than 1.0, the factor had at least two items loading highly onto it (> 0.60); and the factor had to be clinically meaningful. Four factors were extracted (Table 3) The eigenvalues

Table 3

Normalization Scale Eigenvalues and Proportion of Variance

		Variance	
Factor	Eigenvalue	Proportion	Cumulative
Actual Effect on Family Life	7.0	25%	25%
Perceive Family/Child as Normal	3.7	13%	38%
Child similar to CPD Children	1.9	7%	45%
Encourage Normal Activities	1.7	6%	51%

of the four factors were: 7 0, 3.7, 1 9, and 1 7 A cumulative total of 51% of variance was accounted for by these four factors Although the fourth factor only added 6% to the cumulative variance, this factor made the set of factors significantly more clinically meaningful. Communality values of the items tended to be high.

The first factor was labeled the "Actual Effect of the CPD on the Family" (Appendix H) Ten items loaded highly These items dealt with the effect of having a child with a CPD on the family Items that loaded on this factor included how much the family and child would be different if the child did not have a CPD, effect of the CPD on couple and siblings' activities and on family life; amount that family activities had to be planned around the child's CPD, the hassle caused for the family by the child's CPD; the reluctance of others to include the family in activities· the degree to which the child's CPD required different rules and expectations than other children; and the degree to which others treated the CPD family like they would another family. Factor loadings ranged from 0 48 to 0 86

A second factor dealt with how the family and others perceived the child and family. The factor was labeled the "Perception by the Family and Others of the CPD Child and Family Factor" and seven items loaded on this second factor. These items related to how the family and other people viewed the CPD child

The third factor included items relating to perception of the child and family as similar to other children and families with a CPD This factor, labeled the "Comparison of CPD Child and Family to Other CPD Children and Families factor", included all of the questions referring directly to the child's CPD. This factor was made up of four items.

The fourth factor, labeled the "Encouragement of Normal Activities" factor, contained four items that measured how much parents encouraged developmentally appropriate activities in their CPD child and expected normal behaviour from their CPD child. For example, these items examined parental encouragement of the child to participate in extracurricular activities, attend school, and play with others.

Three items did not load highly (< 0.41) on any of the four factors and were excluded from further analyses They included items related to acknowledgement of existence of the CPD, membership in a CPD support group, and the response of other children to the CPD child.

Intercorrelations between factors revealed a low to moderate correlation (.07 to .40) It was decided to use the PCA derived subscales rather than the theoretically derived domains for a number of reasons. Although the derived factors were consistent with Knafl and Deatrick's theoretically derived domains, the statistically derived subscales were mutually exclusive with no items showing high factor loadings across factors, which did occur when the theoretically derived domains were used Having items that loaded onto only one factor facilitated the interpretation of the factor. In future references, the factors will be referred to as subscales.

One item, about whether the parent gave the CPD child leeway in his or her behaviour because of the CPD, was deleted after the pilot study due to poor translation of the item. Thus, the final Normalization Scale was reduced to 25 items, divided among four subscales, namely: (1) Actual Effect of the CPD on the Family (10 items); (2) Perception by the Family and Others of the CPD Child and Family (7 items); (3) Comparison of CPD Child and Family to Other CPD Children and Families (4 items); and (4) Encouragement of Normal Activities (4 items).

Descriptive statistics of the Normalization scale. Table 4 presents the descriptive statistics and the internal consistency of the subscales. With the exception of the "Comparison of CPD Child and Family to Other CPD Children and Families" subscale, the average scores of the subscales were in the high end of the range but the range had acceptable variability.

Internal consistency. Cronbach's alpha was calculated for each subscale (Table 4). With the exception of the "Comparison of CPD Child and Family to Other CPD Children and Families " subscale, the coefficient alphas ranged from .65 to .91, indicating a high degree of internal consistency. The Comparison of CPD factor, which consisted of only four items, had a coefficient alpha of .33.

Normalization as a Predictor of Psychosocial Adjustment

The purpose of the study was to examine the relationship between family use of normalization and CPD children's psychosocial adjustment. The following hypotheses were tested:

Table 4

Descriptive Statistics and Internal Consistency of the Normalization Scale

Subscale	# Items	Range	Mean	SD	Cronbach's α
Actual Effect on Life	10	14-100	71	22	.84
Perceive as Normal	7	13- 70	59	14	.91
Child as CPD	4	8- 39	22	8	.33
Encourage Activities	4	9- 40	36	6	.65

Note. higher scores = greater use of normalization

(1) Families who use high levels of normalization will have CPD children with high personal adjustment and role skills.

(2) Families who use high levels of normalization will have CPD children with a high sense of self-competence.

To test these hypotheses, correlations and standard multiple regression analysis were the statistical methods used. Analyses were computed using the SAS statistical package (SAS Institute, 1989).

The CPD child's psychosocial adjustment was assessed through behaviour and self-concept. The first component, behaviour as exhibited through roles and general functioning, was measured by the Personal Adjustment and Roles Skills Scale (PARS 111) (Stein & Jessop, 1990; Walker et al , 1990) which was completed by the mothers. The second component, self-concept, was measured by the Self-Perception Profile for Children (Harter, 1985) which was completed by the child.

Demographic and Extraneous Characteristics

Before examining the relationship between normalization and psychosocial adjustment, it was necessary to identify potential intervening variables Potential intervening variables included descriptive socio-demographic variables (e.g , age, gender, birth order, grade level, socioeconomic status, and family composition), information specific to the child's illness (e g , "What is your child's diagnosis?"), perceived severity of condition, the effect of the child's condition on school attendance and on activity participation, parental knowledge about the condition, and major recent life events or changes of family members. In addition, because the data were collected in two different settings, at home or in the clinic, setting of the interview was also treated as a potential intervening variable. Correlations were computed between these potential intervening variables and the psychosocial adjustment variables (Table 5).

After examining each variable for outliers (greater than two standard deviations from the mean), correlations were computed between the above mentioned variables and the psychosocial adjustment variables (total and subscales of the PARS 111 and Harter subscales). Correlations between demographic, extraneous variables and all subscales and total scores of the psychosocial variables were low (00 to 36 with no patterns) and non-significant ($p >$ 05). Setting of the interview did not correlate highly with the psychosocial adjustment variables (.01 to .27). Therefore, none of the variables were controlled for when examining the relationship between family use of normalization and psychosocial adjustment of CPD children.

Relationship between Family Use of Normalization and PARS

The 28 item PARS 111 scale was divided among six subscales (peer relations, dependency, hostility, productivity, anxiety / depression, and withdrawal) A total score was also calculated. Higher scores indicated higher psychosocial adjustment. Table 6 describes the descriptive statistics of the PARS 111 scores. The intercorrelations between the subscales were in the low to

Table 5

Correlations between Potential Intervening Variables and Psychosocial Adjustment Variables

(a) PARS 111 Subscales

	Anxiety	Depend	Hostility	Withdrawal	Peers	Productivity
Child's Grade	.29	.20	.24	.08	-.10	.22
Mother						
level of education	.31	.16	.37	.28	.03	.33
has a CPD herself	.02	-.23	-.06	-.03	.07	-.14
Father						
level of education	.26	.13	.35	.24	.06	.24
has a CPD himself	-.07	-.04	-.25	-.11	.16	-.10
Child's CPD						
limits child's activity	-.25	-.04	-.21	.21	.02	-.09
level of severity	.22	.22	.12	.16	-.10	.12
information known	.42	.31	.34	.29	.15	.40
Life Events	-.35	-.20	-.26	-.09	-.11	- 16
Interview Setting	.04	.14	.08	.02	-.02	.20

Table 5 continues

Table 5 continued

	(b) Harter Subscales					
	School	Athletic	Social	Appearance	Behaviour	Global
Child's Grade	-.10	.12	-.05	.07	.02	.12
Mother						
level of education	.21	-.01	.13	-.17	.07	-.08
has a CPD herself	- 18	.02	-.06	-.03	-.08	-.20
Father						
level of education	08	.20	.10	-.01	. 09	-.02
has a CPD himself	.04	-.09	-.03	-.06	.06	-.04
Child's CPD						
limits child's activity	.03	.15	.05	.06	-.14	.09
level of severity	.02	-.18	.04	.10	.13	.15
information known	.06	-.12	-.21	-.04	-.04	-.20
Life Events	.00	-.09	-.11	-.05	-.20	.13
Interview Setting	.12	-.27	-.17	-.06	-.03	-.01

Table 6

Descriptive Statistics of PARS 111 Subscales

PARS 111 Subscales	Mean	Standard Deviation
Anxiety - Depression	20.0	2.7
Dependency	12.8	1.8
Hostility	19.1	3.3
Withdrawal	14.3	1.8
Peer Relations	12.0	2.1
Productivity	11.6	2.7

Note: higher scores = higher psychosocial adjustment (therefore: lower anxiety -depression, lower dependency, lower hostility, lower withdrawal, higher peer relations, and higher productivity) moderate range suggesting a similar underlying structure but separate subscales (Table 7)

To test the first hypothesis that families who use high levels of normalization will have CPD children with high personal adjustment and role skills, the PARS total score and each subscale score were correlated with each of the Normalization Scale subscale scores (Table 8). The PARS total score and specifically, the anxiety / depression, withdrawal, and productivity subscales were positively correlated with the "Actual Effect of the CPD on the Family" subscale. Mothers who described that the child's CPD had less effect of the child's CPD on family life also rated their children low in anxiety / depression, and withdrawal, and high in productivity.

Positive correlations were found between the total PARS score and each PARS subscale score and the "Perception by the Family and Others of the CPD Child and Family" subscale. Mothers who perceived that they and other people viewed their child and family as normal also rated their CPD children as low in anxiety and depression, dependency, hostility, and withdrawal and high in peer relationships and productivity.

The "Encouragement of Normal Activities" subscale was significantly correlated with the total score as well as with the dependency, hostility, and the productivity subscales. Mothers who reported that they encouraged their children to participate in normal childhood activities also rated their children as low in dependency, hostility, and high in productivity.

Table 7

Correlations between the PARS 111 Subscales

	Total	Anxiety	Depend	Hostility	Withdraw	Peers	Productivity
Total							
Anxiety	.81**						
Dependence	.69**	.48**					
Hostility	.82**	.70**	.48**				
Withdrawal	.74**	.49**	.44**	.61**			
Peers	.36*	.17	.11	-.02	.11		
Productivity	.83**	.52**	.58**	.55**	.59**	.31*	

** denotes p < .0001 * denotes p < .006 (both two-tailed)

Table 8

Correlations between Normalization Scale and PARS 111

	PARS 111 Subscales						
Normalization	Total	Anxiety	Depend	Hostility	Withdraw	Peers	Productivity
Effect on Life	.33*	.31*	.14	.22	.37*	.13	.23*
PerceiveNormal	.57*	.57*	.37*	.39*	.25*	.34*	.46*
Child as CPD	-.09	.06	-.12	-.21	.09	.00	-.03
Normal Activity	.27*	.20	.28*	.24*	.18	-.04	.30*

* $p < .05$, two-tailed

Note: Higher PARS scores = higher adjustment

Predictors of psychosocial adjustment by regression analysis Given that the total PARS 111 score and five of the six subscale scores were significantly correlated with two or more of the subscales of normalization, it was of interest to know which of the normalization subscales alone or in combination were related to the different role skills and personal adjustment subscales To explore this issue, separate standard multiple regression equations were computed for the total PARS score and each of the PARS subscales (except peer relationships) using the three significant normalization subscales as predictors For example, the total PARS score was regressed against the normalization subscales (Actual Effect of the CPD on the Family; Perception by the Family and Others of the CPD Child and Family; Encouragement of Normal Activities) The criteria used to accept a predictor was that the part correlation of the subscales had to be significant and to contribute at least five percent of the variance and that the overall F-ratio had to be significant ($p < .05$).

Using regression analysis, it was found that the best predictor of anxiety / depression was the normalization subscale of "Perception of Child and Family by Self and Others as Normal" This subscale accounted for the largest percentage of the variance Once the "Perception of Child and Family by Self and Others as Normal" subscale was entered into the equation, the other two normalization subscales (Actual Effect of the CPD on the Family, Encouragement of Normal Activities) were not significant. This same pattern held for the PARS variables of dependency, hostility, and productivity but not for withdrawal The subscale of normalization that best predicted withdrawal was "Actual Effect of the CPD on the Family". Once this subscale was accounted for, neither the "Perception by the Family and Others of the CPD Child and Family" nor the "Encouragement of Normal Activities" subscale provided any further significant variance

Relationship between Family Use of Normalization and Children's Self-Competence

The second hypothesis tested was that families who use high levels of normalization would have CPD children with a high sense of self-competence. The Harter was the scale used to measure child self-competence. This scale consisted of children's self-perception of their scholastic and athletic competence, social acceptance, physical appearance, behavioural conduct, as well as sense of global self-worth. The descriptive statistics of the Harter subscales are outlined in Table 9. Each of the CPD children's subscale scores on the Harter was correlated with each of the Normalization Scale subscale scores. No significant relationship was found between any of the Harter subscale scores and any of the Normalization subscale scores (r between 0 and .22) (Table 10).

Summary

In summary, the Normalization Scale factored into four subscales: (1) Actual Effect of the CPD on the Family; (2) Perception by the Family and Others of the CPD Child and Family, (3) Comparison of CPD Child and Family to Other CPD Children and Families; and (4) Encouragement of Normal Activities. Psychometric testing indicated that the scale had adequate internal consistency.

Table 9

Descriptive Statistics of the Harter Subscales

Harter Subscales	Mean	Standard Deviation
Scholastic Competence	3.3	0.60
Athletic Competence	3.1	0.70
Social Acceptance	3.3	0.60
Physical Appearance	3.2	0.72
Behavioural Conduct	3.3	0.51
General Self-Worth	3.4	0.54

Table 10

Correlations between the Normalization and the Harter Subscales

	Subscales					
Normalization	Harter					
	School	Athletic	Social	Appearance	Behavior	Global
Effect on Life	-.09	-.05	-.09	.03	.03	.02
Perceive as Normal	.07	.02	0	.10	.08	-.04
Child as CPD Child	0	.22	-.11	-.09	-.08	.07
Normal Activity	-.05	.03	-.04	.10	-.10	.07

all values non significant (p > .05)

The scale was used to examine the relationship between family use of normalization and psychosocial adjustment in CPD children. Significant relationships were found to exist between personal adjustment and role skills subscales and family use of normalization. Specifically, using regression analysis, mothers who perceived their child to be less anxious and depressed, less dependent, or less hostile also reported that their family and others perceived the family and CPD child to be normal. Similarly, mothers who perceived their child to have overall high personal adjustment, or good productivity also reported that their family and others perceived the family and CPD child as normal. In addition, mothers who reported their child as less withdrawn also reported less actual effect of the CPD child on the family's life. However, no significant relationship was found between family use of normalization and CPD children's reported self-competence.

Discussion

The major purpose of the study was to examine the relationship between a family's use of normalization and the CPD child's psychosocial adjustment. To examine this relationship, a scale was constructed to measure family use of normalization. The scale and the relationship between normalization and psychosocial adjustment will be discussed in turn.

The Normalization Scale

Through Principal Components Analysis (PCA), four subscales were extracted. Satisfactory internal consistency was obtained for each of these four subscales, except for the subscale "Comparison of CPD Child and Family to Other CPD Children and Families". The low internal consistency for this subscale may be attributed to the number of items (only four items). Factors with fewer items are not as reliable as factors with greater numbers of items (DeVellis, 1991). Less internal consistency may also be due to sample size. In fact, small sample size decreases stability of the factors (DeVellis, 1991).

Furthermore, the statistically derived subscales corresponded closely with Knafl and Deatrick's theoretically defined domains. Recall, two of Knafl and Deatrick's theoretical domains were "Definition of Family Life as Normal" and "Definition of the Social Consequences of the Situation as Minimal". These theoretical domains distinguished between parents' own perceptions of their CPD child and family, and parents' perceptions of other people's validation of the family's definition of the child and the family. The PCA derived factor solution divided the constructs slightly differently but included the same items The PCA divided the items, not between family and others, but between normal and CPD families. One factor included items that examined both family and others perception of the CPD child and the family as normal ; for example, both the item "How much is your family like other families?" and the item "How much do other people find your family to be like other families?" are included in the same factor. Thus, mothers did not distinguish between how they saw their own child and family and how they thought others saw them. Rather, they distinguished between how they and others compared their family and child to normal families and children versus how they and others compared their family and child to CPD families and children.

A possible explanation for why mothers did not distinguish between their own and other people's perceptions of their family and child may be related to how one's life experience is constructed as "real life". How a person perceives reality is a subjective experience (Robinson, 1993). Normalization has been conceptualized as more of a philosophical approach than a situational reality (Scharer & Dixon, 1989) - in other words more of a self-perception than an objective, impartial actuality. Families with a CPD child may choose to attend to their own behaviours and information that fit their perception of life as normal (for example, the child attending school or the family going on vacation) (Anderson, 1981; Deatrick et al., 1988; Robinson, 1993). They may ignore or discount behaviour and information that contradict the view they hold of the family (for example, that the child does not have a full course load). Similarly, families with a CPD child may choose to attend only to the behaviours and information from others that support their own perceptions and ignore or disregard information from others that contradict their realities (Robinson, 1993; Roskies, 1972). Therefore, if this were the case, the mothers who perceived their family and CPD child to be normal would also perceive that others also perceived the family and CPD child in the same fashion.

Based on the theoretical domains, items for the Normalization Scale were constructed that asked mothers to compare their families to both "normal" families and to CPD families. A second set of items asked mothers their beliefs about how others compared their families to these same two groups. The underlying assumption in constructing these original items was that these items would tap both ends of a continuum with normal families on one extreme and CPD families at the other end and that the distinction would be between the families' perceptions and other peoples' perceptions.

However, the factor solution revealed that mothers in this study did not make this theoretically derived distinction. In fact, the factor solution grouped items in terms of perception of the family as normal versus perception of the family as CPD. In other words, mothers distinguished between "normal" families and "CPD" families rather than distinguishing on the basis of who was judging the family.

Wording of the items is one possibility the subscales divided as perception of normal family versus CPD family dimensions rather than along the perception by self versus others dimensions. Perhaps the wording of the items was not different enough for respondents to distinguish between items questioning their perceptions and those items tapping their perception of other peoples' perceptions about their family and child. The lack of distinction might have caused the mothers to answer both types of items similarly. However, there is reason not to accept this explanation. In piloting the Normalization Scale, mothers were asked to explain the items and they were able to distinguish whose perception was being elicited in each item.

Another possibility for the finding of separate factors for perception of the family as normal and perception of the family as CPD is that mothers did not perceive normal families to be on a continuum with CPD families. In order to compare themselves to other CPD families, mothers first may have to identify themselves as part of a CPD family. If unable to identify with CPD families, the mothers could not make comparisons. Mothers of CPD children may not identify themselves as a CPD family. There is some evidence from this study to support this possibility. Many mothers did not answer items that asked them to compare their family to other families with children with similar conditions. This explanation is supported by the research of Darling (1979) and Roskies (1972) who found that parents tended to perceive their child as unique and "less affected" than other children with a particular disorder and therefore, did not identify with groups for handicapped children. In this study, only 6% of mothers rated their child as more severely affected than other children with a similar condition.

In this study, two factors were extracted from the PCA that divided Knafl and Deatrick's single theoretical domain labeled "Engaging in Behaviours to Demonstrate the Family's Normality". Knafl and Deatrick described families' behaviours and activities that illustrate to other people that the family behaves and is like other families who do not have a CPD child. Mothers in this study separated this single theoretical domain into two statistically derived subscales: (1) Actual Effect of the CPD on the Family, which included items about how family planning and activities were impacted by the child's CPD and (2) Encouragement of Normal Activities, which included items that demonstrated the child's normality to the family and others and tapped the values of the CPD parents. This second factor included items that asked about valued but not necessarily actual behaviours of their child.

Wording of the items may explain why mothers differentiated between actual and valued behaviours in their CPD children. Items were developed that tapped "normal" behaviours. However, some of the items were worded in such a way that tapped desired behaviours that did not necessarily reflect actual behaviours of the child while other items inquired about existing behaviours.

One of Knafl and Deatrick's theoretical domains, namely, "Acknowledgement of the Existence of the Impairment" in which parents confirm that their child does have a chronic physical condition, was not extracted as a factor in the PCA. Theoretically, acknowledgement of the existence of the impairment is essential to distinguish a family's use of normalization from a family's use of denial (Knafl & Deatrick, 1986). Recall that there was only one item to measure this theoretical domain This item did discriminate somewhat between mothers who acknowledged the existence of their child's CPD or not. Although the majority of mothers did acknowledge the existence of their child's CPD through this question, nine percent of mothers answered that they were only "a little" sure (less than 30%) that their child had been correctly diagnosed It may be that with more items, this domain would emerge as a factor.

Relationship between Family Use of Normalization and Psychosocial Adjustment in CPD Children

The findings suggest that high use of normalization is related to CPD children who are better adjusted in terms of personal adjustment and role skills. High-normalizing mothers perceived their CPD children to be less anxious, depressed, dependent, hostile, and withdrawn than did low-normalizing mothers. These high-normalizing mothers also rated their children to have overall high personal adjustment, better peer relations, and good productivity.

Of the four subscales of the Normalization Scale, three of the subscales were related to better psychosocial adjustment by correlation analysis, two by regression analysis The best predictor of the CPD child's overall personal adjustment, anxiety / depression, dependency, hostility, peer relations and productivity was the subscale "Perception of Child and Family by Self and Others as Normal". The best predictor of low withdrawal by the CPD child was the subscale "Actual Effect of the CPD on the Family" Contrary to the hypothesis, family use of normalization was not related to CPD children's sense of self-competence in this study.

These findings raise several issues. Why is perception of normality the dimension of normalization that appears to be most related to children's personal adjustment and role skills? Why is CPD child withdrawal best predicted by actual effect of the CPD on the family's life? Why is family use of normalization not related to CPD children's sense of self-competence? Why is the PARS 111 scale related to family use of normalization but not the Harter's Sense of Perceived Competence? These issues will be discussed in turn.

Perception of normality as the most important predictor of child personal adjustment. There may be several reasons why overall personal adjustment, anxiety, dependence, hostility, peer relations, and productivity were primarily related to the perception by self and others of the child and family's normality. One explanation is methodological. The reason for the high correlations between family use of normalization and high personal adjustment and role skills in the child may be related to common method variance. Recall that mothers completed both the Normalization Scale and the PARS 111. Therefore, mothers' perceptions of their families may also affect their perception of their children. If this was the case, it may be that mothers who saw their family as highly "normal" also perceived their children to have high personal adjustment and role skills.

However, only one of the four subscales was related to the child's personal adjustment and role skills. If mothers' ratings affected both scales then it would be expected that all four normalization subscales would correlate highly with the PARS 111. However, this was not the case.

Another possibility for why mothers who perceived their family and child as normal also perceived their child to be well adjusted with good role skills may be found in other research findings about the process of normalization Normalization has been conceptualized as more of a philosophical approach than as a situational reality (Scharer & Dixon, 1989) Parents who normalize selectively attend to "normal" behaviours and ignore the behaviours and situations that do not fit the desired or expected norm (Anderson, 1981, Deatrick et al., 1988, Robinson, 1993). These parents would also expect other people to do likewise (Roskies, 1972). Robinson labeled this behaviour as "constructing the story of life as normal" (Robinson, 1993, p.9). If this was the case, the CPD child's "normal" behaviours would be attended to and reinforced by the family and others. Therefore, it would then follow that perception by the family and others of the family and child as normal would be the dimension most strongly related to CPD child personal adaptation and role skills.

These findings suggest that mothers who perceive that their family and child as normal are likely to have CPD children with good personal adjustment and role skills. Further research is needed to validate these results However, the findings suggest that a mother's perception and appraisal of the situation is important to the psychosocial adjustment of her CPD child. Therefore, nurses, when assessing mothers, need to explore how mothers perceive their CPD child and how she thinks others perceive their child. Although other dimensions of normalization may be important to other areas of the CPD child and family's health (as yet unexplored), there is now some evidence that the nurse trying to assess and promote the CPD child's psychosocial adjustment and role skills could focus primarily on the family's perception of normality.

CPD child withdrawal as best predicted by actual effect of the CPD on the family By regression analysis, withdrawal was the only subscale of PARS that was not predicted by the "Perception of Child and Family by Self and Others as Normal" subscale but instead by the subscale "Actual Effect of the CPD on the Family". Mothers who felt that sibling and couple activities were more affected by the child's CPD and who felt that their lives would be very different if the child did not have a CPD had CPD children that were more likely to "do nothing" or to seem unaware of things happening around him or herself. It is possible that withdrawn children have a significant effect on normal family life. Further research may test this relationship and provide possible explanations for this finding

Lack of a relationship between family use of normalization and children's self-competence It was hypothesized that family use of normalization would be related to CPD children's sense of self-competence This hypothesis was not supported. The hypothesis was originally based on both theoretical and empirical data. Saylor (1990) theorized that having a CPD could stigmatize an individual which then might affect the individual's sense of self-competence. She noted that redefining the CPD in order to represent it as normal (i e , normalizing it) could be one way to manage the illness' potential effect on self-competence Knafl and colleagues (1992) did find a correlation between lower self-worth in CPD children and parents who viewed them as "not normal"; this relationship was found to be true only when <u>both</u> parents viewed the child as "not normal"

There are several possible explanations for the lack of a relationship between mothers' perceptions of family use of normalization and CPD children's sense of perceived self-competence One explanation is methodological While the children in Knafl and colleagues (1992) study also completed the Harter Scale (1985), normalization was measured differently than in this study In the Knafl study, family use of normalization was assessed by the researchers based on interviews with parents. In this study, family use of normalization was based on mother's reports using a questionnaire. This methodological difference could account for the difference found in the relationship between normalization and global self-worth in these two studies

Other possibilities for the lack of a relationship between mothers' perceptions of family use of normalization and CPD children's sense of perceived self-competence also exist. Self-esteem has been shown to be directly affected by the specific social group to which the child compares him/her- self (Harter, 1985). Recall that the sample of children in this study consisted of school-aged children. These children have access to several groups to which they might compare themselves (e g , peers). If they do not identify themselves as CPD families or children, CPD children may not compare themselves unfavourably to their social comparison groups and therefore might not feel the stigma that Saylor theorized might affect CPD children's sense of self-competence. It would be necessary to know what social comparison group the CPD children in this study are using in their self-judgements in order to further understand whether this explanation is valid Overall, the children in this study perceived themselves as highly competent but the variability within this sample was similar to that reported by Harter (1985)

Another explanation for the lack of a relationship between mothers' perceptions of family use of normalization and CPD children's sense of perceived self-competence is that children's self-esteem may be affected more strongly by factors other than the degree to which a family normalizes. For example, mother's own self-esteem is a factor that has been found to affect child self-esteem (Coopersmith, 1967) This factor or other family factors may be more important than family use of normalization in affecting the CPD child's sense of self-competence

Personal adjustment and role skills but not perceived self-competence is related to family use of normalization The final issue to be discussed is why the PARS 111 scales were related to family use of normalization while the Harter scales of perceived self-competence were not. One explanation is that how parents' perceive their children and how children assess themselves are not identical. The parents are also primarily judging behaviour while the children are measuring their perceptions of their competency. In addition, parents might be less aware of their child's sense of self-competence and the sources from which the children judge themselves and develop a sense of self-competence than they are of the child's behaviour In this case, less attention and reinforcement may be focused on developing the child's sense of self-competence than on the behaviours measured by the PARS 111 scale. Future research would be necessary to further examine this relationship (or lack of it) and the determinants behind it.

Conclusion

Family use of normalization was found to be related to CPD child psychosocial adjustment Specifically, the mother's perception that the family and other people perceived that the family and CPD child were normal was strongly related to overall high personal adjustment, good peer relations and productivity in the CPD child along with low reported anxiety and depression, dependence, and hostility. However, family use of normalization was not found to be related to CPD child perception of self-competence in this study Further research should examine these relationships. The clinician aiming to improve the personal adjustment and role skills of the CPD child could focus on assessing and intervening with the family's perception of the normality of the family and child although it could be that the personal adjustment and role skills of the child are the factors influencing family use of normalization.

The development of the Normalization Scale may also further research into the process of normalization. Concept analysis continues to be the focus of nursing research on normalization in CPD families. Initial psychometric testing of the Normalization Scale indicates that the scale has the potential to better elucidate the concept of normalization and family use of normalization. The scale shows good internal consistency and construct validity. The scale discriminates between the different dimensions of the concept of normalization. Therefore, the dimensions of normalization that affect families and children may be better able to be assessed using this scale. An attempt to quantify family use of normalization may allow the progression of research about normalization. However, further development of the Normalization Scale by expanding the item pool and further psychometric testing would be an important first step.

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Appendices

What I Am Like

Appendix a: Self Perception Scale for Children

Name ______________________ Age ______ Birthday ______________ Group ______
Month Day

Boy or Girl (circle which)

SAMPLE SENTENCE

	Really True for me	**Sort of True for me**				Sort of True for me	Really True for me
(a)	☐	☐	Some kids would rather play outdoors in their spare time	BUT	Other kids would rather watch T V	☐	☐
1	☐	☐	Some kids feel that they are very *good* at their school work	BUT	Other kids *worry* about whether they can do the school work assigned to them	☐	☐
2	☐	☐	Some kids find it *hard* to make friends	BUT	Other kids find it's pretty *easy* to make friends	☐	☐
3	☐	☐	Some kids do very *well* at all kinds of sports	BUT	Other kids *don't* feel that they are very good when it comes to sports	☐	☐
4	☐	☐	Some kids are *happy* with the way they look	BUT	Other kids are *not* happy with the way they look	☐	☐
5	☐	☐	Some kids often do *not* like the way they *behave*	BUT	Other kids usually *like* the way they behave	☐	☐
6	☐	☐	Some kids are often *unhappy* with themselves	BUT	Other kids are pretty *pleased* with themselves	☐	☐
7	☐	☐	Some kids feel like they are *just as smart* as as other kids their age	BUT	Other kids aren't so sure and *wonder* if they are as smart	☐	☐
8	☐	☐	Some kids have *alot* of friends	BUT	Other kids *don't* have very many friends	☐	☐

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
9	☐	☐	Some kids wish they could be alot better at sports	**BUT**	Other kids *feel* they are good enough at sports.	☐	☐
10	☐	☐	Some kids are *happy* with their height and weight	**BUT**	Other kids wish their height or weight were *different*.	☐	☐
11	☐	☐	Some kids usually do the *right* thing	**BUT**	Other kids often *don't* do the right thing.	☐	☐
12	☐	☐	Some kids *don't* like the way they are leading their life	**BUT**	Other kids *do* like the way they are leading their life	☐	☐
13	☐	☐	Some kids are pretty *slow* in finishing their school work	**BUT**	Other kids can do their school work *quickly*	☐	☐
14	☐	☐	Some kids would like to have alot more friends	**BUT**	Other kids have as many friends as they want	☐	☐
15	☐	☐	Some kids think they could do well at just about any new sports activity they haven't tried before	**BUT**	Other kids are afraid they might *not* do well at sports they haven't ever tried.	☐	☐
16	☐	☐	Some kids wish their body was *different*	**BUT**	Other kids *like* their body the way it is	☐	☐
17	☐	☐	Some kids usually *act* the way they know they are *supposed* to	**BUT**	Other kids often *don't* act the way they are supposed to.	☐	☐
18	☐	☐	Some kids are *happy* with themselves as a person	**BUT**	Other kids are often *not* happy with themselves	☐	☐
19	☐	☐	Some kids often *forget* what they learn	**BUT**	Other kids can remember things *easily*	☐	☐
20	☐	☐	Some kids are always	**BUT**	Other kids usually do things by *themselves*	☐	☐

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
21.	☐	☐	Some kids feel that they are *better* than others their age at sports	**BUT**	Other kids *don't* feel they can play as well	☐	☐
22	☐	☐	Some kids wish their physical appearance (how they look) was *different*	**BUT**	Other kids *like* their physical appearance the way it is.	☐	☐
23.	☐	☐	Some kids usually get in *trouble* because of things they do	**BUT**	Other kids usually *don't* do things that get them in trouble	☐	☐
24.	☐	☐	Some kids *like* the kind of *person* they are	**BUT**	Other kids often wish they were someone else	☐	☐
25.	☐	☐	Some kids do *very well* at their classwork	**BUT**	Other kids *don't* do very well at their classwork.	☐	☐
26.	☐	☐	Some kids wish that more people their age liked them	**BUT**	Other kids feel that most people their age *do* like them	☐	☐
27.	☐	☐	In games and sports some kids usually *watch* instead of play	**BUT**	Other kids usually *play* rather than just watch	☐	☐
28.	☐	☐	Some kids wish something about their face or hair looked *different*	**BUT**	Other kids *like* their face and hair the way they are	☐	☐
29.	☐	☐	Some kids do things they know they *shouldn't* do	**BUT**	Other kids *hardly ever* do things they know they shouldn't do	☐	☐
30.	☐	☐	Some kids are very *happy* being the way they are	**BUT**	Other kids wish they were *different*	☐	☐
31.	☐	☐	Some kids have *trouble* figuring out the answers in school	**BUT**	Other kids almost *always* can figure out the answers	☐	☐
32.	☐	☐	Some kids are *popular* with others their age	**BUT**	Other kids are *not very* popular	☐	☐

	Really True for me	Sort of True for me				Sort of True for me	Really True for me
33	☐	☐	Some kids *don't* do well at new outdoor games	**BUT**	Other kids are *good* at new games right away	☐	☐
34	☐	☐	Some kids think that they are good looking	**BUT**	Other kids think that they are not very good looking.	☐	☐
35	☐	☐	Some kids behave themselves very well	**BUT**	Other kids often find it hard to behave themselves	☐	☐
36	☐	☐	Some kids *are* not very happy with the way they do alot of things	**BUT**	Other kids think the way they do things is *fine*	☐	☐

Susan Harter Ph D University of Denver, 1985

Appendix B: PARS 111

Following are a few questions about your child's behavior. PLEASE CIRCLE whether this curs NEVER or RARELY (N), SOMETIMES (S), OFTEN (O), ALWAYS or ALMOST ALWAYS (A)

DURING THE LAST MONTH, HAS HE/SHE...

		NEVER or RARELY	SOMETIMES	OFTEN	ALWAYS or ALMOST ALWAYS
1.	Spent time with friends?	N	S	O	A
2.	Wanted help in things he/she could have done?	N	S	O	A
3.	Done things for attention even though punished for it?	N	S	O	A
4.	Stayed with task or assignment until finished?	N	S	O	A
5.	Complained about problems?	N	S	O	A
6.	Sat and stared without doing anything?	N	S	O	A
7.	Made friends without difficulty?	N	S	O	A
8.	Been unable to decide things for self?	N	S	O	A
9.	Flared up if couldn't have own way?	N	S	O	A
10.	Made full use of abilities?	N	S	O	A
11.	Seemed restless, tense?	N	S	O	A
12.	Appeared listless and apathetic?	N	S	O	A
13.	Joined others of own accord?	N	S	O	A
14.	Asked for help when could have figured things out?	N	S	O	A
15.	Become upset if others did not agree with him/her?	N	S	O	A
16.	Done work without being pushed or punished?	N	S	O	A
17.	Said people didn't care about him/her?	N	S	O	A
18.	Seemed unaware of things going on around?	N	S	O	A
19.	Had many different friends?	N	S	O	A
20.	Asked unnecessary questions instead of working on own?	N	S	O	A
21.	Ignored warnings to stop unacceptable behavior?	N	S	O	A
22.	Kept on with task even though difficult?	N	S	O	A
23.	Seemed sad?	N	S	O	A
24.	Shown little interest in things, had to be pushed into activity?	N	S	O	A
25.	Told lies?	N	S	O	A
26.	Not responded to discipline?	N	S	O	A
27.	Said he/she couldn't do things right?	N	S	O	A
28.	Acted afraid or apprehensive?	N	S	O	A

Normalization Questionnaire (French Version) - Appendix C

Directives Veuillez-vous reporter à la situation de votre enfant et de votre famille au cours des 2 derniers mois Pour chacune des questions, nous vous demandons de coter la fréquence ou la pertinence de l 'énoncé en plaçant une barre oblique (/) sur la ligne qui sépare les deux extrêmes, identifiées par les termes BEAUCOUP ou UN PEU, à l 'endroit qui correspond le mieux à la situation de votre enfant et de votre famille Par exemple, si vous jugez que la question décrit très bien ce que vit votre enfant/famille depuis deux mois, tracez la barre (/) a l'extrémité BEAUCOUP de la ligne. Si la question décrit à peu près votre situation, placez la barre (/) entre les deux extrémités, plus près du UN PEU si l 'énoncé s 'applique parfois à votre enfant/famille, ou plus près du BEAUCOUP, s 'il s 'applique assez souvent. Si la question n 'est pas vraiment pertinente à votre enfant/famille, placez la barre (/) près de l'extrémité UN PEU de la ligne

N 'oubliez pas qu 'il n 'y a pas de bonne ni de mauvaise réponse (vraie ou fausse) Indiquez simplement ce qui correspond le mieux à votre cas.

1 Dans quelle mesure l 'état de votre enfant influe-t-il sur la vie de votre famille?
beaucoup |--| un peu

2 Dans quelle mesure les gens traitent-ils votre famille de la même façon qu ' une autre?
beaucoup |--| un peu

3 Dans quelle mesure encouragez-vous votre enfant à jouer avec d ' autres enfants?
beaucoup |--| un peu

4 Dans quelle mesure le traitement médical à domicile de votre enfant s ' intègre-t-il dans votre routine?

beaucoup |--| un peu

5 Dans quelle mesure êtes-vous sûr(e) de l 'exactitude du diagnostic?

beaucoup |--| un peu

6 Dans quelle mesure l 'état de votre enfant influence-t-il l 'attitude des autres enfants à son endroit?

beaucoup |--| un peu

7 Dans quelle mesure encouragez-vous votre enfant à aller à l 'école?

beaucoup |--| un peu

8 Dans quelle mesure votre enfant est-il semblable aux autres enfants?

beaucoup |--| un peu

9 Dans quelle mesure les gens considèrent-ils votre famille comme d ' autres familles?

beaucoup |--| un peu

10 Dans quelle mesure un enfant comme le vôtre a-t-il besoin d 'être traité différemment des autres enfants en raison de son état?

beaucoup |--| un peu

11. Dans quelle mesure encouragez-vous votre enfant à participer à des activités parascolaires (ex. art, sports, théâtre, musique)?

beaucoup |--| un peu

12 Dans quelle mesure les gens hesitent-ils à intégrer votre famille dans des activites en raison de l ' état de votre enfant?

beaucoup |--| un peu

13 Si votre enfant n 'avait pas cette affection chronique, dans quelle mesure la vie de votre famille serait-elle différente?

beaucoup |--| un peu

14 Dans quelle mesure un enfant comme le vôtre devrait-il être traité comme les autres enfants?

beaucoup |--| un peu

15 Dans quelle mesure les gens considèrent-ils votre enfant comme d ' autres enfants?

beaucoup |--| un peu

16 Dans quelle mesure le traitement médical de votre enfant influe-t-il sur la routine de votre famille?

beaucoup |--| un peu

17 Dans quelle mesure votre enfant est-il semblable aux autres enfants dans le même etat?

beaucoup |--| un peu

18 Dans quelle mesure votre enfant joue-t-il avec ses amis?

beaucoup |--| un peu

19 Dans quelle mesure vous et votre conjoint voyez-vous d 'un même oeil la situation de votre enfant?

sans conjoint _____

beaucoup |-- - ---| un peu

20 Si votre enfant n 'avait pas cette affection chronique, dans quelle mesure la vie de votre enfant serait-elle différente?

beaucoup |- --- --| un peu

21 Quelles proportions des activités quotidiennes de votre famille doivent être planifiées en fonction des besoins de votre enfant?

beaucoup |- ---| un peu

22 Dans quelle mesure votre enfant participe-t-il aux mêmes activités que ses camarades?

beaucoup |--| un peu

23 Dans quelle mesure votre famille est-elle semblable aux autres familles?

beaucoup |--| un peu

24 Quel degré de liberte, au niveau du comportement, donnez-vous à votre enfant en raison de son etat?

beaucoup |--| un peu

25. SI VOUS AVEZ PLUS D 'UN ENFANT Dans quelle mesure l ' etat de votre enfant influe-t-il sur les activités de vos autres enfants?

sans objet________

beaucoup |--| un peu

26 Dans quelle mesure votre famille est-elle semblable aux autres familles dont un enfant est atteint d 'une affection semblable au vôtre?

beaucoup |--| un peu

27. Dans quelle mesure les gens traitent-ils votre enfant de la meme façon qu 'un autre?

beaucoup |--| un peu

28 Dans quelle mesure l ' état de votre enfant influe-t-il sur vos activités avec votre conjoint ou d 'autres adultes?

beaucoup |--| un peu

29 Dans quelle mesure vous et votre conjoint êtes-vous d 'accord sur la façon d 'assumer l 'etat et les traitements de votre enfant?

sans conjoint______

beaucoup |--| un peu

30 Dans quelle mesure les gens considèrent-ils votre famille comme les autres familles ayant un enfant atteint d 'une affection chronique?

beaucoup |--| un peu

31. Faites-vous partie d 'un groupe d 'entraide ou d 'une association lié a l 'état de votre enfant?

____oui ___non

SI OUI. Quel est votre degré actuel de participation a ce groupe?

beaucoup |--| un peu

Appendix D Normalization Scale (English Version)

Instructions Please think about your child and your family over the last two months. For each question, you are asked to rate the frequency with which your child or family has believed something or done something by placing a slash (/) to cut the line somewhere between the two extremes labelled A LOT or A LITTLE- at the place that best corresponds to the answer that fits best for your child and family For example, if you feel that the question describes your child/family a lot over the past two months, you should place the slash (/) at the A LOT end of the line If you believe that the question sort of describes your child/family, you should place the slash (/) somewhere between the two extremes - closer to the A LITTLE end if it only partly describes your child/family and closer to the A LOT end if it pretty much describes your family If the question hardly describes your child/family at all, you place your slash (/) at the A LITTLE end of the line

Please remember -- there are no right or wrong (nor good nor bad) answers. You know what best describes your situation

1 How much does your child's condition affect your family life?

a lot |---| a little

2 How much do other people treat your family like they treat other families?

a lot |---| a little

3 How much do you encourage your child to play with other children?

a lot |---| a little

4 How routine does your child's home medical treatment feel?

a lot |-------------- ---| a little

5 How sure are you that your child has been correctly diagnosed?

a lot |---| a little

6. How much does your child's condition affect how other children respond to your child?

a lot |---| a little

7. How much do you encourage your child to attend school?

a lot |---| a little

8. How much is your child like other children?

a lot |---| a little

9. How much do other people find your family to be like other families?

a lot |---| a little

10. How much does a child with a condition like your child's need to be treated differently because of the condition?

a lot |---------------- --| a little

11. How much do you encourage your child to participate in extra curricular activities (eg., art, sports, drama, music)?

a lot |---| a little

12. How reluctant are other people to include your family in an activity or event because of your child's condition ?

a lot |---| a little

13. If your child did not have this chronic condition, how different would your family be compared to what it is like now?

a lot |---| a little

14 How much should a child with a condition like your child's be treated like other children?

a lot |---| a little

15 How much do other people find your child to be like other children?

a lot |-- --| a little

16 How much of a hassle does your child's medical treatment create for your family's daily routine?

a lot |--| a little

17 How much is your child like other children who have a similar condition?

a lot |--| a little

18 How much does your child play with friends?

a lot |--- -- -------------| a little

19 How much do you and your spouse/partner agree on how you see your child?
No spouse/partner ____

a lot |--| a little

20 If your child did not have this chronic condition, how different would your child be compared to what she/he is like now?

a lot |--| a little

21 How much of your family's daily activities have to be planned around your child's needs?

a lot |--| a little

22 How much does your child participate in the same activities as his/her peers?

a lot |--| a little

23 How much is your family like other families?

a lot |--| a little

24 How much leeway in terms of your child's behaviour do you permit your child because of his/her condition?

a lot |-- ------------- --| a little

25. IF YOU HAVE MORE THAN ONE CHILD : How much are your other children's <u>activities</u> affected by your child's condition?

not applicable__

a lot |---| a little

26 How much is your family like other families who have a child with a similar condition?

a lot |---| a little

27. How much do other people treat your child like they treat other children?

a lot |---| a little

28. How much are your <u>activities</u> with your spouse/partner or other adults affected by your child's condition?

a lot |---| a little

29 How much do you and your spouse/partner agree on how your child's condition and treatments should be managed?

No spouse/partner __

a lot |---| a little

30. How much do other people find your family to be like other families who have a child with a chronic condition?

a lot |---| a little

31. Do you belong to a support group or association related to your child's condition?

______yes ______ no

IF YES: How active are you now in the support group or association related to your child's condition?

a lot |---| a little

Appendix E: Demographic Questionnaire

ID ______

Please answer the following questions about your family

1 Your child's date of birth ___ day/___ month/ ____year

2 Is your child _ male _ __ female

3 What language do you speak at home.___________

4 Where was your child born ___________

5 What grade is your child in?_____________

6 What is your child's diagnosis? ____

7 Does your child have any other illness or problems?___________________________

8 What clinic(s) does your child attend ____________________________________

Who is in your family?

9 Mother your age ___

what is your ethnic background? ___________

In what country were you born? ________

If not Canada, how long have you been in Canada?_________

How many years of school have you had? _____

What is the highest degree/diploma that you have received?___________

What is your occupation? ___________

How many hours a week do you work? ________

Do you have any illnesses or conditions? _____________________________

father/partner : his age. ______

what is his ethnic background? ___________

In what country was he born? ________

If not Canada, how long has he been in Canada?_________

How many years of school has he had? _____

What is the highest degree/diploma that he has received?___________

What is his occupation? ___________

How many hours a week does he work? ________

Does he have any illnesses or conditions? ___________________________

Are you: __ married ___ remarried ___single ___ separated ___ divorced _ widowed?

remarried since when?___ separated or divorced since when?____

Number of years you and your husband/partner have been together _____

children :(1) birthdate _______________

any illnesses? (if yes, what?)___________________________

(2) birthdate _______________

any illnesses? (if yes, what?)___________________________

(3) birthdate _______________

any illnesses? (if yes, what?)___________________________

(4) birthdate _______________

any illnesses? (if yes, what?)_______________________

other family members? who? ____________________________________

10.When was your child diagnosed?

_____ _____ (month/year)

11 Does your child miss school because of his/her condition? __ yes __ no

12 Over the last 2 weeks, how many days of school or play has your child missed because of his/her condition? _________ days

13. Is this usual? __ yes __ no

14 Is your child limited in the kind or amount of activities and play because of her/his condition? __ yes no

Please slash the line at place that you feel best answers the question.

15 How severe is your child's condition in comparison to other children with the same illness?

much more severe|--| much less severe

16 How much information do you feel you have about the medical aspects of your child's condition?

everything I |--| nothing that I
need to know need to know

17 Have there been any changes or stressful events in or for the family in the last few months? if yes, What? _ ______________________________

Consent Form - Appendix F

McGill University - School of Nursing
Montreal Children's Hospital

I understand that this study is exploring how families manage a child's long term condition and how children with chronic conditions behave and develop I understand that this study is being carried out by Frances Murphy, a Masters of Nursing student.

I also understand that :

1. My participation is completely voluntary. The decision to participate or not in this study will in no way affect the care received at the Montreal Children's Hospital.

2. I will be asked to complete three questionnaires and answer some questions about how my family manages my child's condition This will take about one hour My child will complete one questionnaire.

3. The interview will be tape recorded. Only Frances Murphy and her research advisor, Dr. Laurie Gottlieb will hear the tape. The tape will be destroyed after the study is completed.

4. The information received is completely confidential. Questionnaires and taped interviews will be identified only by number.

5. I am encouraged to answer all questions but I do not have to do so

6. I agree that Frances Murphy have access to my child's chart for information on diagnosis and treatment.

7. Questions that I have about the study will be answered.

8. While neither my child nor I will benefit directly from participation in the study, the information gained may be useful in the future in assisting other families with children with chronic conditions. At the completion of the study, group results will be sent to me.

9. My child and I may withdraw from this study at any time.

Having read the above information, I agree to participate in this study. This study and the requirements of participation have been explained to me by Frances Murphy.

parent's signature	date	child's signature

Appendix G

Verbal Explanation Provided by Researcher

I'm Frances Murphy and I am a nurse who has worked with families who have children with chronic conditions. I am presently working on my Master's degree in nursing at McGill University. I am doing a project to learn more about how families manage chronic conditions and children's development. I hope that results of the study will improve future nursing care of families with children with chronic conditions.

If you agree to participate in this study, it will involve a one hour visit in your home. You will be asked to fill out three questionnaires and to answer questions about how your family manages your child's condition. The interview will be tape recorded. Your child will be asked to fill out one questionnaire. After you have finished, I will answer any questions that you may have about the study.

I would also be asking permission to have access to your child's chart for diagnosis and treatment information.

All the information is confidential. Only my research advisor and I will see the questionnaires and hear the tapes. Your name will not be used.

Your decision to participate or not will in no way affect the care you receive at this hospital.

If you decide to participate, we will arrange a time to meet that is convenient to you. Would you be interested in participating?

Appendix H

Items of each Normalization Subscale and their Factor Loadings

Actual Effect of the CPD on the Family Subscale

1. If your child did not have this chronic condition, how different would your family be compared to what it is like now? (.86)

2. If your child did not have this chronic condition, how different would your child be compared to what she/he is like now? (.80)

3. How much of your family's daily activities have to be planned around your child's needs? (.73)

4. How much are your activities with your spouse/partner or other adults affected by your child's condition? (.73)

5. How much of a hassle does your child's medical treatment create for your family's daily routine? (.71)

6. If you have more than one child: How much are your other children's activities affected by your child's condition? (.67)

7. How much does your child's condition affect your family life? (.55)

8. How much do other people treat your family like they treat other families? (.54)

9. How much does a child with a condition like your child's need to be treated differently because of the condition? (.52)

10. How reluctant are other people to include your family in some activity because of your child's condition? (.48)

Perception by the Family and Others of the CPD Child and Family Factor Subscale

1. How much does your child participate in the same activities as his/her peers? (.86)
2. How much do other people find your child to be like other children? (.83)
3. How much is your child like other children? (.80)
4. How much do other people find your family to be like other families? (.80)
5. How much does your child play with friends? (.74)
6. How much do other people treat your child like they treat other children? (.63)
7. How much is your family like other families? (.62)

Comparison of CPD Child and Family to other CPD Children and Families Subscale

1 How much do other people find your family to be like other families who have a child with a chronic condition? (.78)
2. How much is your family like other families who have a child with a similar condition to your child? (.65)
3. How much is your child like other children with a similar condition? (.57)
4. How routine does your child's medical treatment feel? (-.57)

Encourage Normal Activities Subscale

1. How much do you encourage your child to play with other children? (.75)
2. How much do you encourage your child to participate in extra curricular activities ? (.71)

3. How much do you encourage your child to attend school? (.69)

4. How much should a child with a condition like your child's be treated like other children? (.45)