PARENTS' PERCEPTIONS OF FAMILY-CENTERED CARE

IN A PEDIATRIC TERTIARY HOSPITAL

by

SONIA BUSCA OWCZAR

A THESIS

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A Thesis/Practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial
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ABSTRACT

Family-centered care is the latest paradigm shift in health care practice, aiming to empower parents to be collaborators in their children's health care. Do parents perceive this shift?

Using the nine principles of family-centred care that are well established in the literature as a framework for evaluation, a qualitative research design was employed to determine how parents of children with special health needs experienced the family-centeredness of services in an urban tertiary pediatric hospital.

Ten mothers and one father were interviewed. Their inclusion in the study was based on their experience with the hospital as determined by the needs of their children. These parents had children who were diagnosed with an on-going illness or disability, requiring inpatient or outpatients services at least three times annually, and who were cared for by more than one medical or allied health care provider. Purposive sampling was used to ensure that the parents had experience with a broad range of service areas to provide a general portrait of the hospital.

The findings reveal that not all of the nine principles were perceived to be implemented equally. Those principles which reflected health care activities that were consistent with conventional patient care were generally the more successfully implemented: competent medical treatment, supportive, informative relationships with parents and the respectful care of

children. The principles that were least implemented were those that required

giving parents more control outside the sphere of conventional medical care:

full participation at meetings, access to the medical record, linkages with

other parents, and access to external sources of information."

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INTRODUCTION

There is a revolution in the philosophy of service delivery in pediatric health care. Family-centered care (FCC) is an approach that is charging health care providers to put the family, not the institution, nor even the patient at the center of health care interests. It is an approach that aims to empower parents of children with special health needs to be partners in a collaborative relationship with medical professionals, respecting each other's expertise, supporting them in their natural care giving roles (Brown, Pearl, and Carrasco, 1991) and building on family strengths to better the health of their children(Shelton, Jeppson, Johnson,1987; Ahman, 1994; Hostler, 1991). There has been a paradigm shift that allegedly sees professionals as consultants and parents in charge: A change that has moved from an attitude of "Tell us your problem and we'll fix it" to "How can we help you"? This also involves a shifting emphasis from the assessment of family stress and dysfunction to that of exploring family strengths and needs (Ahman, 1994).

If there is in fact a movement towards family-centered care as just defined, do parents of children with special needs perceive this shift? How closely do the experiences of parents of children with special health needs reflect the principles of family-centered care in a pediatric tertiary health care facility?

This study endeavours to explore these questions. Chapter One will describe the elements that comprise the construct "family-centered care" as it relates to children with special health needs, and will apply the literature to elaborate on, and understand the concepts in practice, and the barriers to implementation. It will compare the principles of FCC to social work values and methods and demonstrate the utility of this type of inquiry to the social work literature.

Chapter Two will describe the qualitative research method, and how this method was used to address the question of how closely the experiences of parents of children with special needs reflect the principles of family-centered care in a pediatric tertiary hospital.

Chapter three describes the findings of the study, characterized by direct quotations from the respondents.

Chapter four draws conclusions from the data, suggests responses for social workers, and makes recommendations for future research,

CHAPTER 1

LITERATURE REVIEW

Definition Of Family-Centered Care

To place family-centered care, (FCC) in a broader conceptual framework of family oriented intervention models clarifies the extent to which this paradigm is consumer driven and competency based. Dunst, Johanson, Trivette and Hamby, (1991) outline four broad classifications of family oriented work:

(1) The Professional Centered Model sees professionals as experts who determine family needs from their perspective. Families are seen as pathological, or deficient and in need of help.

(2) The Family Allied Model sees the family as an agent of the professional, enlisted to implement professional interventions.

(3) The Family Focused Model sees families and professionals as collaboratively defining family goals. Families are encouraged to use professional services to meet their needs.

(4) Finally, the Family-Centered Model sees family needs and desires determining all aspects of service delivery and resource provision. Professionals are seen as agents of the family, and intervene in ways that are entirely committed to eliciting strength and competency in families.

The authors state that there is often confusion about the meaning of the concept of family-centeredness causing inaccurate use of the term.

Shelton, Jeppson, and Johnson, (1987) are credited with helping to shape, redefine and expand the meaning of family-centered care to encompass a broad range of practice and policy considerations as they relate to services for health impaired children and their families.(Trivette, Dunst, Allen and Wall, 1993). They did so by challenging the established thinking about how families should be treated in relation to their children's health care; then delineating eight elements of care that, taken together, constitute a philosophy about how practices, policies and systems need to change in order to become family-centered. Shelton, Jeppson and Johnson's work has become the gold standard used to examine personal interactions and institutional policies and procedures in the evaluation of FCC (Dobbins, Bohlig, Sutphen, 1994). So influential is their work that a study by Trivette, Dunst, Allen and Wall (1993:252) "concluded that CHC [the Children's Health Care journal] authors of family-oriented articles generally attended to family-centered care notions more often after compared to before the publication of *Family-Centered Care".* Although the work was pioneered around the first eight principles, the table below indicates a later addition, intended to respond more directly to the racial, ethnic, cultural,and economic diversity of families (Johnson,1990).

Table I.
Principles of Family-Centered Care
(Shelton, Jeppson and Johnson, 1987)

1.	Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate
2.	Facilitation of parent/professional collaboration at all levels of health care
3.	Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner.
4.	Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families
5.	Recognition of family strengths and individuality and respect for different methods of coping.
6.	Understanding and incorporating the developmental and emotional needs of infants, children and adolescents and their families into health care delivery systems.
7.	Encouragement and facilitation of parent to parent support
8.	Assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs.
9.	Honoring the racial, ethnic, cultural and socio-economic diversity in families.

Special health needs are defined through practice wisdom as chronic illnesses, physical disabilities, and developmental disorders. Jessop and Stein (1988) further define them as conditions that are long term, incurable, or have residual features that result in limitations in daily living requiring special assistance or adaptation in function. The number of these children has nearly tripled from 1960 to 1988, and their survival rates have increased such that nearly 90% reach adulthood (Hostler, 1991). Consequently, children with special needs and their families embark on a life-long relationship with the health care system, experiencing on-going chronicity and repeated hospitalizations. Parents must be able to negotiate that system to obtain health care for their children, while fulfilling the role of primary health provider at home (Robinson,1987). They also must manage

the on-going and long term psychological, social, educational and recreational needs of their children.

Origins Of Family-Centered Care

With the realization of the complexity of this relatively new social phenomenon, then American Surgeon General C. Everett Koop initiated a series of workshops in 1982 entitled "The Surgeon General's Workshop on Children with Handicaps and Their Families". This was followed by the Division of Maternal and Child Health of the U.S. Public Health Service supporting the Association for the Care of Children's Health (ACCH) in their efforts to enhance the implementation of family-centered care (Handmaker, 1988). It was from these initiatives that Shelton, Jeppson and Johnson defined the elements of FCC. In Canada, The Canadian Institute of Child Health(CICH) encouraged a federal task force to develop a comprehensive review of children's health care which resulted in the 1983 publication of "Guidelines for Care of Children and Adolescents in Units in General Hospitals" (Health and Welfare Canada, 1983). CICH and ACCH currently cooperate to improve and promote family-centered services for hospitalized children (Avard, Post and Drown,1990).

Long before these initiatives, the rise in the consumer movement of the 1970's laid the attitudinal foundation for FCC. The word "patient" derives from the Latin "pati"-to suffer and "clinare"-to lean. This passive role of patient before the experts was challenged by the consumer movement which

advocated for the recognition of the rights and responsibilities of health care recipients (French, 1979). The tenets of FCC emphasize that services must be designed to view patients and their families not as passive recipients, but as active participants in health care.

Principles

"While it is important to discuss the individual components of FCC, it is equally important to consider all the elements as a whole. FCC is not just one component. Each element reinforces and facilitates the implementation of the others. Together the elements convey a new philosophy of care-- moving from an institution/agency oriented approach to a child centered approach and most recently to a family-centered approach" (Shelton, Jeppson and Johnson, 1987:1). However, to best understand these principles, each will be defined, drawing largely from the ACCH publication of Shelton, Jeppson and Johnson(1987).

1.   Recognition that the family is the constant in the child's life while service systems and personnel within those systems fluctuate

The first element establishes the assumptive grounding for the entire philosophy of FCC, emphasizing that the ultimate responsibility for the management of a child's health, developmental, social and emotional needs lies with the family. Professionals must remain ever mindful of their brief involvement with families (Rushton, 1990). The family's needs must be of

paramount concern, with professional assessment done with, not to them to develop a joint plan of care (Bond, Phillips, and Rollins, 1994), based on parents' concerns, desires and needs. The health care system must enable families to act as primary decision makers, caregivers, teachers and advocates for their children to the extent which is possible for individual families. Shelton, Jeppson and Johnson (1987:4) quote one parent as saying "I'm not a member of the [health care] team, I'm the captain of the team". However, Rushton (1990) cautions about assuming what level of participation is appropriate for individual families.

Cultural beliefs, attitudes towards authority or life complications may predispose some families to choosing minor roles in their child's care in hospital. Roles and responsibilities of both parents and professionals must be defined. Parents should be asked how they would like to participate in the care of their hospitalized child and be active participants in discharge planning so that care at home can be most effective (Hostler, 1991).

2.   Facilitation of parent/professional collaboration at all levels of health care

For many years health professionals operated in an environment in which they provided care, made decisions and controlled the information to parents. Professionals, not parents were in control (Shelton, Jeppson and Johnson 1987). Collaboration improves the outcomes for children with special needs by recognizing and respecting the knowledge, skills and

expertise of all the child's caregivers (Bishop, Woll, and Arango, 1993). As the collaborative model is relatively new, both parents and professionals must acquire skills that foster open communication, negotiation and conflict resolution: and must develop trust. The degree to which parents participate as equal collaborators, however, is a decision each family must make. This decision may change at various times depending on their life circumstances. Hostler (1991) advocates that true collaboration gives parents access to their child's medical file, and also extends to them the right to record in it, especially in the event of conflict. Such access would help to keep the record as a clearly written document, free of pejorative labelling. Effective collaboration grows in an organizational climate where it is encouraged. Before health care providers can constructively collaborate with parents, the degree of collaboration with each other should be examined. The decision making structure of the staff, the roles and status of each discipline, and the methods of resolving conflict are essential contributors to effective collaboration (Rushton, 1990). A Family Advisory Committee, comprised of parents and staff can provide a forum for collaboration at the organizational level.

3. **Sharing of unbiased and complete information with parents about their child's care on an on-going basis in an appropriate and supportive manner**

Knowledge eliminates parental powerlessness and dependence on staff (Hostler, 1991); and can be shared by professionals, by referrals to

outside information sources or through a Family Information Library within the hospital. Information not only has an emotional impact, but also empowers parents to participate in decision making to the extent that they wish. Information shared in lay language, verbally, in written form, or through demonstration will be most effective, especially if it is well timed and offered in the presence of as many family members as appropriate. Parents who are new to the medical system may have difficulty articulating their needs, as parents and professionals may speak a different language. For example, offering "respite services" to a parent who simply wants a few hours off may create a barrier in communication. As information is mutually shared between health care providers and parents, issues of confidentiality become paramount. Parents should be told the reason that they are being asked sensitive questions, and their right to decline information should be respected.

4. **Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families**

Lum, (1982) defines health policy as a collection of goals, directions and guidelines that regulate the execution of programs and activities in public or private health organizations. As such, FCC principles can guide hospital policies from an organizational point of view. The physical structure of the institution has a vital role to play in the comfort felt by families. Rooming in by parents, and unrestricted visitation by family members has

been demonstrated to result in more favourable hospital adjustment of children and greater performance of developmentally appropriate behaviour (Thompson, 1986). Facilities that encourage this, such as beds, bathing facilities, family kitchens and parent lounges would be beneficial to families of hospitalized children. Procedures that eliminate or shorten admissions, or conversely, that allow for admissions during periods of family stress should be sensitive to family needs. A policy of routinely offering parents extra support from mental health professionals such as social work, psychology, or chaplaincy before it may be requested may be helpful to those that may not be aware of those services or who might be hesitant to ask for them (Rushton,1990). Supporting families by referrals to, or information about appropriate resources reinforces the understanding that the lives of hospitalized children and their families continue far past the institution's walls. The financial implications of having an ill child, such as the cost of medication, transportation, or lost wages, should be acknowledged with appropriate supports.

5. **Recognition of family strengths and individuality and respect for different methods of coping**

Parents respond to illness in their children in many different ways. Information seeking behaviours, crisis reactions, and mourning reactions are examples of those coping strategies (Rushton, 1990). Recognizing that families cope in diverse ways, and affirming their strengths and coping

mechanisms provides an important service to families of ill children (Ahman, 1994). An understanding of each family's circumstances; its relationships, beliefs, financial situation, lifestyle and emotional status, will assist in understanding how those roles and responsibilities are affected by parenting a child with a chronic illness. It is of great importance to understand the goals and priorities that parents have for their child, as undoubtably, that child is more than a disability or set of symptoms to his/her family.

6. **Understanding and incorporating the developmental needs of infants, children and adolescents and their families into health care systems**

Health care organizations and professionals within them can go beyond the physical care of children by displaying a sensitivity and commitment to the normal developmental tasks of children with special needs. This is particularly important in this population which is at risk of having normal development interrupted by frequent hospitalizations, and greater physical, and emotional challenges in daily living. As much as possible, inpatient routines should follow home schedules for naps, snacks, playtime and bedtime (Hostler, 1991). Limit setting and discipline in hospital should be enforced by both staff and parents to normalize the hospital experience and afford the child the greater sense of security which structure provides. Age appropriate programming in hospital, such as play activities for youngsters or pizzas and videos for adolescents, respects patients as children first. School attendance, to the extent that the child is able, assists

in structuring the day, normalizing the hospital experience and encouraging the child to keep up with academic requirements during absences from school. Success in achieving these ideals depends both on the policies and programs in the institution and on the staff's readiness to support their use on behalf of children in hospital.

7. Encouragement and facilitation of parent to parent support

Support groups for parents of hospitalized children can be beneficial in many ways. Winch and Christoph, (1988) suggest that parents gain confidence in becoming advocates for their children, themselves and other parents by gaining an awareness of themselves and of the system. Communication skills can be learned and practiced while sharing information, educating one another and correcting misconceptions. A support network that begins in hospital often initiates friendships beyond the group sessions and may act as a springboard for a community based self help group. Organized groups are not the only way to foster parent to parent support. Routinely asking parents if they would like to meet another family in similar circumstances, or if they would like to be available to someone for support can establish links with others. Policies that protect the privacy of families may also work against them by isolating people from each other. Permission must be sought to share names, or to develop a roster of interested support people. Shelton, Jeppson and Johnson stress that a perfect "match" is not necessary as parents of children with special

needs have many similarities regardless of diagnosis.

8.   Assurance that the design of health care delivery systems is flexible, accessible and responsive to family needs.

Health care efforts must be accommodating to children with multiple needs and their families. "Services tied to narrow diagnostic categories may penalize those children whose complex conditions either overlap several disease categories, or fall between them, and may prevent families from obtaining needed services" (Shelton, Jeppson and Johnson, 1987:45). This calls for effective coordination of information among health care professionals and with external agencies. Attention to the coordination of appointments is also helpful to streamline the time taken in obtaining health and social services. Of great value is the designation of a primary physician and/or nurse to provide continuity of care and ease of entry into the medical system. Rushton (1990) states that a critical assessment of the setting must be made to determine what detracts from, or enhances family-centered care in order to develop goals, objectives and evaluation criteria, and then to proceed in a deliberate and well planned manner to implement those policies.

9.   Honouring the racial, ethnic, cultural and socio-economic diversity of families

This later addition to the elements of FCC is poorly examined in the literature, and is most often ignored. In fact, it is not included in the latest

edition of Shelton, Jeppson and Johnson, revised in 1992. However, as reference to its inclusion was made by one of the original authors, (Johnson, 1990), it will be included in this study. Its inclusion is particularly important when assessing health care settings serving a wide range of families.

Obstacles To Family-Centered Care

The preceding principles represent the ideals of family-centered care. Yet there is reason to believe that obstacles exist to the realization of these ideals. Wayman (1996) asserts that the shift in thinking to FCC involves a transformative process within professionals and institutions that is philosophically in conflict with the existing guiding principles of these institutions. Hospitals, she contends, are a logical extension of the scientific method, guided by linear, mechanistic processes describing "a reality in which causality, prediction, certainty and control all appear possible" (Wayman,1996:2). A clash occurs when attempting to apply this thinking to human behaviours, attitudes and thoughts which by nature are complex, unpredictable, and influenced by what each element, person, and interaction brings to an event.

Hostler (1991) claims that significant changes in the roles played by both parents and professionals must occur alongside reforms in policies and practices of the health care system to ensure successful implementation of family-centered care. "Many professionals agree that respect for families and involvement of them in the care of their children is the foundation of

quality pediatric heath care. Yet when specific attitudes, policies, and practices concerning families are examined, both subtle and overt actions sometimes fail to reflect a commitment to such respect and involvement" (Rushton,1990:68).

Berman (1991) interviewed 22 nurses in a children's hospital to determine their understanding and implementation of FCC as defined by the nine elements. It was found that although nurses supported the family, there were different and varied interpretations of family-centered care, some at odds with the accepted definition. The study concluded that in the absence of a clear mission statement from the hospital about the value of FCC, it would be difficult to expect nurses to adhere to similar interpretations. One could extrapolate that these findings may hold true for all disciplines.

Health care delivery, which is largely organized by diagnostic classifications or sub-specialties, is in danger of being oriented more towards the needs of the institution than to the functional needs of families. This may result in fragmented care and run counter to the goals of optimum independence for the child and family. (Kohrman and Diamond, 1986). Services to families that reach across diagnoses, encompassing a non-categorical approach to chronic illness are as yet not the norm in most health care institutions, despite significant benefits for families (Stein and Jessop, 1994).

Rushton (1990) makes observations about barriers to family centered care practices in a critical care environment that have applicability to

services for chronically ill children. Specialization in a highly technical environment risks increasing the emphasis on the physiological well-being of the child and minimizing the socio-emotional issues relevant to families. The high level of acuity and rapid turnover of patients in many modern hospitals make it difficult for staff to sustain meaningful relationships with families. Shortages create a busier and potentially less emotionally responsive staff that may feel that parent participation increases demands on already limited resources. Increasingly sophisticated technology creates more complex ethical dilemmas necessitating decisions that are considered too burdensome for already stressed families.

In a Canadian study, Robinson (1987) interviewed nine parents from six families to ascertain what were the roadblocks to FCC. She classified her findings into four themes:

(1) Parents and service providers have a discrepant orientation to sickness. Acute care teaching hospitals tend to have a "here and now" perspective treating each hospitalization as though it were the first, or focussing on the admission problem. Parents of chronically ill children view hospitalization within an ongoing long term experience with illness.

(2) Discrepancy exists between parents' and staff's therapeutic goals. The health care providers interest in curing or ameliorating a particular difficulty may clash with the family's primary goal of normalization for the child.

(3) Providers and families may have discrepant expectations about the hospital experience. Kagle and Hsieh, (1991) strengthened the argument about the need to understand patient/family expectations when they found that patients were more apt to express satisfaction with services if their expectations were met, and more satisfied patients tended to be more effective participants in their health care.

(4) Robinson's fourth theme relates to discrepant perspectives about family involvement in care. Parents in her study expected collegial relationships with providers founded on mutual trust and negotiation. Instead, "the parents got the message that the health care professionals were in charge, that parents could be involved if it did not interfere with professional care and that they would be told what they needed to know...family involvement was hindered by the 'life' of a busy acute care hospital"(p.190).

Professional attitudes may also inhibit FCC practices. Kohrman and Diamond, (1986) charge that traditionally medical institutions maintained their integrity though the perpetuation of medical roles vested with power and prestige. This would run counter to a model of empowerment.

Baily, Palsha, and Simeonson, (1991:156), "found that professionals reported substantial discrepancies between how they actually worked with families and how they thought they should be working with families". In a study of 142 early intervention professionals, they found that nurses and social workers were the most comfortable with their own skills related to

work with families. Given that these professional groups have the greatest amount of formal training in work with families, one might expect that those disciplines whose training is predominantly child focused would experience the greatest challenge in shifting their orientation to family-centered care (Baily, Palsha, and Simeonsson, 1991).

Many studies evaluate or describe FCC mainly on the basis of parental participation in the care of hospitalized children. Romaniak(1993) interviewed ten mothers and six fathers of children with cancer to understand how parents share the care of their children with staff nurses. She developed a conceptual framework that consists of three main themes: nurses and the care they give, parents and the care they give, and parents and nurses and the care they give together. Each of these care activities are influenced by several factors: life inside the hospital, life outside the hospital, personal characteristics of the parent and child. Personal characteristics of nurses were not emphasized. The nature of the parent-nurse relationship depends upon each individual's ability to work together to successfully negotiate health care activities within these circumstances.

Dobbins, Bohlig and Sutphen, (1994) studied 204 families to explore parental perceptions of the obstacles to their assumption of parental roles within the neonatal intensive care unit. They found that the chief barriers to parental participation related to the parents' ability to visit their baby due to the hospital's distance from home and the length of the baby's stay in

hospital. Other environmental obstacles related to the lack of space at the bedside, and little privacy while visiting.

Gill (1993) sampled 1022 multidisciplinary members of the Association for the Care of Children's Health to determine which personal and professional characteristics were most compatible with acceptance of parental participation in the care of hospitalized children. She found that participation by parents was more greatly accepted by respondents who were parents themselves, currently or previously married, educators, older, more experienced, and had a higher level of education.

Although parental participation is a vital component of family-centered care, FCC is too often narrowly defined, both in practice and in the literature, as the involvement of families in the treatment of their children in hospital. This definition neglects the more comprehensive philosophical and ecological assumptions of family-centered care.

Empirical Measures

O'Brian and Dale (1994:78) state that "despite the emphasis on family-centered services in current legislation and in the theoretical literature, little empirical research is available to document the effectiveness of such approaches".

Murphy, Lee, Turnbull and Turbiville(1995) reviewed the literature to locate existing family-oriented program evaluation instruments. Those

chosen for mention in their review were those that were designed to help

parents or staff members think about how their programs met the needs of

families and not just the children for whom services were targeted. They

report "substantial differences between instruments in their degree of

specificity, length, planned uses, and the rigor with which they have been

developed and tested" (1995:27). Two other measurement scales have

been chosen for further elaboration here due to their direct relevance to

family-centered care both in their construction and in their intent to evaluate

FCC in its most ecological sense. There is utility in exploring these

quantitative measures to expand the understanding of the constructs that

make up family-centered care from the point of view of parents.

"A major barrier to full implementation of family-centered practices is

the lack of clearly defined practice indicators" (Murphy, Lee, Turnbull and

Turbiville,1995:24). To address this issue, these researchers developed the

Family-Centered Program Rating Scale (FamPRS). FamPRS is a paper and

pencil program evaluation instrument designed for use with families of

children with disabilities, aged birth to 5 years. The items on the

questionnaire were derived from focus groups and feedback from both

professionals and parents across diagnostic categories, geographical

locations, and educational levels. Eleven subscales were distilled:

1)flexibility and innovation in programming, 2)providing and coordinating

responsive services, 3)individualizing services and ways of handling

complaints, 4)providing appropriate and practical information,

5)communication timing and style, 6)developing and maintaining comfortable

relationships, 7)building family-staff collaboration, 8)respecting the family as

decision-maker, 9)respecting the family's expertise and strengths, 10)

recognizing the family's need for autonomy, 11) building positive

expectations.

Content validity for the rating scale was ensured by soliciting expert

judgment at every stage of instrument development. Information and advice

was sought from parents of children with special needs, national leaders,

program administrators, teachers, therapists and para-professionals.

Evidence of construct validity was not clearly demonstrated in this paper,

however, reliability of the eleven subscales was deemed to be moderate to

high. Internal consistency coefficients of the subscales ranged from .72 - .84

for parents. Internal consistency coefficients for staff were marginal to high:

.63 and .64 for individualizing services and ways of handling complaints, and

building positive expectations respectively to .87 for appropriate and practical

information.

A group of Canadian researchers have recently developed a 56 item

questionnaire entitled the Measure of Process of Care (MPOC) (King,King

and Rosenbaum,1995). Like FamPRS, it was designed for use with families

of preschoolers with disabilities, aged 3-6 years. It's purpose is two-fold--to

aid in program evaluation when assessing the extent to which parents

perceive pediatric rehabilitation services to be family-centered, and to measure the process of caregiving and how that relates to the outcome of parental stress or wellness. It is based on the assumption that interactions between health care providers and parents contribute both to satisfaction with services and also to parental stress or well-being. The items on the scale were generated with the use of focus groups and feedback from parents to determine which behaviours among health care providers were important to parents of children with chronic health and developmental problems. Five subscales were developed: 1)enabling and partnerships, 2)providing general information, 3)providing specific information about the child, 4)coordinated and comprehensive care for child and family, 5)respectful and supportive care. The instrument was reported to be reliable and valid, however, details of its psychometric properties were contained in the MPOC manual and not available in this report. Consultation with fifteen hundred parents from thirteen children's treatment centres occurred to ensure that the items in the scales were relevant. Internal consistency of the five subscales ranged from a marginal .63 for providing specific information about the child, to a high of .94 for providing general information.

A limitation of both of these instruments is that they were designed based on populations that were relatively well educated (high school or higher for both instruments). The racial/ethnic composition of the participants in the FamPRS development is not known, but that of MPOC

was made up of predominantly English speaking and caucasian individuals. Whether or not the items in the subscales would rank with the same importance for families not of these categories is not known.

Relationship to Social Work

Family-centered care is consistent with the ecological model of thinking and practice insomuch as it emphasizes the individual, the family and the environment of which they are a part. It concerns itself not only with supporting families, but also with altering the delivery of care so that it is more responsive. The model requires not only helping the child and family to fit the environment, but also changing the environment to fit the child (Brown, Pearl and Carrasco, 1991). Brown, Pearl and Carrasco (1991:55) claim that "ecological concepts of family empowerment and 'goodness of fit' are beginning to influence the [health] service delivery system, but remain little known and accepted".

Ecological practice is both well known and widely accepted by social workers in health care. Twenty years ago Naeman (1975-76:140) wrote that the social work role in health care was to maximize human potential and change social institutions so that human potential could be realized. "Of equal importance in considering patient care is the internal makeup of the health organization that is providing the service. Structural and attitudinal factors influence how services are rendered...the social worker, with

combined knowledge of the hospital organization and the patients' physical, emotional and social needs is in an advantageous position to diagnose organizational problems regarding staff attitudes, communications, the appropriateness of facilities and programs and the degree of coordination and continuity of services both within and outside the specific health facility". Naeman adds that social work skills related to organizational theory, change strategies and conflict management lend themselves to practice that includes direct service, organizational change and social action programs.

Coulton (1981:26) states that "substantial agreement seems to exist among social workers that the focus of social work is the person and environment in interaction and that the profession's purpose is to promote or restore a mutually beneficial interaction between individuals and social institutions".

Germain (1984:230) recognizes that "the health care organization can help to maintain the competence of patients and families, or it can undermine it...support or diminish self esteem, sustain or dismantle their self directedness, and enhance or stifle their capacity for human relatedness". She maintains, therefore that social work advocate or influence change in procedures, structures and policies that are not responsive to family coping, needs or cultural patterns.

At the core of social work practice are the concepts of client self determination and empowerment. Family-centered care is also based on

principles that promote self determination, decision making capabilities and self efficacy (Dunst, Trivette, Davis and Cornwell, 1988). According to the above authors, a help giving model that is empowering and enabling to families is predicated on three conditions:

a)   People are already competent or have the capacity to become so.

b)   Failure to display competence does not reflect personal deficits but rather the failure of social systems to create opportunities for competence to be displayed.

c)   Clients must have information to make informed decisions, be able to access resources to meet needs, and attribute behaviour change to their own actions.

Clearly, the concept of family-centered care is consistent with the values, skills and practices of social workers. Yet, while there is a revolution in the philosophy of service delivery in pediatric health, social workers have remained conspicuously silent in the literature. As the value base and competency requirements that underscore family-centered care is indigenous to social work, social workers have an opportunity, a right and a responsibility to further the goals of FCC in pediatric health care facilities.

CHAPTER 2

METHODOLOGY

QUALITATIVE RESEARCH

The aim of this study was to determine how closely the experiences of parents of children with special health needs reflect the principles of family-centered care in a tertiary health care facility. Drawing on the perceptions of parents, the following research questions were considered:

(1)   Are each of the principles of family-centered care (FCC) being implemented at Children's Hospital?

(2)   How are they being implemented successfully?

(3)   What are the barriers to the implementation of FCC?

(4)   How do parents generally experience FCC at Children's Hospital?

The methodology of choice for this study was to employ a qualitative design. Qualitative research design facilitates a mode of empirical inquiry that explores and describes naturally occurring social phenomena. "Qualitative measures describe the experiences of people in depth. The data are open-ended in order to find out what people's lives, experiences, and interactions mean to them in their own terms and in their natural settings" (Patton 1980:22). The emphasis in qualitative research is on

understanding, rather than predicting social phenomena.

Marshall and Rossman (1989) describe qualitative inquiry as research that values the participants' perspectives on their worlds, relying on people's words as the primary data. It entails an immersion of the researcher in the experiences of the participants, creating an interactive process among the researcher, the participant and the data.

Knowledge born from qualitative analysis is inductive in nature. By examining the data for patterns and relationships, the researcher is able to generate theories or use developed theories to explain the data. Thought processes move from specific ideas, to more generalized ideas that can then result in the identification of concepts and potential relationships. This inductive process is directed towards bringing knowledge into view (Field and Morse, 1985).

The investigation in this study, although using inductive techniques, was not entirely inductive in nature. By using the nine principles of FCC to guide the formulation of the interview schedule, the data was evaluated based upon a priori concepts of family-centered care. Although limiting the scope of the data collected, this approach ensured that the evaluation was acutely focussed on the implementation of the nine principles.

WHY QUALITATIVE METHODOLOGY?

The qualitative research method was chosen for this study because it is a strategy that is particularly well suited to work that aims to describe phenomena from the participants' point of view. (Field and Môrse,1985; Patton,1980; Marshall and Rossman,1989). This method lends itself to in-depth, and detailed study of participants' subjective experience, without the constraints of predetermined categories of analysis (Patton 1987). Allowing the data or information to emerge from the parents, is respectful of the vision of family-centered principles as being consumer driven and competency enhancing.

Qualitative research focuses on context, using disciplined subjectivity to understand reality from many points of view. It is most useful in understanding the impact of the setting on participants (Bernheimer,1986).

To gain greater awareness of where the strengths and the gaps lie relative to the delivery of family-centered services at Children's Hospital, it is most useful to obtain the perceptions of the parents who use those services. It is only through a systematic assessment of parents' perceptions of needs, services received and outcomes that professionals can begin to understand whether interventions were in fact family-centered (Mahoney, O'Sullivan and Dennebaum,1990; Flynn and McCollum,1993; Bond, Phillips and Rollins,1994).

SETTING

The study was carried out at Children's Hospital of the Health Sciences Centre in Winnipeg, Manitoba. Children's Hospital is the largest pediatric tertiary care facility offering medical services to children of Manitoba and Northwestern Ontario. The hospital is actively pursuing the implementation of family-centered care principles in philosophy and practice. The philosophy is most clearly found in the policy statement of the Children's Hospital Department of Nursing which clearly supports FCC and seeks to operationalize it by putting forward relevant standards. These standards relate to involving the family in planning and participating in the child's care, supporting the family by the provision of information, referrals to appropriate services within the hospital and the coordination of services. The standards also promote developmentally appropriate services and activities for children, and activities that support and enhance community programs that are relevant to the children who use Children's Hospital (Philosophy Statement, Pediatric Nursing revised Jan,1992). As well, the Children's Hospital Management Advisory Committee(CHMAC), the governing body of the hospital endorses and supports the Family Advisory Committee (CHMAC minutes, November,1993). The Family Advisory Committee (FAC) is composed of parents who represent "the diverse backgrounds, skills, interests, needs, and perspectives of Children's Hospital families" and whose purpose is to "endeavour to ensure that the highest quality of family-centered

care at Children's Hospital is provided, preserved and enhanced" (FAC

terms of reference,1993). Clearly, groups with significant authority have

sanctioned the adoption of family-centered care principles at Children's

Hospital.

PROGRAM EVALUATION

This study takes an interest in describing the experiences of parents

of children with special health needs in a setting that offers family-centered

care. It is expected that clinical value is derived by this inquiry in furthering

the understanding of the experiences of a segment of this population with

the health care system. Such knowledge could assist health care providers

in maximizing their relationships with parents, thereby improving services to

children. Compatible with the aims of the study is also an aspect of program

evaluation, examining how Children's Hospital achieves its mandate of

implementing one aspect of a very complex health care delivery program.

Raymond defines program evaluation as "the degree to which a social

program succeeds in reaching its predetermined objectives"

(Raymond,1981). Bigman identifies several primary processes of program

evaluation, with the following being most pertinent to this study: (1) to

discover whether and how well objectives are being fulfilled (2) to determine

the reasons for specific successes and failures (3) to uncover the principles

underlying a successful program (Bigman,S,1961 cited in Raymond 1981).

In so far as the principles of family-centered care are accepted as the philosophy of care at Children's Hospital, and aim to provide direction and guidelines for the execution of programs, it is useful to evaluate their implementation from at least one perspective: the experience of parents.

Information about implementation describes whether or not a policy is being put into operation according to design. If policies are not implemented, there is no reason to assume that desired outcomes will be achieved (Patton 1980). Williams and Elmore define implementation as the stage between decisions and operations. "The fundamental implementation question remains whether or not what has been decided actually can be carried out in a manner consonant with that underlying decision. More and more, we are finding, at least in the case of complex social programs, that the answer is no. So it is crucial that we attend to implementation"(Williams and Elmore 1976:xi).

Qualitative research methods are suitable when the evaluator needs to do more than confirm the presence of an anticipated outcome (Broughton,1991), by exploring the reasons for the natural and common deviation from the original objectives (Patton,1980).

True implementation analysis starts with a consideration of the clarity, precision, comprehensiveness and reasonableness of a policy (Williams and Elmore,1976). This investigation was not intended to be a full implementation analysis in that it did not critique the policy itself, but rather accepted family-

centered care principles as given. Also, it did not intend to analyze the policy from multiple points of view. The scope of the study was to undertake an assessment of the degree of correspondence between a stated policy--the adoption of family-centered principles at Children's Hospital, and the actual outcome--the experience of parents as valued participants in the health care of their child.

DATA GATHERING

Lofland (1971) identifies four elements of collecting qualitative data:

(1)   getting close enough to the people and the situation to be able to understand the depth and details of events.

(2)   capturing what actually takes place and what people actually say.

(3)   obtaining abundant pure description of people and interactions.

(4)   reflecting the data by direct quotations from research participants. (Lofland 1971 cited in Patton 1980)

The data in this study were gathered with the aid of a semi-structured standardized interview guide. As Lofland and Lofland (1984) state, the goal of the interview in qualitative research is to discover the experience of informants on a particular topic. It focuses on what exists in the first place, and not on the frequency of the occurring phenomenon. The fundamental

purpose of the qualitative interview is to provide a framework within which informants can express their own understanding in their own terms (Patton, 1980).

With the interview being the primary vehicle for data collection, its structure and content must be carefully considered. A semi-structured standardized format provides for a set of questions to be "worded in a predetermined fashion, while permitting the interviewer more flexibility in probing and more decision making flexibility in determining when it is appropriate to explore certain subjects in greater depth or even to undertake whole new areas of inquiry that were not originally included in the interview instrument"(Patton, 1980:24).

The information sought from each respondent in this study was the same, but the wording and sequence of the questions occasionally changed to suit the nature of the interview. This approach assumes that although the instrument is not entirely standardized, the goal of the interview is to seek meaning that is standardized. To achieve this, the interview must be formulated in words that are familiar to each respondent, and questions asked in a sequence and at a pace comfortable to him/her(Bernheimer,1986).

In order to have the study methodology reflect the philosophy of family competence and parent/professional collaboration, the assistance of the Family Advisory Committee(FAC) was sought to help to formulate the

interview questions. A letter was sent introducing the project, and asking for members to participate in a focus group to help formulate the interview questions and later to help in the recruitment of respondents (see Appendix 1). Three active members of the FAC volunteered to participate in conceiving the questions. All three had substantial experience with Children's Hospital due to the needs of their children. In their capacity as committee members, all had reflected a good deal on the meaning of family-centered care. The three participants were women, two Caucasian, one Aboriginal, and all interacted with different services at the hospital from one another. They were sensitive to the fact that their involvement with the FAC may similarly influence their thinking and tried to recognize the views of dissimilar parents.

In preparation for this meeting, the author drew together relevant points from the literature that related to each of the principles to assist in directing the discussion. Included in these points were also items from the Family-Centered Care Rating Scale (Murphy, Lee, Turnbull, and Turbiville,1995). This small group worked for three hours to tease out the salient points of each principle and to word questions in a way that was open-ended and not leading. The author was charged by the group with the task of refining the wording once the general groundwork was laid. The group members were generous with their stories and perceptions of their experiences as they related to their child's time in hospital. This information

would have added richly to the ultimate data collection but was not gathered as such. In the rethinking of the questions, their substance did not change, as they were conceptually grounded. In some cases, however, slight changes had to be made to comply with Patton's (1980) suggestion that each question be open-ended, neutral, singular and clear. The interview schedule was further refined through feedback from the thesis committee and from the experience of interviewing parents in two pre-tests. One critical change was to clarify with respondents that they in fact agreed with each principle rather than simply assuming that the principles were universally relevant. The final questions were resubmitted to the focus group for feedback. No objections were raised (see Appendix 2).

Nine interviews were conducted in the homes of respondents; two occurred at the hospital. The author reviewed the consent form with the respondents, and asked for assurance of their understanding, and therefore their signature. All interviews were taped, and lasted about 90 minutes. The interview schedule seemed to address the relevant constructs, so was followed quite closely. As is acceptable and necessary in qualitative interviewing, other leads were occasionally followed, and probes such as "Can you think of an example of that?", or "Can you tell me a little more about that?" were used. At the end of the interview, respondents were asked to fill out a short face sheet that ultimately provided a demographic description of the sample (see Appendix 3).

Notes were taken after each interview to reflect general themes or curious variations in the data. The interviews were then transcribed to prepare them for data analysis.

SAMPLING

Purposive sampling was used to select cases for the project. This approach to sampling is defined by Field and Morse(1985) as a method that selects informants who will most encourage the emergence of theory by specific characteristics that support or refute the theory. The objective of purposive sampling is to maximize the information received from a small sample and not to facilitate generalizations(Lincoln and Guba, 1985). The sample size was not established at the outset; rather, sampling stopped when no new material became available, and incoming information was redundant. Purposive sampling allows the researcher to choose those cases which will be the most useful in fleshing out the data.

The original inclusion criteria targeted those families who have a child with an on-going illness or disability, where in-patient or out-patient services are required with a frequency of at least three times per year. This ensured that respondents had sufficient experience with the services of Children's Hospital. Inclusion was limited to those families who required medical services from Children's Hospital until responsibility for those services is transferred to an adult facility.

Respondents were recruited by the generous cooperation of the FAC and hospital personnel who came across families through the course of their work. Individual or collective meetings were held with FAC members, nurses and social workers to describe the purpose of the study and outline the inclusion criteria, particularly highlighting the need to recruit Aboriginal and ethnic minorities. Information was handed out on paper (see Appendix 4), along with a package to be distributed to potential respondents. A self-addressed, stamped envelope contained the principles of family-centered care, a description of the study and an invitation to participate (see Appendix 5). Interested parties were asked to respond to the researcher directly, using the enclosed tear-off sheet. This procedure ensured that all participation was totally voluntary, and that the author could not influence the respondents to enter the study. Despite actively requesting that Aboriginal and immigrant/refugee families be recruited, no Aboriginal families became available through this process. A separate approach to the Aboriginal Services Department of the hospital was made to try to include this population in the sample. When this did not result in successful recruitment of Aboriginal families, a request was made of an outside agency that shared service delivery to First Nations families with Children's Hospital. Unfortunately, no Aboriginal families were recruited for the study despite these efforts.

ETHICAL CONSIDERATIONS

Safeguarding the rights of respondents and ensuring that they did not feel in any way forced to participate in the study was of paramount concern. This project was reviewed and granted ethical approval by both the Faculty of Nursing and the Faculty of Social Work of the University of Manitoba (see Appendix 6). It was also reviewed and passed by the Pediatric Research Coordinating Committee of Children's Hospital: a committee designed to ensure that patients are protected, and that no one population or service area is over burdened with research activity (see Appendix 7).

As previously noted, the recruitment procedure was devised to protect respondents by using hospital personnel and FAC members to describe the project. In that way, all persons who ultimately agreed to participate did so voluntarily after also being assured by the recruiters that they could terminate at any time, and that their decision about participation in no way affected the care their family received at Children's Hospital. Because the author is also a staff person at the hospital, she did not recruit from her own caseload so that there was no misunderstanding about her role in the lives of the respondents, and so that she would not be perceived to be in a position of power vis a vis respondents. Another safeguard was that it was up to respondents to approach the researcher for further information about the study, or to indicate their willingness to participate.

She had no contact with families until they expressed their interest directly to her.

Pre-screening of the respondents consisted of a telephone call to them once the researcher had received the tear-off sheet that was included in the recruitment package. The pre-screening contact was to ensure that the respondents understood the purpose of the study, and that they met the inclusion criteria (see Appendix 8). In all cases, those whom had expressed interest were eligible and were admitted to the study.

The consent form (see Appendix 9) was reviewed prior to commencing the interview. The respondents were assured that the purpose of the study was to explore the experiences of parents of children with special health needs in a hospital that offers family-centered care, and not to evaluate themselves nor their families. They were asked permission to audio tape the interview, and for note taking throughout, but were told of their right to turn the tape recorder off at any time. They were reassured that they had to right to refuse to participate, to withdraw from the study at any point, or to refuse to answer any questions in the interview, and doing so would have no effect on the treatment that the family receives at Children's Hospital. Confidentiality was assured by indicating that all identifying information from the study would be changed or omitted and that no one other than the researcher would know who participated in the study. The risks and benefits to participants were assessed to be minimal, but

respondents' feedback could play a direct role in improving services at Children's Hospital. The respondents were offered a written summary of the research results at its completion, and then were asked to sign the consent form.

DATA ANALYSIS

The purpose of any evaluation is to provide answers that relate directly to the research questions asked, to make the information received useful by ensuring that the answers are understandable and clearly presented, and to submit the work to scrutiny to ensure its credibility (Patton, 1980). Patton (1980) breaks down the analytic process into three interrelated components:

(1)   Analysis: the process of bringing order to the data by organizing it into patterns, categories and descriptive units

(2)   Interpretation: the process of attaching meaning and significance to the units by looking for relationships and linkages, and explaining descriptive dimensions.

(3)   Evaluation: the process of making judgements and assigning value to what has been interpreted.

An inductive approach to analysis was used, meaning that the categories, patterns and relationships emerged from the data. There were no a priori assumptions about what the categories would be.   Content analysis

is the procedure whereby embedded information from the raw data is discovered and made explicit (Lincoln and Guba, 1985). In this study, the principles of family-centered care, and the questions about them, formed a well-defined framework, therefore guiding the analysis. All categories and observations built into more general patterns. In the conventional qualitative approach, there is no point when data collection ends and analysis begins. Ideas about analysis occur while collecting data; analysis occurs simultaneously with data collection; hunches derived from analysis may inform ongoing data collection.

Miles and Huberman (1994:10) further define analysis "as consisting of three concurrent flows of activity: data reduction, data display and conclusion drawing/verification". The following describes their framework that was useful in the analysis of data in this study.

Data Reduction

This concept refers to the process of selecting, focusing, simplifying and transforming the raw data by coding and teasing out themes. Data reduction is a critical part of analysis because all coding decisions are analytic decisions.

The transcribed data was examined line by line, and assigned codes-- "tags or labels for assigning units of meaning to the descriptive or inferential information compiled during the study" (Miles and Huberman,1994:55).

Codes were assigned to pieces of information of varying size such as words, phrases sentences or paragraphs. As more and more information became available, some of the codes changed to better reflect the data.

Lincoln and Guba (1985:62) elaborate on the coding technique by delineating four methods of second stage coding:

(1)   Filling in: Adding codes, reconstructing a coherent scheme as new insights, and new ways of looking at data emerge.

(2)   Extension: Returning to materials coded earlier and interrogating them in a new way, with a new theme, a construct or relationship.

(3)   Bridging: Seeing new or previously not understood relationships within units of a given category; (that relationship will itself have a name, and it may call for a new configuration of the categories).

(4)   Surfacing: identifying new categories.

Each interview was coded before conducting the next so that ideas about what was happening in the data could surface, and guide further data collection.

The next level of data reduction is referred to by Miles and Hubberman (1994) as "pattern coding". This moves beyond the naming and classifying of data to beginning to understand patterns, themes, or

constructs. The purpose of pattern coding is to further reduce large amounts of data into a smaller number of analytic units. This helps to focus the data, beginning the work towards a conceptual map, and lays a foundation for cross case analysis. Cross case analysis occurred by examining the answers to each question across cases to begin to understand the shared themes and dissimilarities. Pattern codes are often hunches, that may or may not prove useful as the data grows. Guba (1978) suggests ways of examining these categories to look for recurring regularities.

"Internal Homogeneity" is the extent to which data in a certain category fit together.

"External Homogeneity" is the extent to which each category differs from one another. If there are many overlapping data items, or items that don't fit anywhere, the category system needs to be reevaluated.

"Divergence" is the process of elaborating categories by building on information that is already available, making connections among items or proposing new information that should fit, then verifying its existence.

Guba (1978) and others (Miles and Hubberman,1994; Patton, 1980) determine this process to be finished when categories are saturated; when new information leads to redundancy; when clear patterns have emerged and when the analysis begins to grow beyond the parameters of the original research questions.

Data Display

Miles and Hubberman (1994) are strong advocates of the use of data display techniques that may include matrices, graphs or networks. Data display is "designed to assemble organized information into an immediately accessible, compact form so the analyst can see what is happening and either draw justified conclusions or move on to the next step of analysis the display suggests may be useful" (Miles and Hubberman,1994:11). A display shows focussed information on one page rather than in extended text. After a preliminary analysis, the data was displayed on a graph comparing each aspect of demographic information to significant themes in the findings to further the understanding of potential trends and clustering of data.

Conclusion Drawing/Verification

Establishing the trustworthiness of the study is critical if its findings are to have merit. This is of particular importance in the qualitative method that is vulnerable to criticism about subjectivity and may not have the credibility in some circles of the more established quantitative method. Yet, Guba and Lincoln(1985 cited in Marshall and Rossman) argue that the traditional categories of reliability and validity do not accurately respond to the assumptions of qualitative inquiry, and propose the following alternatives:

Credibility

The study is "conducted in such a way as to ensure that the subject was accurately identified and described"(Guba and Lincoln cited in Marshall and Rossman, 1989:145). The investigator must clearly delineate the boundaries of the setting, the population, and the theoretical framework, therefore so deeply embedding the interactions with data that they cannot help but be internally valid.

Transferability

Generalizing findings is not the goal of qualitative research due to the small and selected sample size. However, the researcher has the responsibility to clearly state the theoretical framework of the research, thereby allowing another researcher to judge whether the original cases can be applicable to a different setting. The role of showing how one set of findings is applicable to another context (the study's external validity) rests with the researcher that wants to make that transfer.

Dependability

The researcher must account for the changing conditions in the object of study. Also, she must remain conscious of the changes in the design that have occurred due to an increased understanding of the setting. The assumption that a study can be replicated, and therefore is reliable, is

discordant with the qualitative view that the world is constantly changing. This makes replication problematic. One key to reliability is to be clear where one is in the qualitative process ie, research design, data collection, analysis or documentation. "The researcher must ask "Where am I" and "When am I done" many times" (Kirk and Miller,1986:72).

Confirmability

Confirmability relates to the concept of objectivity. A piece of qualitative research is by its nature shaped by the investigator's subjectivity. Rather than detract from the data, this enhances it by providing an understanding of the participants deep enough to gain entry into their world, thereby richly describing the situations being researched. It is, however, the responsibility of the researcher to control for biases in interpretation. Marshall and Rossman(1986) suggest that this can be achieved by checking and rechecking the data, posing rival hypothesis, constantly searching for negative instances, and by asking questions of the data. Using another person to critically analyze the researcher's interpretations is another technique that can be used to control research bias.

Confirmability was strived for in this study by two separate means. First, a summary of their own interview, in the author's own words was given to a sample of three respondents (see Appendix 10). The three were chosen partly due to their availability; but largely due to their differences with

one another in terms of their child's diagnosis, gender, and length of contact with Children's Hospital. The intent of their reading the author's interpretation of their words was to confirm that it was accurate in their case, and presumably in other cases as well. The three confirmed the accuracy of the interpretation.

Second, a summary of the preliminary findings of the study was given to one of the original members of the focus group from the Family Advisory Committee (FAC) who helped formulate the interview guide (see Appendix 11). The other two members of that focus group were no longer active with the FAC, and therefore unavailable. The intent of the summary was to confirm that the findings did indeed address the original questions, and to obtain feedback from a knowledgable source that the findings could be an accurate depiction of parents' perceptions of Children's Hospital. This focus group member did confirm that the findings reflected the original questions, and sounded plausible from her experience. She also added some rich insights which were included in the interpretation of the findings.

To summarize, this was a qualitative study, designed to examine parents' perceptions of family-centered care in a pediatric tertiary care hospital. A summary of the findings will follow.

CHAPTER 3

FINDINGS

The intent of this project was to gain an understanding of parents' perceptions of the family-centeredness of the services at Children's Hospital. A set of questions addressed each of the nine principles. Each set was preceded by a question to determine if the respondent agreed with the principle to safeguard against assuming the principles were applicable to all families.

DESCRIPTION OF SAMPLE

The respondents were screened by telephone to ensure that they met the aforementioned inclusion criteria. All that had responded were eligible for participation in the study.

The sample consisted of ten mothers (two of whom were foster mothers) and one father of children with special health needs. Two of these families were headed by single women; three families had more than two adult caregivers in the home due to adult children or extended family living there. These families represented twelve children with special health needs, as one family had two children who fit the inclusion criteria. In only two of the families was the ill child the only child in the family.

The sample was varied by diagnosis. With the exception of four families who interacted with the same sub-speciality team, all others worked with different health care providers. In total, seven sub-specialty medical areas were represented. These will remain unnamed to ensure the confidentiality of the respondents.

The children ranged in age from one year to fifteen years, (mean=7.7 years; s.d.=4.4; median=9). This large amount of variation did not necessarily relate to the amount of contact or experience each child and family had with providers, as some older children were less involved, or diagnosed more recently than younger ones.

They had contact with the hospital, either as in-patients, out-patients, or with the emergency room from three to fifty three times over the course of the last twelve months, (mean=18.4 contacts, s.d.=15.4; median=10). This also represents a large amount of variation. However, the small number of contacts does not necessarily represent less experience with the hospital, as some children that had infrequent contact over the last twelve months were frequent consumers of services in past years.

The date of diagnosis ranged from 1984 to 1996, meaning that the length of relationship between families and the hospital varied from seven months to twelve years (Table 2), (mean=5.7 years; s.d.=3.9; median=5)

TABLE 2
LENGTH OF EXPERIENCE WITH CHILDREN'S HOSPITAL
(N=11)

YEARS SINCE	FREQUENCY	PERCENT
<1 - 3 years	4	36.4
4 - 6 years	3	27.2
7 - 12 years	4	36.4

Families in this sample had contact with a wide variety of health care providers. Each had a range of three to twelve different disciplines participating in the care of their child, (mean=7.4 disciplines; s.d.=2.9; median=8). Only one of the eleven families was from a rural area, travelling two hours by car to attend Children's Hospital. Of the six families that chose to reveal their family income, that income ranged from $10,000-$19,999 to $70,000+, with the median being found in the $50,000-$59,999 category (Table 3).

TABLE 3
FAMILY INCOME (BEFORE TAXES AND DEDUCTIONS IN LAST TAX YEAR)
(N=11)

FAMILY INCOME	FREQUENCY	PERCENT
$10,000 - $19,999	1	9.0
$20,000 - $29,999	0	0
$30,000 - $39,999	0	0
$40,000 - $49,999	2	18.2
$50,000 - $59,999	1	9.1
$60,000 - $69,999	0	0
$70,000 +	2	18.2
No Response	5	45.5

The education level of the respondents ranged from partial high school to one university degree, with the median category of some university/no degree (Table 4).

TABLE 4
EDUCATION LEVEL OF RESPONDENTS
(N=11)

LEVEL OF EDUCATION	FREQUENCY	PERCENT
Elementary	0	0
Partial High School	2	18.2
Completed High School	2	18.2
Community College	1	9.1
Some University/No Degree	3	27.3
One University Degree	3	27.3
More Than One Degree	0	0
Other	0	0

Only one respondent identified herself as a member of an ethnic or cultural group. Given the ethnic and cultural diversity within the patients of Children's Hospital, this result was disappointing. No First Nations families were successfully recruited for the study, although this particular population comprises a large percentage of the families who use the services of the hospital.

As well, the sample over-represented those with upper incomes and moderate to high education. These issues of sampling may have influenced the findings.

SUMMARY OF FINDINGS

The data was categorized around each of the nine principles. Each of the eleven respondents was assigned a number which identifies them at the end of each quotation.

1. **Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate**

This concept is critical to the understanding of, and implementation of family-centered care as it underscores the philosophy of families and not professionals as being central in a child's health care. All the participants agreed with the principle, recognizing that they had greatest knowledge of their child. These comments describe how parents are in the best position to assess changes in their children's health.

> ...we are with him 24 hours a day so we recognize changes so that our feedback is relatively important (1).

> You recognize changes in your own child, you know what the circumstances are, and you know that those circumstances are going to have certain consequences attached to those circumstances (2).

> Like the parent knows their child the best. When the parent tells you there's something wrong, then they should look into it and not shrug it off as part of the sickness because maybe it's not (4).

Parents assumed an advocacy role as part of their belief that they were central and constant in the child's life,

> You are the person that knows your child
> the most, and I think the health care providers
> should include you. Especially children, they
> can't communicate much of their needs and being
> parents is like being their sort of voice(6).

When asked if they felt health care providers saw them as the constant, the outcome could be summed up by one parent's statement,

> Some do, some don't(4).

In describing a conflict with a doctor, she reminded him that,

> I know what my daughter needs. You're just
> somebody that's doing the surgery(4).

Some felt disregarded when they were not informed of the professional's role in their child's care,

> When these people come into the room you
> never know who they are(7).

This other parent elaborates on this theme and reinforces the importance of her role as advocate for her child,

> We had one time a doctor bring a team of people
> in and start to rattle off all the characteristics of
> [my child's condition]. He never introduced himself
> or his students and they were looking at [my child].
> I wouldn't let them touch him 'cause I sat there and
> thought like, who are you?(8).

Another parent perceived a discrepancy between what is said to be

done, and what is actually done,

> They recognize that by what they say, but not
> always by what they do. Very often they say you
> 'know your child the best' and they ask for your
> opinion but sometimes in the treatment, that is
> totally disregarded(11).

Whereas the above respondent expected that her opinion be sought

and heeded, this next respondent felt that being given opportunity to provide

an opinion was sufficient. The discrepancy in these comments begins to

suggest that definitions of centrality are not homogenous among all parents,

> In this institution anyways they've been very
> good in that way. Like including us, like letting
> us know the plan, getting our opinion about it(6).

Others had experiences that supported their centrality in their child's

care,

> I've always felt like when you're a parent you
> just feel like you're on the other side. But now,
> I feel like a part of it, and I don't feel like I'm on
> the other side(10).

> I have grown a lot more, grown, I guess to respect
> Health Sciences Centre more because I've seen a
> bunch of professional people working as a team and
> working with the parent(8).

The variability in perception is explained at least in part by the

evolution of the relationship between parents and providers. This comment

suggest that the parent/professional partnership develops over time as trust

grows and skills in collaboration develop,

> When we first entered the system, our opinions
> weren't effective I don't think. Certainly, as much
> as we progressed though the system now, I think
> that they've, the same as in any job, they've given
> us credit for experience. And so I think that they're
> recognizing the longer you're with the system the
> more we're able to say to them, 'this is what I think
> is happening' and they will follow up on that(1).

Skills in collaboration may also include learning to be more

discriminating in one's expectations and assertive in one's demands,

> I basically used to let them do pretty much
> whatever as long as it was explained to me
> what was happening. Just this last admission
> I refused specific treatment   until I was able to
> speak with my doctor. So I think I'm learning as
> I go that I can do that and do have that right(11).

> I think the more you're there, you tend to see
> what goes on and learn the system and meet
> with some really professional, wonderful people
> that explain things to you and really respect you
> and your opinion and do take that into account.
> And then you come across other people that don't
> and you just realize that you don't need to put up
> with that(11).

If centrality is a right that is earned over time, then there are

implications for those families who are new to the system or less assertive in

their demands. One parent summed it up this way,

> I feel sorry for the parents that are newly diagnosed
> or... they don't know they have the right to speak up
> and say 'what are you doing and why are you doing
> it'...Those are the people that are very probably very
> frustrated by the time they leave the hospital(3).

The respect afforded parents due to their experience with the system can occasionally be inconsistent for experienced parents as well. These comments suggest that respect and centrality are experienced unevenly throughout the hospital depending on the credibility that parents have been able to gain through their relationship with providers. Typically, this credibility has evolved with regular caregivers as opposed to those who provide occasional or intermittent care,

> It depends who it is and where you are. I know
> with the [specialists] they value me very much. They
> know that I'm a no-nonsense person, the pediatrician
> knows that I will not bring a child to hospital unless
> I know...that I cannot treat the child at home...but
> sometimes in the emergency room, they don't know
> me from diddly-squat and they kind of look at me(8).

> Depends on what health care [provider] you're
> talking about. If you're talking about the...team they
> work very well, if we're talking about nurses or people
> that don't know a parent as well, I feel they don't trust you as
> much(3)

Three themes emerged to describe the notion of parents being constant in the context of their childrens' health care: partnerships between parents and providers, control over the level of participation in care while their children were hospitalized, and input into medical decision making.

Partnerships Between Parents and Providers

The notion of partnership is the cornerstone of family-centered care, illustrating the importance of the family in the health maintenance of the

child. As a general principle, most respondents in this sample felt that they had achieved a working partnership with health care staff,

> We've developed a very strong partnership, that's my impression. And I feel like we're definitely working as a team for the good of the child(1).

> I think they've been working very well. Like they consider me like part of the team...They're almost like our second family there(6).

An example of partnership in practice was described by this mother,

> [My son] was really ill one time and the doctor asked me,'so what do you think, should we admit him'? and I said 'yea for a couple of days because he's dehydrated'. I thought this is how good it is when a doctor will ask a parent what she really feels cause they know that I don't really want to admit him but if there is a feeling that I should, it's because I know I can't handle this anymore, and I'm concerned that whatever we're doing at home isn't enough for him(8).

Input into Decision Making

One indication of partnership is the extent to which decisions are shared between parents and providers. In this dimension there existed greater variation in both parents' expectations of their role as decision makers and providers' willingness to provide the opportunity to do so. The following indicates the range of input into decision making experienced by parents.

> Here, they give me total control. I make the decisions; they give me the options, and I make the decision...they present something to you but they always ask if it's okay with you. Like, you're left to make the final decision almost. And that's fine with me, I like it that way(3).

Others have taken less of a lead in medical decision making,

> What decisions did I make? I don't think I made
> many. I think it was a matter of the doctors saying
> we need this test and that test and etc, and I basically
> agreed with whatever he wanted to do(7).

> No they've never dumped it [a decision] on my
> lap totally...they've never left me alone in a decision(10).

One explanation of the variation in parents' expectations about

decision making is related to the recognition of their own limitations and the

acknowledgment of the provider's expertise,

> I wouldn't say we make any [decisions] really.
> I mean his protocol is laid out. His prescriptions,
> his drugs,what he gets every day. Really I can't
> say that we have any decision as to whether he
> should or shouldn't have it. I mean, like we don't
> know anything about it so we have to follow along
> with the doctors, they're the experts(9).

> So they gave you what's happening and you...just
> have to go and say God Bless, do your best because
> they're the professionals and I have to know I'm not a
> doctor...I agree with parent involvement but I think we're
> limited too(8).

> Another parent was adamant in her decision about
> something in the treatment regime, but conceded that,
> it was a comfort kind of thing. I mean in a life and death
> situation they just take over and do what they have to do,
> that's understandable, you know(11).

Participation in Hospital Care

The third theme related to constancy of family is the control over the

level of participation in care of the hospitalized child. Again, significant

differences were expressed by respondents about the degree to which they wanted to be involved in the physical caretaking of their child while in hospital. Some expected to maintain the same caretaking tasks that they maintained at home,

> What I would do at home I did there...taking care
> of her, bathing and all that. And most of the nurses
> like that and some nurses complain,'well we're
> supposed to be doing this'. I says, I'm doing what
> I would do at home. She feels comfortable with that(4).

Although generally approved, some parents reported instances when their high level of participation was not easily accepted by staff,

> I look after [my son] when he's not in hospital.
> When I come into hospital the nurses treat me as
> if I'm not knowledgable...I'd be respected by the
> doctors to do it at home, but wouldn't be respected
> to do it in the hospital(3).

This parent's response to an emergency with her hospitalized son engendered a reaction from a provider that gave the clear message that some activities in hospital were not allowed unless supervised by a physician, despite her competence to carry out those activities at home,

> I was doing most of the care and that one time
> that he was getting really bad, I decided to change
> the trach...being on the ward, they're not covered
> to change a trach and here am I, 4:00 in the morning...
> the nurse was so really, really mad...'what are you
> doing, there's no doctor here, what are you doing'.
> But like I'd been doing that at home as long as there's
> somebody there...I'm not going to wait for a doctor,
> there's no doctor at home too(6).

However, not all parents are comfortable with the technical aspects of care that may be required in hospital,

> They told me how to shut one [monitor] off when
> it started beeping and they'd eventually come around.
> Well I wasn't going to touch that thing, I let it beep. I
> said the beeping thing's beeping and I'm not touching
> it. I was thinking maybe I'll blow it up! I was scared and
> I had to watch for the longest time before I could do
> some stuff(10).

Another parent described an expectation of participation during an admission that she felt she could not fulfil at that time,

> I've had an experience where I was asked to do
> physio and at the time I wasn't capable to do it. And
> when I refused to do it, the nurse got mad and
> walked out and never did his physio at all. It's like it's
> expected. If we don't do it they get mad. They don't
> respect us(3).

A high level of preferred participation by parents in hospital care, therefore, should not be assumed. This next parent indicated a need for breaks while spending 24 hours with her son in hospital, and also saw a hospital admission as a respite to the heavy demands of his care at home. She makes an important recommendation to consult with the parents about what level of participation they desire, and how best to divide the caregiving tasks between parents and providers.

> I'm there 24 hours to attend to his emotional
> needs and his comfort because I know that they
> don't have time for that. But I feel that the physical
> things should be done by them. Now, maybe that
> does vary from patient to patient too. So maybe that's
> something that should be asked of the parent, would

you prefer that we do this or would you rather do it?
Because sometimes I think they take it for granted that
you would rather do the bathing and do the care because
you always do it. You know the various ways that are
more comfortable for him. For myself, I prefer a bit of a
respite there(11).

She goes on to describe the issues that precede an admission to

hospital that explain her need for respite once admitted,

Before we land up in the hospital there is maybe a
week or two of ongoing stress when you're trying
to decide, do we need to be hospitalized, how sick
is he, and maybe running to the doctor a couple of
times. Sometimes running to emergency, being sent
home and then, you know, the antibiotic whatever not
working and then you have to go back. So you're
pushed to the limit before you arrive in that emergency
department(11).

The notion of parents being seen as constant in the context of their

children's health care by providers was framed by the concept of partnership

with health care providers, and described by the concepts of control over

the level of participation in care while their children were hospitalized, and

input into medical decision making. Most respondents felt that they had a

working partnership with providers. The extent to which this was achieved,

however, depended in large part on the relationship that parents and

providers developed over time. Parents felt that partnerships grew in time

when respect and trust between parents and providers was earned. As well,

a mature relationship with providers resulted in greater discrimination

regarding expectations of services and greater assertiveness in parental

demands. However, this raised the issue that parents new to the system, or

those who interacted with new or occasional services might not be afforded the same privileges. It is also noteworthy that respondents were not homogeneous in their definition of partnerships as described by input into medical decisions and control over the participation in care while the child was hospitalized.

2. Facilitation of parent/professional collaboration at all levels of health care

Simply stated, collaboration means people working jointly with one another. In order for children to achieve the greatest benefits from the health care provided them, both parents and providers must contribute to the effort. According to the participants in this study, trust and relationship are the attitudinal foundations of good collaboration, without which collaboration would not be possible,

> You have to have a good working relationship
> with them to get the best care, the best atmosphere
> possible for the children...we get along great with
> 98% of the nurses(9).

Trust was described in terms of providers trusting parents as well as parents trusting providers with the care of the children.

> I'm encouraged by them [health care providers]
> trusting me first of all...I'm encouraged by the
> confidence that they give me and they believe
> me [that] I can do it(3).

> Some of the people that we do meet at the hospital
> time after time know that your concern is real and
> that I don't run to the hospital every time something's
> wrong. I wait and I watch him and then when I'm there
> it's because we really need to be. And the people that
> we see on an ongoing basis know that, that when you're
> there that there is a concern, that you better get down to
> it and find out what it is(11).

Speaking of the faith necessary in medical staff, one mother

described her son's first hospital admission in this way,

> Well, your whole life is uprooted. You're no longer
> the one that looks after your child really...Like the
> first time I left [my son] here, I walked in with two kids,
> walked out with one and I have to trust other people.
> Well what happens if they have a bad day? And I mean
> people do, we're all human(3)

More concretely, collaboration was described in operational terms by

two processes: whether or not parents attended meetings about their child's

treatment and progress, and the manner in which conflicts were dealt with.

Attending Meetings

Collaboration can occur through various media--one on one, formal

meetings between parents and providers,or planned reviews. In cases

where formal meetings with parents were held, they tended to occur at

diagnosis or for discharge planning purposes. It is not clear from the data if

the following is a typical example of a discharge planning meeting, but the

tone suggests one of information-giving by providers rather than a

collaborative sharing between providers and parents,

> If they've been preparing a child to go home,
> you have these meetings that you go to and they
> tell you the plan and the goal, and that's when
> they start training the parents to do the different
> care that the child needs when he goes home(6).

Many respondents were not aware of whether information sharing, or planning meetings were conducted on behalf of their children in the regular course of care, and most were not invited to attend meetings of that nature. Some expressed a desire for participation at meetings.

> Well there's lots of meetings behind closed
> doors but parents aren't involved...but we're
> told what's going to be happening(8).

> I know the [team] have meetings on [my son]
> but we're not invited to them, I wish we would be.
> Sure, I'd love to be there(3).

> I would like to be able to be involved, to listen
> in on any discussion, ask questions, have people
> ask questions of me, sort of view it as a partnership,
> because anything that involves [my son's] care is
> something I want to be involved in(5)

This level of participation in information exchange could arguably be the ideal in a collaborative model of care. One parent described what she saw as the reality this way.

> I find sometimes what happens is that decisions
> are made as to treatment and you are more informed
> about it than an actual collaboration of do you agree
> with this? should we go ahead with this? or how do you
> feel about it? I think that is the majority of times more
> the way it would go(11).

Some parents, however, did not feel the need to be present at all meetings, recognizing that they may not understand the medical discussion. They trusted that the information would be effectively communicated once the professionals meet,

> I think what has happened is that they collaborate
> with each other and let me know their opinions. I find
> with the very very professional people that this is never
> an issue(11).

Suggestions were made to formalize meetings between parents and health care providers,

> It might be a good idea to have a meeting every
> two months or something like that especially with
> the newer families...sit them down and talk to them
> for half and hour or something...just to see how things
> are going(9).

Another wished for a meeting modelled after parent/teacher meetings in the school system where at least once annually a review would be conducted with both parents and the child present.

Conflict Management

Managing conflict was another area that became apparent as being critical to effective collaboration. The respondents in this study had for the most part found constructive means to deal with disagreements in their relationships with providers. Their experiences suggest that disagreements and challenges were tolerated and respected by providers,

> If I don't agree with how things are being handled
> I usually talk to the doctors or the staff. Generally
> I can get my point across and I can pretty well
> understand their point so that everything comes
> across equal(5).

After a disagreement with a physician, one mother said,

> He didn't get angry at me as many doctors could,
> just telling me, leave me alone, you're one of those
> troublesome mothers. He was really good, really
> professional. He spent long enough with me that I
> knew he wasn't just trying to push me away from the
> whole thing, and he found something that he could
> do that would show me that he was doing his best(7).

Effective collaboration is guided by trust, relationship and good conflict management. The respondents in this study felt that those factors were well attended to in their interactions with providers.

The meeting, as a vehicle for collaborative information exchange was also discussed. Parental participation in meetings other than those related to diagnosis or discharge from hospital was not the norm in this sample. Some parents did not know whether meetings occurred about their child; others were aware that they were not invited to attend meetings that did occur. Not all parents, however, felt the need to participate in the medical discussions about their child in the form of a meeting. Among this sample, conflict resolution was thought to be good.

These first two principles lay the philosophical foundation of the construct of family-centered care. The data presented some overlap between the concepts of constancy and collaboration, with parents not

making clear distinctions between the two. However, the themes, as they emerged in the two categories, were true to the working definition of the principles as it arose from the formulation of the interview guide with the members of the Family Advisory Committee, thus judged to be trustworthy.

3.   Sharing of unbiased and complete information with parents about their child's care on a ongoing basis in an appropriate and supportive manner.

All the parents in this sample placed a high value on information and knowledge, and could identify nothing that they would rather not know about their child's condition or treatment. The notion of information as empowerment arose in terms of parents' ability to cope and make decisions,

> I find that the more knowledge I have, the better
> I can equip myself emotionally for what I have to
> deal with the child(8).

> My personality is such that I need information and
> that's how I put things into perspective. I want all
> information, whether it be positive or negative, so that
> I can come to terms with it, so that decisions can be
> made based on that information(2).

Most parents felt that their questions were encouraged by providers, but also recognized their role in ensuring that they received the information they needed,

> If there's any questions, I feel comfortable to ask
> and I'm never made to feel stupid or anything(10).

> I've never seen a doctor who ever got annoyed
> with me for asking the same thing over and over
> again(8).

> The staff seems to enjoy having questions asked
> of them. I know that sometimes they find my questions
> challenging [but]if you don't ask the questions they
> won't be able to give you the information you need(5).

One parent suggested that information had to be sought, as she felt it

was not always freely given,

> If you want any kind of information, you have to
> ask. They won't give it to you just freely(3).

Some parents commented on the emotional impact of the information

they are receiving, and the importance of providers attending to their need

for reassurance,

> In a lot of case, we're getting information and
> half way through there I would just love to have
> somebody say 'but this is okay, he's okay' and
> then give me more information so that the panic
> in my brain can slow down enough to process
> the next piece of information(1).

Related to the importance of reassurance, is the value of relationship

in the comprehension of information,

> Also when you're discussing things like that with
> people, they need to have a really good bedside
> manner, otherwise sometimes you do feel intimidated,
> and that person leaves and you try to latch on to
> somebody that you feel comfortable talking with to get
> the information from them(11).

The communication style and skill of providers, and their use of medical terminology could also be seen as a barrier to clear understanding of information,

> They're so used to dealing with those[medical] terms
> that they don't realize that you don't understand what
> they mean. I don't think that's intentional, but when
> you don't know the questions to ask, sometimes it's
> difficult to draw that information out and understand(11).

Although parents were encouraged and supported by providers to ask questions relevant to their children's medical needs, it was rare among this sample for parents to be encouraged to seek information beyond their particular providers. None were encouraged to explore libraries, professional journals, or the internet for additional information,

> I'm sure that there are medical journals that a lay
> person could not even begin to understand, but there
> must be some information that's coming out that's
> up-to-date on current research that would be very
> beneficial to say 'gee, you might be interested in reading
> this article'. We've never been offered that opportunity
> [even though] we've expressed interest(1).

Many parents come across information about their child's condition in the popular press, or through other sources which they have sought. This parent has not had the confidence to bring this material forward to the health care providers in her life, fearing an unaccepting attitude by them,

> I have come across things and I have had questions.
> Maybe I'm not assertive enough yet, but I'm reluctant
> to ask. What's the worst that can happen? I guess
> they can just sort of look down their noses at you and
> think that you don't know very much and that you don't
> need to know. It might take a lot of energy that I don't
> have to get through to them(11).

Several others would have disagreed with the above sentiment,

finding that providers were quite open to discussing alternative material,

even if it is not consistent with current medical thought,

> I could have brought in anything. I could have
> brought in a stick with a wart on it and said hey
> This is supposed to cure cancer, and they'd probably
> say 'well,hey, maybe'(9).

> It's happened to me numerous times [where I bring in]
> newspaper clippings and stuff. I get the full low-down
> on what this particular little newsline has meant. It usually
> tells you its a cure. Well, by the time you come in here,
> it's not a cure. They'll take the time to explain what it really
> means(3).

> We've actually had one of our [specialists] come and
> do a talk about alternative treatment and she didn't say
> 'oh no, don't touch it, don't touch it'. She just challenged
> us in looking into it with open eyes and using our brains,
> and really thinking about this whole aspect...(8)

> I think they're [the doctors] very open to challenges
> and they'll just look at you and explain to you why
> they think it won't work(8).

Another vehicle for acquiring knowledge that was raised by several

parents was the ability to access their child's hospital chart. They saw that

the chart was a way to gain more information about their child's condition

and that it was their right to read it,

> This [reading the chart] is part of family-centered
> care. It gives me the information that I want without
> having to call the doctor...See when your child is
> hospitalized every six weeks for two years, you
> can't retain [all the] information that the medical
> profession gives you(3).

Not to have access to the chart created an imbalance in the relationship with providers, and caused suspicion and mistrust between parents and staff,

> I had an incident one time. [My son's] chart was left
> in the room and I started glancing at it and the nurse
> came in and she said OH, she got so upset with me
> and I was going-I'm an adult. I have a grade twelve
> education and if I have a problem with this, I'll ask. It
> just kind of threw me, and well he's my child and I
> should be allowed to know what's being written about
> him(5).

> I don't want to have to go through any hospital legal
> mumbo jumbo just so I could see my kid's chart. That
> kid belongs to me. I have every right to. Plus they want
> me to do all this care for him and everything but they
> don't want to give me access to the information that I
> should have. The only reason they don't is because they're
> afraid of what the nurses write about you(3).

> I don't think it's bad that the parents read the charts
> either. They'll send someone with you [to another
> department] even though you can do it yourself because
> you've got that stupid little chart and you might read it...
> what are they hiding? They should never hide things from
> parents(8).

The comments from the parents in this sample suggested that they felt that the information they received directly from providers about their child's care was readily available and thoroughly delivered. There is a sense however, that providers continue to maintain control over the information offered, and do not readily encourage exploration of other sources that may provide knowledge about the illness or treatment alternatives.

Access to the medical record was spontaneously raised by several respondents although there was no particular invitation to do so through the interview schedule. For those parents who raised the issue, they saw the medical record as an important tool for information exchange, and their denied access as an example of the unequal power in parent-provider relationships.

It appears from these findings that providers are more readily sharing information over which they have some control, and less likely to encourage information seeking from sources where their control over the information would be more limited.

4. Implementation of appropriate policies and programs that are comprehensive, and provide emotional and financial support to meet the needs of families

This principle was examined along three major dimensions: availability of mental health services, policies or approaches that help families feel at home in hospital, and the extent to which services of the hospital accommodate life outside the hospital.

Mental Health Services

Parents reported having supportive relationships with those providers with whom they had contact, but none in this sample was formally offered mental health services, namely those of social work, chaplaincy, psychology

or psychiatry. The exception were those in programs that had mental health representation established on their teams and whose involvement with families had become a routine expectation. This parent describes the experience of several respondents,

> I never knew that they [mental health services]
> were available. No one said they were available(9).

Another parent took responsibility to request mental health services when none were offered. She implies that those less comfortable to ask may not be noticed,

> I think again it's [mental health services] by request.
> I feel that sometimes families may not request help,
> either because of pride, or they feel that they're gong
> crazy and they just don't want anyone to know. [Help]
> is available but I don't think it comes freely. I have
> found myself in trouble mentally before anybody
> recognized it. And I'm the one that's asking for help.
> Nobody's saying 'I think she needs help'(3).

A poorly resourced team may explain why mental health services are not freely offered, as is this respondents' perception,

> I think maybe it's a question of the team being bigger
> than it is...The doctor can't do much with the information
> that there's two brothers and there's no father and I
> work and whatever...I don't know what the nurse can
> do either, but the person who could do something with
> it would be a social worker who's part of the team. And
> there isn't any such a person(7).

Some parents who were not aware of the availability of these services also had enough trust in their providers that the services would be made available should the need arise,

I know that if I had any need for them, I'm sure they'd
be offered. I wasn't too worried about it(5).

If we were in a crisis they would say 'here's some help
in this area, if you want, this is available. I'm very confident
that that would happen(1).

Those receiving mental health services found them helpful,

There is a social worker and she touches base with
us and there is [the chaplain] and she touches base
with us, so there's doors open. Now whether you want
to work with it, it's up to the parent. I use it. I value it.
I use whatever they can give me(8).

Mental health services appear to be unevenly distributed throughout

the system. Many parents were not offered such services, and did not know

they had the right to request them.

Feeling At Home

Most respondents believed that it was important to feel at home when

they were at the hospital with their child. One, however, disagreed,

Quite frankly it is not a place I relish to go. To be
very honest with you it's not a place you go unless
you have to go. Forgive me for saying so, but it's not
a place I call home(2).

Feeling at home or not depended upon both attitudinal factors and

also on the physical facilities available. The following two respondents have

different perceptions about the attitude of staff on the ward. The difference

may be explained by the fact that the first respondent spends extended

periods of time in hospital with her son, while the second experiences very

short admissions,

> The one thing that makes me feel that you're
> never going to be at home [is that] you're always
> being watched. And you're being written about
> and you have absolutely no say(3).

> I've found that the staff was very relaxed and I'd
> be wandering around in my socks all the time all
> over the ward(5).

Most were generally comfortable with the facility,

> We keep telling people that going to Children's is
> like going to the hotel...every kid has his own room,
> his own t.v., the games they can play, the play room.
> You know it's almost like saying 'hi mom, I'm home'(9).

Complaints were largely about the uncomfortable beds for parents

that were rooming in, and lack of kitchen facilities,

> The biggest complaint we've ever had is the sleeping.
> Ever tried sleeping on one of those things? They're
> ugly! There's the green chair and the blue chair which
> are recliners ...and everybody fights for. See if you can
> get the chair, bribe the nurses, here have a pizza or
> something...because those other things are just impossible
> to sleep on. You might as well sleep on the floor(9).

> You can't really go in the kitchen and microwave your
> stuff...Some people, especially of different cultures have
> different food and it would be nice to bring your food(6).

> There's no place for you to go warm up food or even
> make your child a piece of toast. Sometimes they're
> so ill they don't want to eat this hospital food and you're
> at the mercy of asking a nurse. Two hours later as she's
> still running around with her head cut off, you don't have
> this toast which is very exasperating and you would end up
> by spending alot of money by going to the cafeteria(8).

and parking,

> That hospital's incredible for parking. Your heart stops
> when you reach that corner to see if that light is flashing
> [by the parkade]especially with a baby. I bring my mom
> with me so I can let them out at the front door...It takes two
> of us with a 15 month old(10).

> My biggest pet peeve is parking...One day in a
> 24 hour period, it cost me $18.00 to park. I was
> furious(9).

Noise at night was also raised as a problem for some,

> At 3:00 am three nurses were talking very loudly and
> laughing outside of our door. I really wish they would
> respect that you're not getting the rest you normally
> would and when you do, you really need it. I feel that
> that's a lack of respect...then again at 7:00 am when
> there's another shift change and maybe the child has
> had a really, really bad night and you're trying to just
> catch up a little bit, boy it's difficult(11).

> Sometimes you feel you just gotta get out of that room
> and there's not enough place where parents can just
> go and read a book or be quiet(8).

Concerns about uncomfortable beds, lack of kitchen facilities,

expensive parking and noise at night were issues raised to describe physical

factors which inhibit parents from feeling at home while in hospital. Lack of

privacy and a feeling of being watched were attitudinal factors that were

reported which inhibited comfort in hospital.

Accommodating Life Outside Hospital

Parents responded favourably to health care providers' attempts, as

much as possible, to coordinate admissions, discharges, and appointments

with the personal demands outside the hospital,

If you don't have a problem opening your mouth
in saying you know, 'I don't want him home, I haven't
slept in three days and I'm tired and this and that is
going on. Yeah you do have control over it(3).

They would ask 'is this day okay? if not we could
work something out', or make two appointments
that day so that it doesn't take up your whole week(10).

Respondents also felt comfortable in accessing hospital services

when their children were at home either through their doctors, nurse

coordinators or the Emergency Room. This respondent discusses how she

was taught to present herself when accessing services from home,

[I know who to call from home when my son is sick]
because you're trained to do that. You always had
your Emergency number and every time I phone
Emergency I've always had excellent help no matter
what the situation was. We were told how to give
information: you don't just say 'my child has a fever',
you say 'my child has a congenital heart defect, he's
a patient of the heart centre, this is his pediatrician,
this is the symptoms, what should we do?'(8).

5.   Recognition of family strengths and individuality and respect for different methods of coping

Respondents generally felt valued and respected as was

demonstrated by the positive feedback given to them by providers,

Most of the staff told me they think I'm a very strong
person for doing what I do(4).

We have been encouraged by their praise actually,
basically telling you that you're doing a good job...
basically stating facts--you've got a big load and you
have to carry it and you're doing okay...I do feel
encouraged by that because as a caregiver you really

feel that nothing is ever appreciated and also that people
don't really know what you're going through(11).

The power of positive reinforcement cannot be underestimated as a
means of validating parents' ability to manage their child's health care. This
parent highlights the importance of recognizing the smallest gains, which, in
her experience, are ignored by health care providers.

> There's no positive reinforcement. It's not an
> overt negative reinforcement but there's no 'gee,
> he's gained eight ounces in this last three months,
> you must have really worked hard. Whatever you're
> doing at home is paying off for this kid'(1).

For another parent the extreme respect that she feels from one group
of providers, does not transfer to her experience once her child is admitted
to hospital.

> I have never felt that I was ever judged by the
> team, ever...if I had to talk to a friend or something,
> I felt like I was judged. They just don't understand like
> the team does(3)

She goes on to describe an alternate experience in hospital,

> Well, they almost don't make you feel that you
> have the right to be under stress. You know they
> see this every day. They're not the parent sitting
> there watching their child being poked five times
> because it's a teaching hospital and the person doesn't
> know how to do it. And the parent is sitting there
> ready to slap the guy because he's hurting her kid
> and the nurses expect you to just stay calm and not
> worry about it. That's just not the way it is(3).

The comments of this last respondent suggest that she feels greater
respect from the providers with whom she has an on-going relationship, and

less from the nurses with whom she interacts during the course of an admission to hospital. This might lead to speculation that the more intensive the day to day contact with providers, the more opportunity there may be for lack of understanding between parents and providers.

Another plausible explanation is that family strengths are more commonly recognized in long term relationships. This next respondent's comment reinforces the notion that respect grows over time,

> I feel as if we're fairly respected there. When you're
> in a long time they observe you and how you deal with
> things and how you react to situations and how you
> interact with your child. I think they've seen so much
> that they know how to assess you. We generally deal
> with things fairly well and they respect that so that if
> you do get angry or have a problem I think they tend
> to listen to you(11).

Parents generally felt respected by staff. However, there were experiences, particularly during hospital admissions that one respondent described as feeling judged. Even though this sentiment was not widespread throughout the sample, it is worthy of consideration. One may speculate that parents are more vulnerable due to fatigue, worry, or the crisis of acute illness during admissions. Therefore their coping resources are strained, and they may be more sensitive to the reaction of others. As well, hospital admission puts parents and providers in closer proximity in a more intimate day to day relationship, thereby raising opportunity for observations and judgements by either party to arise.

The comments also suggest that respect for coping and recognition of strengths in families is more likely to occur in on-going or long-standing relationships between families and providers.

6. **Understanding and incorporating the developmental and emotional needs of infants, children, and adolescents and their families into health care delivery systems**

The discussion to this point has dealt primarily with the needs of parents and with their relationship with the health care system. Questions related to this principle allowed for the opportunity to examine providers' relationships with the patients themselves, the children. Unanimously, parents applauded the respectful manner with which children were treated by health care providers. Respect was demonstrated by the way providers talked directly to the child in describing procedures or answering questions.

These parents state,

> Even though he's nine, they talk to him first, discuss
> with him, and then talk with us...Even though one of us
> is there, I'd say that 99% of the time they talk directly to
> him to tell him--this is going to happen or that is going
> to happen; do you want this or that(9).

> They let her say what she wants to say and if she has
> a question they answer if they can. She likes that and
> she feels like she's a big girl as she puts it. And I like
> it because it shows respect for her(4).

Parents also felt that children were treated with genuine caring by staff,

> When [my daughter] had her birthday in there, all
> staff came and sang happy birthday to her. That
> kind of made me moist around the eyes. [She] was
> happy, it made her happy(4).

This boy's parent acknowledges how her son's individuality is respected and appreciated,

> I always admire actually the way they interact with
> him. They treat him as a person, as an eleven year
> old boy, and they talk to him in that manner. He's a
> very loveable child and I always appreciate when they
> find that he is, too. They can relate to him and interact
> with him [in a way that's] really caring(11).

There is recognition by providers of the normal developmental changes in children, and this parent noted how that was taken into account by those that know children over time,

> Questions about his interests have changed. [He's]
> twelve now and in the last two years more of the questions
> have been directed towards [him] rather than myself...as the
> child gets older, they're turning more and more of the focus
> towards the child, getting them ready to be going on to an
> adult clinic...the focus is actually turning away from the
> parents, and that's not a bad thing(1).

One parent thought that more could be done to encourage independence and self care in this group of children,

> Children taking charge of their own health...quite frankly,
> a whole lot could be done in the area of education, and
> I strongly recommend that that's the direction you go. I
> think you'd have lots of people like myself that would be
> very very interested in helping in any way. But I don't think
> unfortunately that it's a top priority, so I don't think we're
> going to see much happening in that area(2).

The parent of an older child was anticipating that her child would soon

outgrow the pediatric services and made this recommendation,

> I think that the hospital should take steps to ensure
> that there is an effective transition for children out
> of the Children's Hospital into adult care, cause that's
> a huge, difficult thing for them to do(7).

One area of concern was the way in which normal activities of daily

living would not be consistently carried out for children while in hospital,

> I used to feel that I had to be here from 7:30 in the morning
> till 11:30 at night because things didn't get done. Yes, his
> meds got done, not always his physio, but if I wasn't here, he
> wouldn't get to bed on time, he wouldn't be bathed, you know,
> all those kinds of things(3).

For an older, more active child, daily structure was an issue for this

same parent who could not be with her son at all times in hospital,

> They let them get away with too much here...I used to
> come here at midnight and he was still playing nintendo
> and had been for eight or nine hours. There's times I'd
> come here and he hadn't had a bath in a week because
> he says he doesn't want one(3).

A frustration that was expressed by some was the way in which

hospital procedures interfered with the child's routine.

> One day [after] this last surgery, he was sleeping and
> he was supposed to have braces on his arms and I got
> kind of frustrated because he was nicely asleep and the
> nurse came in and said he's supposed to have braces on
> his arms. And she woke him up and it took me another hour
> and a half to get him to sleep...basically when I brought him
> home I kept them off because he wasn't putting his hands in
> his mouth anyway(5).

This parent blamed funding cuts and the resulting staff shortages as

adding to the problem of disrupted family routines,

> We're big on routine [in our home] otherwise we'd never
> survive. It was harder there because the waking up and
> the medication and the blood test really threw you off and
> sometimes waiting for that piece of toast will give you an
> hour or two later bedtime than what you'd anticipated...That
> would be ideal [to accommodate the family's schedule] but I
> think it's almost near impossible with the funding cuts and not
> enough staff, I don't know how they could do it(8).

The life of the hospital, with it's 24 hour care schedule, and rotating

shifts posed some difficulties, as described by this mother,

> The change of shift is usually bedtime and there's so
> much commotion going on in the hallway. Then they come
> to see the children and any care that maybe should be
> done before bedtime is put off because the shift is ending
> and they wait for the new shift to come in and take over. By
> the time they get around to you it's atrocious...like sometimes
> 9:30-10:00 before they're going to do his before bed physio...
> I think that when you're ill and need rest, which they say of
> course in the hospital you don't get, you like to maintain as
> much a routine as you can, but you really can't(11).

The non-medical programs designed for the children were very highly

regarded by the parents who saw them as a way of normalizing the hospital

experience and neutralizing the pain,

> What they have here is wonderful...the kids here do
> need more than just pokes and [tests]. They need to
> have some kind of normal living, which is school, which
> is crafts, which is all the stuff that they get here...they
> need things to take their minds off the pain and worry
> [like]the play room, and the television and the bingos
> and the gifts they always get, the little prizes they win(3).

Hubert the clown deserves special mention as he was particularly acclaimed by many of the respondents.

> Hubert the Clown should win an award. He's a godsend
> to that place(8).

Based on the above comments, one could conclude that the area of greatest compliance with this principle is the approach and attitude with which providers deal with children. Genuine caring and respect for children was experienced in providers' direct interaction with them. The developmental/recreational programs were generally seen as positive contributions to the children's recovery and development.

Although the attitudes and behaviours of staff towards children and their illness were favourable, concerns were raised about issues related to the normal caretaking tasks of children. The conflict between hospital routines and procedures and the daily routine of the children, was raised, with the recognition that hospital routine generally took precedence. Dissatisfaction was also expressed at the lack of boundaries for children around daily activities such as bedtime, baths and school attendance which are all necessary components in fostering normal development.

7. Encouragement and facilitation of parent to parent support

Although one mother indicated no need for parent to parent support due to the strength of her personal network, most others agreed with the benefits of sharing their experiences with others in similar circumstances, as illustrated by the following comment,

> I've sat in the hallways with mothers and I realized I'm
> going through the same thing that they went through.
> If I wanted to get angry I could, if I wanted to cry I could(4).

Even for those with a strong personal network, the support of parents

in similar situations is seen as important, as stated by this parent,

> I realized that even though I had a lot of loving people
> from my church and my family, they didn't know what
> I was going through as much as another parent. I
> realized how important it is to have parent support(8).

Parent to parent contact was also seen as a valuable tool for

problem-solving or negotiating the system,

> I think that new parents should really have a chance
> to meet parents that have little kids[with the same
> conditions] so that they can have somewhere as a
> support so that if they're running into a problem with a
> doctor, or [if they need to ask] what did you do in this
> situation [they have that chance](5).

The parents in this study felt that health care providers could take a more

active role in connecting parents with one another.

> I think they're [health care providers] certainly the
> group that could tie people in who have the most
> common needs, common background(1).

> It may be the health care professional should help
> that out, especially if there's no support group.
> They're the only ones that can tie us all in here
> somewhere(3).

With the exception of a few cases, it appeared by the data that

providers did not take an active role in linking parents with each other.

These respondents describe how in many cases the linkages that were

made were done so informally by the parents themselves.

> We did that in the hallways and the nurses let us
> do it(4).

> I don't think we were encouraged, but we sort of
> did it on our own. We see other parents and we
> talk on our own(6).

Also infrequent, was parents being asked to be of support to others,

although most expressed willingness to do so if asked. For those who were

connected to others by providers, the experience was helpful.

> When [my son] was first diagnosed, I was given
> phone numbers to help me with questions I may
> have. They look at kids that are diagnosed at almost
> the same age with sort of the same kind of problems
> and make sure the parent isn't a parent that's having
> a hard time coping. I've been given the numbers and
> I have used them and I found them very very helpful(3).

A parent who was willing to be of support to others, suggested a

formal means to enable this to occur,

> Someone one time from the hospital called me and
> asked if I would speak with another mom and I would
> gladly do that. If there was some formal way or some
> kind of system I would gladly do that...if you could just
> have your name and number down on a list and if
> things came up where some of the professionals thought
> that you could specifically be helpful to that person and
> both parties agree to an exchange of phone numbers(11).

Rather than being encouraged by providers to link with other parents

for support, some felt discouraged by them,

> I think the hospital staff at one point were leary about
> encouraging that [parent to parent contact] because,
> you know, there's maybe some 'flakes' out there...
> they don't even like you going talking to another child
> in another room, because of lawsuits or whatever(8).

This next parent responded to perceived non-verbal cues from

providers that she was not welcome to connect with another parent,

> You have to initiate all that [meeting another parent].
> How I took it was that it's none of my business, that
> it's private, it's confidential...I'm a sensitive person, but
> it didn't feel to me that the door was open for more
> discussion(10).

From the experience of these parents, it appears that health care providers are not making optimal use of one valuable resource for families-- the support of other parents in similar circumstances. There is a suggestion that some health care providers may be passively discouraging these links. Those in this sample indicated an interest in being both the 'helped' and the 'helper' in their interactions with others. This implies the possibility for an expanded role for providers in facilitating those links, especially since, as the parents observed, it is providers who hold the information about each family, and their potential compatibility with each other.

8. Assurance that the design of health care delivery systems is flexible, accessible and responsive to family needs

This principle is characterized by the degree to which parents found hospital services to be coordinated with one another. Also, what emerged was the extent to which services external to the hospital were accessed to benefit families.

For the most part parents felt confident that the "right hand knew what the left hand was doing" even though they were often unaware of the logistics of how that occurred.

This parent is consulted about how information about her son is shared,

> I think they're coordinated very well. I think they try
> to keep themselves updated. I know for a fact that when
> I see one of them they say is it okay to send information
> to [others involved in care], to update them(6).

A health care team which takes all the needs of the patient into account is commended by this parent, who also suggests that this approach is not consistently applied by all health care providers,

> [Our team] plug in whatever they can...they plug in "
> with the eye doctor, they plugged in the dentist, they
> plug in everywhere you can. And I love that, I wish
> it was like that all through the hospital. It would be
> such a success(8).

Another parent described her frustration when she perceived that services for her daughter were not unified and coordinated.

> I got so upset with one doctor, I says, why don't
> you guys get together and have a meeting. I says,
> because one doctor's telling me one thing, another
> doctor's telling me another thing and you're telling
> me something different. But it all concerns one
> patient so why don't you get together and discuss
> it...And, I says, if you guys don't agree, I'll put you all
> together in one room and you can fight it out(4).

A case manager, someone who was knowledgeable about all aspects of the child's care, was seen as a valuable and necessary resource in the medical treatment of complex cases. In most cases that person was a physician, who either assumed that role, or the role was negotiated with him/her by the parents.

> [The case manager] is somebody that I've
> identified. Like if I'm going to deal with an issue,
> I'm going to deal directly with a physician. If I want
> to have something changed in terms of nutrition,
> then I usually end up saying to the physician "this
> is what I think needs to happen here and if he wants
> to bring in the nutritionist to add some information...that's
> up to him...I don't want to have to re-explain to every
> single person whose got a specialty. I'll use this one
> person...and then if they can't do it, I feel that it's their
> responsibility to go and get it(1).

Another parent said that she played the role of case manager for her son because she was not confident that she could rely on providers to be familiar enough with his needs,

> I carry this book around not just so that I know
> what's going on from appointment to appointment,
> [but] so that they know what's going on. Because
> without it, he would be kept being put on medications
> that didn't work. They're busy and they don't have
> time to go through all his charts(5).

She felt that this was a necessary role, particularly in this economic climate.

> With all the cuts and everything going on with the
> medical profession, if I wasn't getting so involved,
> [my child] probably would not get the services that
> he needed(5).

Confidence in the coordination of care was sometimes questioned by the fact that the parents found themselves retelling their child's medical history,

> Because the staff changes so often, it gets somewhat
> repetitive and frustrating to have to repeat the history
> of the child and to again justify to a new staff person
> why this is important(1).

Another reiterated this source of frustration,

> It's the most annoying thing. You repeat your story.
> You should get a little tape recorder, every parent
> should have one. Do you know how many times you
> go and repeat the same thing over and over again(8)?

In this other parent's experience, although she found coordination among medical services to be good, there was little coordination among all the systems involved with her child, such as school, rehabilitation or other

support services. She wishes for centralized services of all professionals

involved with her family.

> I don't feel they work together at all. A lot of times
> the various things that you could have access to, you
> don't really know about until a specific need and
> someone happens to say 'oh yea, we can get you that
> information or that device'. But you really don't know.
> you could have benefitted from that a long time ago.
> I wish there was a way of centralizing information
> and people(11).

Parents in this study felt that the hospital should play a role in

accessing external services for children and families, especially since the

hospital was often the first point of contact regarding the child's special

needs.

> Otherwise, how would you know where to go or
> who to go to(10)?

Among this sample it appeared that the extent to which health care

providers did assume this role depended in large part on the complexity of

the child's needs, or the obvious need of the family. For this family, whose

child had multiple physical disabilities, a helpful referral was made by the

social worker,

> They [hospital staff] were actually the ones that
> introduced us to using the Society for Manitobans
> with Disabilities. The referral was provided by a social
> worker. We're very fortunate having everybody
> working together(6).

A woman supported on social assistance felt that her financial needs

were recognized and acknowledged at critical times,

> The past couple of years when Christmas came
> around they always gave me a hamper with food
> and a lot of gifts for [my child]. It was always a big
> box and they always helped me out. They're very
> considerate, most of them are very considerate(4).

One parent was given information about outside resources at the

diagnosis of her child but assessed that the value of that information was

minimal without greater investment and follow up by providers.

> I know I was given a bunch of paper when we went
> to hospital, brochures and things and I know that
> there is an association of some kind, but I didn't
> think that's enough, frankly. If you really want people
> to make contact it needs to be more than a piece
> of paper. It needs to be-there's this particular
> person that you can phone, and they'll arrange to
> see you. You know, something that makes you
> want to do it. But give me a brochure and I probably
> threw it out(7).

For those parents where no external resources were offered, there

was no perceived need from the family's point of view. This suggests that

assessment regarding outside referral is made on an individual basis, and

completed as need dictates.

Coordination of internal service was judged generally to be good from

the point of view of parents in this sample. In situations where that

coordination was lacking, parents felt the comfort to take on an advocacy

role to ensure that services were available. This was especially illustrated

by the mother who saw herself as the case manager in her child's care.

Frustration was expressed, however, at the need to frequently repeat the

child's history to multiple providers, thereby minimizing faith in optimal

coordination.

External resources were seen to be offered appropriately on an as needed basis.

9.   **Honouring the racial, ethnic, cultural and socio-economic diversity in families**

The findings related to this principle are weakened by the fact that only one participant in this sample identified herself as a member of a minority cultural group. Others did, however, use their own experience to speculate how someone of a non-majority culture, or with limited education might experience the services of Children's Hospital. This respondent speculates that lack of education or proficiency in language could be a barrier to some families,

> My impression is that the way that I'm being treated
> is the general way that everybody is being treated,
> and I would think that if there was some language
> problems I would find it difficult to believe that they
> would be able to scale down the information [or]
> instructions. My impression is that they've already
> done that for me...I have two years of anatomy, two
> years of physiology. I have some terminology and I
> am relatively well-educated. So when I get confused
> with directions and information...I have said to myself
> 'how do people who aren't in my position follow this'(1)?

Recognizing that the cultural orientation of staff is predominantly middle class caucasian, another respondent feels that it is advantageous to his family that he shares that orientation,

> Because we're a majority, not a minority, I guess we
> fall into a category that probably most of staff falls
> into. There wouldn't be any friction, or very little
> friction, as opposed to being[a member of a minority](9).

Some aspects of family-centered care may be quite compatible with the experience of some immigrant populations, namely, participation in the hospitalization. This respondent reflects on the practices in her Asian homeland.

> Back home there's not much staff[so] you have to
> look after the needs of your relatives...If your child
> is sick in hospital you stay with him, you don't go
> home until that child goes home. You participate in
> that care(6).

However, as evidenced by these comments, the spirit and intent is very different. Lack of resources and economic hardships, not partnership and empowerment are what drive the activity in such hospitals. As well, there may be a different expectation and orientation towards those in authority that disallows full partnerships in health care,

> Sometimes you see the doctor as a person in
> authority that you accept whatever they say [because]
> they know best. Some were intimidated to even ask
> questions, even if sometimes they're not sure of
> what they're talking about. It's almost like I don't want
> the doctor to think that I'm dumb(6).

The greater involvement of extended family in some cultures was raised as another issue that could potentially clash with the practices of the hospital,

> When [my child] was in the intensive care unit,
> some other [family] would like to visit and visitations
> are limited to about four. So it was difficult...to know
> which ones will you allow(6).

Socio-economic status was also considered in the analysis of this principle. One mother noted how her similar socio-economic standing to

health care providers facilitates how she can relate to them,

> When you have a close relationship with doctors
> and nurses as friends, you recognize them as human
> beings with the same good things and bad things as
> any human being--the same family experiences,
> then I think you communicate differently because of
> the exposure that you've had(2).

One might speculate that for those who are not in a social position to

befriend doctors and nurses, assuming that friendships are largely

determined by social class, then communication with health care providers

may not come as easily. However, bearing in mind that only six

respondents revealed their income, there was no evidence among these to

support differences in relationships and perceptions based on parental

income.

The above comments give ample suggestion that cultural and socio-

economic diversity would be a challenge to accommodate within the health

care system, whose own culture is influenced by white, middle class ideals.

Although those in this sample did not experience significant difficulties based

on their preferred ways of doing things, they also recognized that being

members of the majority culture probably sheltered them from greater

barriers in dealing with providers. Further study with a more culturally and

economically diversified sample is needed to confirm these suspicions.

Concluding Impressions

Some concluding impressions of family-centered care were offered by some of the respondents. Of significance was this respondent's concern about the lack of clarity in peoples' definition of the concept. ʳ

> The whole idea of it[family-centered care] is a little
> frightening, because there's no definition and
> everybody's definition is different. One nurse may
> think that you're responsible as a parent to do the
> physio because she's too busy. The next nurse may
> feel that family-centered care is your responsibility
> of giving them a lot of information that they need(3).

Another parent thought that the services represented,

> A very fragmented family-centered care. They deal
> with the person who brings in the child in...It's the
> person who has the most flexible timetable or who
> has the most sick time. They may not be the main
> caregiver, but they may be the person who is
> available to do the hospital thing, and so somebody
> is left out of the picture(1).

She recommends that clinics also be run in the evenings to accommodate both working parents.

This parent identified the key elements of family-centered care for her,

> To me, family-centered care is having the total
> respect that you should be getting as a family...
> they don't just look after the kids, they look after
> everybody(3).

A lack of clarity about the meaning of FCC raises a critical issue related to education of both parents and providers in the spirit of these principles, so that all can be of one mind about their rights and responsibilities as health care providers and parents.

Variation

The findings in this study revealed important variations in the perceptions and wishes of the parents relative to family-centered care, and also variation in how FCC was implemented by providers. In an effort to gain an understanding of these differences, a data display technique was used to analyze the data as a comparative case study. The aspects of demographic information collected (Appendix 3) were displayed along the side of a graph and compared to the important components of family-centered care as they emerged from the data along the top of the graph. The hope was that some patterns would emerge that may explain the variations in individual parents' perceptions.

Strikingly, what did emerge, were differences between perceptions and expectations of families who were relatively new to the system from those whose children had been diagnosed for some time. This is consistent with the comments of several parents that their relationship with providers had evolved over time.

The parents whose children had been diagnosed from less than a year to 3 years typically took less control in decision making, and expressed less of a need to play a large role in that arena. Those parents, although they spoke infrequently of partnerships, were also the most satisfied with the services they received from Children's Hospital.

Parents who had long-standing experience with the hospital services (7-12 years) expressed a high value in their role as decision makers. It was this group that spoke of strong partnerships with health care providers, but also recognized that those relationships of trust and mutual regard resulted from a long process of repeated contact and occasional conflict. Parents with long-standing relationships with providers (7-12 years) were somewhat more critical and discriminating about the services they had grown to expect, and had gained confidence in being clear and assertive about their rights. One might speculate from the findings in this sample that the relationships and expectations between parents and providers that are most consistent with family-centered care are born of the trials and triumphs experienced along the trajectory of the chronic illness over time.

A desire for strong partnerships with providers, and control over decision making in this experienced group did not necessarily translate to a desire for a high level of participation in care while the child was hospitalized, nor to participation in meetings. Perhaps due to the chronicity, complexity, and experience of this group, there was less need or energy to participate in all aspects of care. This group may have enough experience to participate in executive decisions, but feel comfortable about leaving the practical work to the professionals.

Another explanation for the variation in parents' experience with hospital services seems to be related to the style of health care provision

within the individual service areas. Seven medical service areas are represented by this sample. Of those, three operate on a model of service delivery from a multi-disciplinary team, including medical and allied health staff, who meet and communicate regularly. Four do not formally sit as a team, but consult others as they deem necessary. Those parents in this sample whose families were involved with a multi-disciplinary team felt that their family situation was generally better appreciated by providers. For example, there was a greater awareness of the needs of siblings and other family demands. Those that were not served by a multi-disciplinary team felt less that providers had a view of their life situation. They also had a more narrow scope of services available to them. For instance, this group was not offered, and did not know that other mental health services may be available to them.

Uneven Implementation

Finally, the findings reveal that some of the principles of family-centered care are being more successfully implemented than others. The greatest strengths in the system were related to direct patient care: medical treatment, supportive, informative relationships with parents and respectful care of children. Activities that were least in compliance with principles of family-centered care were those that required giving parents more control outside the sphere of conventional medical care: full participation at meetings, access to the medical record, linkages with other parents and

access to external sources of information.

These findings reveal an inconsistent approach to family-centered services at Children's Hospital. Not all principles are successfully or uniformly implemented, not all staff consistently implement the principles, nor do all families have the same expectations for such implementation.

CHAPTER 4

DISCUSSION

The feedback received from parents in this study was generally positive and reflected the experiences of people that were in the main satisfied with the services they and their children received at Children's Hospital. Many of the findings supported a recent study conducted at Children's Hospital whose intent was to look at consumer satisfaction and quality improvement (McLaren, 1995). In that study, the greatest areas of strength were identified as good interactions with capable staff, and the ability to participate in the child's care. Weaknesses identified by that study related to the need to repeat the child's history to numerous caregivers, repeated medical examinations by trainees, and uncomfortable sleeping arrangements.

The purpose of this study, although similar in some of its findings, was not to asses client satisfaction. Specifically, it was designed to determine whether or not each of the principles of family-centered care are being implemented, and what the successes and limitations of that implementation might be. The assumption does exist that families who feel like valued partners in their children's health care will also be happier with the providers and services with whom they interact.

The themes that arose from the parents in this study were similar to those that were distilled by the quantitative measures previously mentioned. Murphy, Lee, Turnbull and Turbiville (1995), derived eleven subscales in the FamPRS, several of which emerged in this study. For example, providing and coordinating responsive services, providing appropriate and practical information, communication timing and style, developing and maintaining comfortable relationships and respecting family as decision maker are a few areas that parents in this study also discussed. As well, King, King and Rosenbaum (1995) described subscales in the MPOC that were also reflected in this study: enabling and partnerships, providing general information, providing specific information about the child, coordinated and comprehensive care for the child and family, and respectful and supportive care. The compatibility between the findings in this study and the subscales of these quantitative measures adds to the confidence that the findings are descriptive of family-centered care principles.

The findings suggest that although family-centered care is a stated policy of service delivery at Children's Hospital, the principles of FCC are not consistently and uniformly applied in practice: Not all principles are successfully implemented, not all health care providers consistently implement the principles, nor do all families share in the definition of family-centered care, therefore their expectations of FCC are not homogenous.

The findings from this study are not dissimilar to others that have attempted to understand the application of family-centered care to pediatric health care facilities. Discrepancies, particularly in providers' implementation of the principles, are clearly documented in the literature. Baily, Palsha, and Simeonson, (1991) describe the difference between providers' ideals of family-oriented work and their practice. Berman, (1991) found that nurses have varied interpretations of the nine principles, some at odds with the accepted definition. Gill, (1993) found that personal characteristics of providers play a large role in their comfort level with parental participation in their children's care.

Not All Principles Are Successfully Implemented

As stated previously, the greatest strengths in health care provision that were identified by the parents in this study related to a more conventional model of direct patient care.

Parents generally experienced providers as supportive, and enjoyed good relationships with them. They received adequate information about their child's condition and treatment, and were never discouraged from asking questions. Providers were seen as patient and thorough in their response to questions and the delivery of information about the child's care.

No one in this sample questioned the medical competence of the individuals that provided care to their children, except to comment on the

inexperience of some of the trainees. Perhaps the most favourable feedback related to the respect and genuine caring that was afforded to the children themselves. Providers were seen as respectful in their ability to talk directly to children and treat them as important individuals, mindful of their developmental needs.

Where practice was seen as least consistent with principles of FCC was in those activities that required giving parents more control outside the sphere of established medical care.

Full participation by parents at meetings was not the norm in this sample. Meetings that did include parents were generally called at time of diagnosis or for discharge planning purposes. This suggests that the major purpose of the meeting was for providers to deliver information or instructions to parents rather than planning with them. Some parents did not know whether meetings were held for on-going treatment planning, or knew of the meetings but were not included in them.

Lack of free access to the medical record was seen by many as an example of providers maintaining control over the information and treatment of the child. Inability to read their child's medical record caused some to feel suspicious about its contents, thereby diminishing a sense of equal partnership with staff. Hostler (1991) contends that access to the medical record is a sign of true collaboration with providers, and ensures that the document is kept factual and free of judgments.

Although information was readily available from health care providers, little or no encouragement was given parents in this sample to seek information from other sources. Suggesting alternate sources of information, or sharing journal articles, would help to harmonize the power between parents and providers that is inherent in the uneven distribution of knowledge.

Another principle of family-centered care that was inadequately attended to was the linking of parents to each other. All but one parent in this sample felt that this would be helpful and that providers could take more leadership in this regard. Those that were connected to other parents by providers found the contact to be beneficial. There was a feeling by some that providers were reticent about making these links in their efforts to protect the confidentiality of families. Respect for privacy is of paramount importance in health care, but it may be that the very policies that protect privacy may in fact work against families in keeping them in isolation (Shelton, Jeppson and Johnson,1987). Links can be made by mutual consent of the families involved and using discretion about the information shared about each.

In addressing the question of whether the services of Children's Hospital are family-centered in light of these findings, it is useful to revisit the framework of family oriented intervention models as developed by Dunst, Johanson, and Hamby,(1991). These authors describe a continuum of

services based on four classifications of family oriented work:

(1)   The Professional Centered Model sees professionals as experts who determine family needs from their perspective. Families are seen as pathological, or deficient and in need of help.

(2)   The Family Allied Model sees the family as an agent of the professional enlisted to implement professional interventions.

(3)   The Family Focussed Model sees families and professionals as collaboratively defining family goals. Families are encouraged to use professional services to meet their needs.

(4)   The Family-Centered Model sees family needs and desires determining all aspects of service delivery and resource provision. Professionals are seen as agents of the family, and intervene in ways that are entirely committed to eliciting strength and competency in families.

The feedback of parents places the greatest strengths in service delivery in those areas of direct patient care. Philosophically, parents felt that they had collaborative relationships with providers, and that they worked well together for the benefit of the child. However, providers were seen as maintaining significant control over activities that they could not directly regulate, for instance, parents sharing information with one another, or having access to information which providers could not verify as accurate.

Within these parameters, professionals could not be seen totally as agents

of the family as is defined in the truest sense of family-centered care.

Indeed, families did not consistently expect providers to take that stance.

Given these circumstances, it could be advanced that the model of service

delivery at Children's Hospital is generally most compatible with the Family-

Focused Model, and not the Family-Centered Model.

Not All Providers Consistently Implement the Principles

A new approach to service delivery would take time to permeate such

a complex organization as a pediatric hospital. The literature shows that

there are personal and professional differences within disciplines

(Berman,1991), and among disciplines (Baily, Palsha, and Simeonson,1991;

Gill,1993) about what family-centered practice entails. This study did not

intend to examine those individual differences but did expose a suggestion

that the way in which services were delivered may make them more or less

congruous with family-centered principles.

It was found that those parents who were served by a formal multi-

disciplinary team were more likely to receive a broader scope of coordinated

services. Common sense would not dispute the fact that groups of health

care providers who have varied professional expertise and a forum for formal

discussion and consultation would be in a better position to address the

complex needs of families. Yet this formal multi-disciplinary arrangement is

not operational across diagnostic categories throughout the hospital. As well

children with multiple health problems, or children without a firm diagnosis

may be investigated and followed by several groups of providers.

Cuts in health care may also result in the erosion of these resource-

rich teams, and the diminishing likelihood that other sub-specialties will

receive committed time from a variety of disciplines. The onus for providing

comprehensive care, then would rest on fewer and fewer providers, usually

the physician, upon whose assessment referrals to other professionals are

generated. In order to strengthen the commitment to family-centered care,

this erosion should not be allowed to occur. If multi-disciplinary teams in fact

provide more comprehensive services, they should be maintained and

enriched. In light of the organizational constraints, innovative methods of

linking the appropriate disciplines both with each other and with families

must be developed to ensure that family needs are being adequately met.

Not All Families Share the Definition of Family-Centered Care

The lack of uniform implementation is also mirrored in the varying

expectations of the families themselves. Parents do not approach the

hospital with the same definition of family-centered care. Consider the

following statements:

"In this institution they've been very good in that
way. Like including us, like letting us know the
plan, getting our opinion about it"(6).

"I find sometimes what happens is that decisions
are made as to treatment and you are more informed
about it than an actual collaboration of do you
agree with this? Should we go ahead with this? or
How do you feel about it? I think that is the majority
of times the way it would go"(11).

What the parent in the first example perceives as a strength in the

system, the parent in the second example sees in a less positive light.

Some families are more comfortable than others with the Professional

Centered Model, seeing the providers as experts, and judging their own

input to be secondary. It is noteworthy that although most respondents felt

philosophically that they had strong collaborative partnerships with providers,

as illustrated by their comments about the first two principles of FCC, their

experience with some of the more operational principles did not always

support that opinion.

Some of this difference has already been explained by the length of

parents' career as recipients of health care; with more experienced parents

desiring greater partnership in health care, growing more discriminating in

their expectations of service and assertive in their demands of providers.

Other plausible explanations for the differences may relate to the

personalities of individual families, their orientation towards authority as

determined by culture or socio-economic standing, or other social or family

circumstances.

Although family-centered care may be considered the ideal method of practice, it may carry a set of assumptions about parental involvement that are not entirely relevant to all families. Rushton (1990) and Hostler (1991) caution about assuming what level of involvement is appropriate for individual families and advise that roles and responsibilities of both parents and providers should be contracted in each case. This on-going negotiation would in itself be reflective of some of the core constructs of family-centered care, namely, collaboration, respect for different methods of coping, and honouring diversity in families.

APPLICATION TO SOCIAL WORK PRACTICE

Social workers in pediatric health care facilities have a tremendous opportunity to further the aims of family-centered care. As previously described, the basic tenets of this approach to health care delivery are also rooted in the philosophy of social work practice both currently and historically. Social workers, if true to their code of ethics, are already providing services that are competency enhancing, promoting of self determination, and sensitive to diversity in the context of individuals, families and environments. Practice within an ecological framework comes naturally to social workers.

The first task for social workers in pediatric hospitals is to familiarize themselves with this new paradigm of health care, and take on its

implementation as a natural extension of their practice. Using the language of FCC that is being adopted by other disciplines will assist all health care providers in working together towards a common purpose.

Social workers could also contribute practically to innovations in service delivery that promote family-centered care. As a mental health discipline with skills in interpersonal communication, mediation, conflict management, and individual, social and organizational assessment, social workers can share those skills with parents so that parents themselves can assertively negotiate and advocate for the services their families require. Although likely occurring quietly in many social work caseloads, this activity could be formalized by offering workshops or psycho-educational groups to fulfil this aim.

Group work has been long recognized as a social work skill, and a valuable approach in working with consumers of hospital services. As well as a tool to enhance coping, mutual support, and education, group work has also been used to foster a sense of community between families and providers (Lonergan, 1980). Longergan describes a group program in which attempting to create a greater sense of community resulted in improved staff-patient communication, with patients and families becoming more active participants in the treatment process.

Social workers can model collaborative behaviours by formally engaging with parent groups such as the Family Advisory Committee to

ensure parental participation in any new program initiative meant to benefit families. However, success in this type of collaborative practice requires sincere commitment. A study of mental health professionals in community mental health centres, private hospitals and state hospitals in the USA was designed to rate how helpful these professionals thought certain group work modalities were. In analyzing attitudes towards professionally led, support, and self-help groups, the results suggested that professionals may hold certain attitudes that may not be compatible with collaboration with self help groups (Salzer, McFadden, and Rappaport, 1994). This finding points to the fact that there is not unanimity in the mental health community about the best way to promote self-directedness in clients and families in the context of group work.

This study of parents' perceptions at Children's Hospital identified a gap in the fostering of parents as resources for each other. Social workers could assist by taking more initiative to link parents to one another. This could be done by designing groups for parents to meet and share common concerns, introducing people from individual caseloads or consulting with colleagues about a good match for a particular family. Maintaining a roster of interested parents by mutual consent will also help to locate appropriate contacts for those who are interested in meeting others.

Working systemically and ecologically predisposes social workers to meet the aims of family-centered care. It is within social work's sphere of

practice to go beyond the institution and to collaborate and consult with other social organizations on behalf of families. This leads to improvement of overall coordination among all service providers involved with a family: coordination which at least one respondent in this study claimed was lacking. Gatti and Coleman (1976) described some practices which indicate that some of the dominant notions of family-centered care are not new to mental health professionals. Describing what they called community network therapy, they identified some key principles that arguably are also an integral part of current social work practice in pediatric hospitals: 1) the whole family is involved, 2) Contact is established and maintained with as many community people and agencies that affect the child's life as possible, 3) Therapists view themselves as one element in the network, 4) Therapists maintain and share a cultural perspective on the problems in living. They advance that this model has its roots in the advocacy model of helping behaviour, as well as more traditional family therapy work.

Social workers are well positioned by their skills and philosophical orientation to promote the tenets of family-centered care and to address some of the gaps in service that have been illuminated by this study.

Above all, social workers have the opportunity and responsibility, simply by remaining true to their professional practice, to promote the centrality of the family in all aspect of children's health care, with the families themselves, and in their interaction with other health care providers.

LIMITATIONS OF THE RESEARCH

This research is limited by the parameters set out in its qualitative design. It describes in depth the experiences of 11 parents of chronically ill children and their perceptions of family-centered care at Children's Hospital. Its findings are not intended to be generalized to the entire population, but can be applied to similar populations, addressing similar questions.

There were some limitations ensuing from the composition of the sample. Ten mothers and one father were recruited. Although caregiving and child care are roles typically adopted by women, many men also assume responsibility in this arena, and their perceptions are not fully discussed in this study. It is unknown whether men perceive the services of Children's Hospital differently from women, or if gender influences parent/provider interactions.

Also problematic is the lack of ethnic or cultural variation in the sample. Silent in this study are the voices of First Nations families who comprise 40%-60% of the patient population. Despite aggressive attempts to recruit this population, none came forward. Discussions with members of this community led to speculations that recruitment of Native families was problematic because of their weariness of being studied by non-Aboriginals. Illiteracy and lack of access were also cited as possible barriers. The lack of a culturally varied sample renders the findings unable to speak to the experiences of a great number of service users. It does not address

whether minority cultures perceive the services differently from the majority culture, nor whether the principles of FCC are in fact relevant across cultures.

Greater variation in level of education, and socio-economic standing would benefit further study, as this sample tended to be biased toward more highly educated, upper class respondents.

Only seven sub-specialty medical areas were represented in this study. This requires caution when drawing conclusions about differences in service delivery.

Finally, all the respondents in this inquiry were, for the most part, satisfied with the services they received from Children's Hospital. Although it would be difficult for respondents to be overtly critical of services upon which their children are so highly dependent, the project may have taken a different tone had some participants expressed dissatisfaction.

OPPORTUNITIES FOR FURTHER RESEARCH

Future research in this area should make a concerted effort to correct the problems aforementioned about limitations derived from the sample. Achieving greater cultural diversification, especially by recruiting Aboriginal families should be a priority. This may occur if greater collaboration took place with members of that community to publicize, and enlist families. Seeking to interview families in their own communities, by their own people,

in their own language, and away from the immediate hospital experience may aid in fostering trust.

Recruitment of respondents with a greater range of income would also give a truer picture of those families that are served by Children's Hospital.

Including a gender analysis after the recruitment of more fathers may also give new insights about the culture of the hospital and how services are delivered.

A more complete implementation analysis would be valuable. This study focussed on parents' perceptions of family-centered care, but greater depth could be achieved in studying policy implementation at all levels of the organization, from policy development to staff attitudes about FCC.

Suggesting that the services of Children's Hospital are family-focussed rather than family-centered describes a subtle but significant difference in philosophy and service delivery. However this analysis begs a vital question--Does family-centered care improve health outcomes for chronically ill children? For that is the ultimate mission of both the hospital and of the parents. This question must be put before empirical scrutiny in order to defend a change in standard health care practice.

RECOMMENDATIONS

A number of suggestions and recommendations were made by, or implied by the respondents in this study. In an effort to represent the voices

of the parents, these recommendations are outlined in this concluding section of the project.

-Providers should negotiate with parents what level of participation they would feel comfortable with each time their child is hospitalized.

-When dealing with parents of children with special needs, occasional and intermittent health care providers (ie., Emergency Room staff, trainees, consultants, ward staff) should be particularly mindful of their brief involvement with the family, along the trajectory of chronic illness or disability.

-Collaboration between parents and providers could be strengthened by greater participation in meetings about the child's treatment.

-Regularly scheduled meetings to provide an update on the child's condition and treatment should be considered as a compliment to the on-going information sharing that already occurs.

-Contact with other parents in similar circumstances should be routinely offered and facilitated by health care providers.

-Attention to parents' need for information should be paid by providing access to external sources of information.

-The use of mental health professionals should be considered to provide support to families, especially where there is no such service as an integral part of the health care team.

-Sleeping facilities for parents rooming in with their child in hospital should be improved.

CONCLUSION

This project represents parents' perceptions of family-centered care in an urban tertiary pediatric hospital. It was found that although FCC is a stated policy of the hospital, there was an uneven approach to its implementation. The greatest coherence to the principles were in areas of direct patient care. The least coherence to the principles were in areas where providers would have to give up control over activities which they could not directly regulate. The study is followed by some recommendations that arose from the parents through the course of the interviews.

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APPENDIX 1

LETTER TO THE FAMILY ADVISORY COMMITTEE

Sonia Busca Owczar

R·
Aug. 22, 1995

Brenda Agusta and Diane Jones
Co-Chairs
Family Advisory Committee
Children's Hospital
Wpg, Man.

Dear Brenda and Diane,

As a social worker on staff at Children's Hospital, and a graduate
student at the University of Manitoba, I am writing to inform you, and ask for
your support in a study that I am initiating in the coming months in partial
completion of the requirements for my Master of Social Work degree.

The study is entitled "Parents' Perceptions of Family-Centered Care at
Children's Hospital". My intent is to conduct in depth interviews of selected
parents of children with chronic illness to determine to what extent their
experiences with the hospital reflect the nine principles of family-centered
care as developed by ACCH.

I'm hopeful that you would find this study compatible with the aims of
the Family Advisory Committee and that we can work together to
methodically evaluate the strengths and the gaps in family-centered services
at Children's. Specifically, I would appreciate your committee's assistance in
two ways. First, I need to develop an interview guide that will address how
participants' experienced each of the nine principles. In order to ask the
questions in a way that is meaningful to the parents, I would like to work with
a small focus group to refine the wording of those questions. Second, I
need to recruit a sample of 10 to 20 families and will be asking the
assistance of the staff and your committee to identify families for the study.
If there are other ways that we can work together I would be most happy to
do so.

The study will be conducted under the supervision of Sid Frankel and
Esther Blum from the Faculty of Social Work and Isobel Boyle from the
Faculty of Nursing/Children's Hospital. The proposal has met with the
approval of the above mentioned committee and will soon be under
consideration by the Ethics Committee. I would be glad to share it with you
in its current form.

I appreciate your consideration of these requests and hope for your ongoing support. Hopefully together, we can further the aims of family-centered care at Children's Hospital. I look forward to hearing from you at the following phone numbers: (h   , (w)   .

Yours truly,

Sonia Busca Owczar

cc.Isobel Boyle

APPENDIX 2

INTERVIEW GUIDE

Interview Questions

I plan to use a semi-structured standardized interview format. The following questions allow for variation and alterative ways of attaining answers to questions as they relate to respondents' perception of family-centered care. These questions were conceived with the help of a group of 3 volunteers from the Family Advisory Committee(FAC). These parents all have ample experience with Children's Hospital, and due to their role on the FAC have had opportunity to reflect on the meaning of these principles for themselves and their families. The respondents will be given an overview of the themes within the questions, and a copy of the nine principles to reflect on throughout the interview.

1.   **Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate**

Do you think that health care providers should see you and your family as the central people in your child's treatment plan?

Do you feel that health care providers recognize you as such?

How do you see yourself participating in your child's health care?

Do you feel that health care providers value your input when assessing and treating your child?

What type of decisions do you make about your child's treatment?

What happens when you express concerns about your child's treatment?

2.   **Facilitation of parent/professional collaboration at all levels of health care**

What is your view about how much parents and health care providers should work together in relation to the care of your child?

How well do health care providers work with you?

In what ways are you encouraged to be involved in your child's health care?

In what ways are you discouraged from being involved with your child's health care?

How is disagreement about your child's health care worked out between you and the health care providers?

Do you attend meetings about your child's health care? If so, what is your role in these meetings? Who is at these meetings?

Do health care providers spend enough time with you?

3. **Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner**

Do you believe that complete information about your child's condition and progress should be shared with you?

Are there things that you'd rather not know?

Do health care providers share information about your child's condition with you ?

What kind of information do you want health care providers to share? Current status; Long term prognosis; Side effects of medication...

How complete do you feel that the information given is?
Do health care providers give you all sides of the issue?

How much are you encouraged to seek information?
From health care providers?
From other sources?

When you bring information that you have discovered about your child's condition or treatment to the attention of the health care providers, how is it received?

4. **Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families**

Do you think that health care providers should help you and your family to manage emotionally with your child's condition?

Have you ever met anyone from the Departments of Social Work, Chaplaincy, Psychology or Psychiatry?

Are you aware that these services are available?

Do you think it is important for you to feel at home at the hospital?

What is missing that would make you feel more at home and welcome while you are at the hospital with your child?

When your child comes into hospital for an admission, or leaves the hospital at discharge, do health care providers consider other demands that you or your child may have at home?

When your child is at home, do you feel that you can still ask for services from Children's Hospital?

5. **Recognition of family strengths and individuality and respect for different methods of coping**

Some families describe feeling valued and respected by the staff, some feel judged by staff, some feel both at different times. What is your experience?

Have health care providers ever thanked you for your efforts, or encouraged you in your care of your child. Describe.

Have health care providers ever been critical of you, ignored you or redone what you have done? Describe.

6. **Understanding and incorporating the developmental and emotional needs of infants, children and adolescents and their families into health care delivery systems**

Do you find that the health care provider's' contact with your child is different now that from when he/she was_____ie) 5 years old?

Do you think that health care providers should help you to prepare for the future with your child? Do they?

Describe the role of the non medical hospital programs such as the school room, in-house t.v., the clown or the play room in the life of your family when your child is in hospital.

To what extent are family rules about discipline, bedtime or snacks enforced while your child is in hospital?

Do health care providers recognize that your family's needs change as your children grow? How? What's missing?

7. **Encouragement and facilitation of parent to parent support**

Do you think that it would be helpful to talk to other people in similar situations to yourself?

Are you encouraged by the health care providers to talk to other parents?

Are you encouraged to share your experience and give help to other parents in a similar situation as yours?

Are you aware of the Family Advisory Committee? How did you find out?

8. **Assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs**

How are the various services that your child needs co-ordinated?

Can you identify a case manager or someone who knows all aspects of your child's treatment?

What is your opinion about how health care providers share information about your child with each other?

Do you think that health care providers should help you get services from other agencies outside the hospital? Do they?

Do you feel that you can get the services you need?

Do health care providers respond to your concerns?

9. **Honouring the racial, ethnic, cultural, and socio-economic diversity in families**

All families do things differently. Sometimes that is because of their culture. Do you feel that the way you do things is accepted by health care providers? ie.) food, activities, holidays.

Do you feel that health care providers understand your family situation? ie) work schedule, transportation problems, expense of treatment, other responsibilities.

10. Are there any other issues related to family-centered care that are important to you that I may have missed?

Do you have any suggestions about what would make the hospital experience better for you and your family?

APPENDIX 3

DEMOGRAPHIC FACE SHEET

DEMOGRAPHIC FACE SHEET

1.   Diagnosis of child/ren who use services of Children's
      Hospital_____

2.   Date of Diagnosis_____

3..   How many admissions has he/she had in the last 12
      months?_____

4.   How many visits to outpatient clinics or emergency has he/she had in
      the last 12 months?_____

5.   Underline the professionals with whom you have had contact?
      (Names are not necessary)Doctors, Nurses, Social Worker,
      Physiotherapist, Occupational Therapist,Dietician, Child Life
      Therapist, Pharmacist, Chaplain, Home Care, Native Services,
      Hospital Based Teacher, Other_____

6.   What is your relationship to the child?_____

7.   What is your child's date of birth?_____

8.   What are the ages of the other children in your
      home?_____

9.   How many adult care givers are there in your
      home?_____

10.   Do you see yourself as part of an ethnic or cultural group?
      Which?_____

11.   If you are not from Winnipeg, how far do you travel to attend
      Children's Hospital?_____

12.. What was your family income(before taxes and deductions) in the last
      tax year?

      less than $10,000.00
      $10,000-$19,999 $50,000-$59,999
      $20,000-$29,999 $60,000-$69,999
      $30,000-$39,999 $70,000+
      $40,000-$49,999

13. What is your level of education? Please underline.

Elementary   Some University/No Degree
Partial High School   One University Degree
Completed High School   More than one Degree
Community College/   Other (please specify) _____
Technical School

APPENDIX 4

INFORMATION FOR RECRUITERS

Parents' Perceptions of Family-Centered Care at Children's Hospital

INFORMATION FOR RECRUITERS

Sonia Busca Owczar, social worker at Children's Hospital and graduate student of social work at the University of Manitoba is conducting a study in partial fulfilment of the requirements of a Master of Social Work degree. The study is under the supervision of Sid Frankel and Esther Blum from the Faculty of Social Work, and Isobel Boyle, Faculty of Nursing/Children's Hospital. Your help would be greatly appreciated in recruiting participants for this study.

PURPOSE

The study, entitled **"Parents' Perceptions of Family-Centered Care At Children's Hospital"** will attempt to answer the following questions:

(1) How closely do the experiences of parents of children with chronic illness reflect the principles of family-centered care at Children's Hospital?

(2) What are the barriers to the implementation of family-centered care?

(3) How are these principles being implemented successfully?

Family-Centered Care Is:

1. Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.
2. Facilitation of parent/professional collaboration at all levels of health care.
3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner.
4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families.
5. Recognition of family strengths and individuality and respect for different methods of coping.
6. Understanding and incorporating the developmental and emotional needs of infants, children and adolescents and their families into health care delivery systems.
7. Encouragement and facilitation of parent to parent support.
8. Assurance that the design of health care delivery systems is flexible, accessible, and responsive to family needs.
9. Honouring the racial, ethnic, cultural and socio-economic diversity in families.

Shelton,Jeppson&Johnson(1992).Family-Centered Care For Children with Special Health Needs(2nd ed.).Washington,DC: ACCH

DESIGN

This is a qualitative study. I plan to interview ten to twenty primary caregivers of children with chronic illness or disability for about 90 minutes in a mutually convenient location. The questions have been formulated with the assistance of the Family Advisory Committee, and relate to parents' experiences with each of the above principles as they use the services of Children's Hospital.

SAMPLE

In order to provide a general portrait of the "family-centeredness" of Children's Hospital without singling out any particular areas, families from a variety of service areas are requested. Respondents with abundant information about the services of Children's Hospital are required and should meet the following criteria:
Respondents come from a variety of service areas, having had contact with various medical and/or allied health services. Implied is that the diagnoses of the children in the sample will vary.

The child for whom medical services are sought has an on-going chronic or disabling condition which requires in-patient or out-patient services with a frequency of at least three times annually.

Children and their families will likely require services from Children's Hospital until responsibility for those services is transferred to another facility.

The respondents have had a range of experiences with Children's Hospital, some positive, some negative.

Aboriginal families and immigrant/refugee families should be actively recruited to begin to explore the issue of the ethnic or racial sensitivity of the organization.

ETHICAL CONSIDERATIONS

Please reassure interested persons that they have the right to get more information from the researcher before agreeing to participate in the interview. They can refuse to participate, refuse to answer particular questions, or withdraw from the study at any point without any impact on the services they or their child receives at Children's Hospital. No one but the researcher will know who agreed to participate in the study, and confidentiality is assured. The study is designed to examine the services of the hospital and not the individual families.

I very much appreciate your cooperation in approaching parents/caregivers that meet the criteria to participate in this study. Enclosed is an information sheet that can be handed out to interested parties. Once they have indicated their interest by the enclosed SAS envelope I will contact them by telephone to ensure their eligibility. I will be most happy to answer questions and can be reached at   . A summary of the study will be available upon its completion.

THANK-YOU

APPENDIX 5

INFORMATION FOR RESPONDENTS

Parents' Perceptions of Family-Centered Care at Children's Hospital

Family-Centered Care Is:

1. Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.

2. Facilitation of parent/professional collaboration at all levels of health care.

3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner.

4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families.

5. Recognition of family strengths and individuality and respect for different methods of coping.

6. Understanding and incorporating the developmental and emotional needs of infants, children and adolescents and their families into health care delivery systems.

7. Encouragement and facilitation of parent to parent support.

8. Assurance that the design of health care delivery systems is flexible, accessible and response to family needs.

9. Honouring the racial ethnic, cultural, and socio-economic diversity in families.

Children's Hospital strives to provide services to children and their families in accordance with the above principles. Your opinions and experiences are valuable in evaluating the successes and the barriers to the delivery of family-centered services at the hospital.

A study is being conducted by Sonia Busca Owczar, social worker at Children's Hospital and student of the University of Manitoba. The study is designed to evaluate the extent to which the services of Children's Hospital are family-centered. It is not intended to evaluate your individual family. The study consists of an interview for approximately 90 minutes in your home, or other convenient location.

IF YOU:

-Have a child with a long-term illness or disability

-Require the services of Children's Hospital (in-patient or out-patient) at least
 3 times per year

-See more than one medical or allied health care provider

Then I would like to hear from you.

You are under no obligation to participate. If you choose to participate your involvement in the study and your responses will be treated with the strictest confidence.

If you are interested in participating, or require more information, please mail the tear off sheet below in the envelope provided, or call
    . I will be in touch with you. Thank you for your interest.

I agree to be contacted about the study of family-centered care at Children's Hospital

Name: _____

Address: _____

Phone: _____

Child's Diagnosis: _____

APPENDIX 6

ETHICAL REVIEW COMMITTEES APPROVAL

The University of Manitoba

FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number **N#95/46**

Proposal Title: **"PARENTS PERCEPTIONS OF FAMILY CENTERED CARE AT CHILDREN'S HOSPITAL."**

Name and Title of
  Researcher(s):   SONIA BUSCA OWCZAR, BSW, RSW
                          FACULTY OF SOCIAL WORK, UNIVERSITY OF MANITOBA
                          CHILDREN'S HOSPITAL, DEPARTMENT OF SOCIAL WORK.
                          GRADUATE STUDENT

Date of Review: OCTOBER 02, 1995.

APPROVED BY THE COMMITTEE: OCTOBER 02, 1995.

Comments: APPROVED WITH SUBMITTED CHANGES AND CLARIFICATIONS.

Date: DECEMBER 01, 1995.

                               Linda J. Kristjanson, PhD, RN   Chairperson
                               Associate Professor
                               University of Manitoba Faculty of Nursing

                                                        Position

NOTE:
Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.

Revised: 92/05/08/se

THE UNIVERSITY OF MANITOBA   FACULTY OF SOCIAL WORK   Winnipeg, Manitoba
                                                                  Canada R3T 2N2

                                                                  Tel: (204) 474-7050
                                                                  Fax: (204) 261-3283
                                                                  E-Mail: Social_Work@UManitoba.CA

Ms. Sonia Busca

R

January 2, 1996

Dear Sonia:

        Re: Research ethics committee approval for thesis
        research

        Please find enclosed a memorandum from the chair of the
Faculty of Social Work Research Ethics Committee confirming that
the Faculty of Nursing ethics committee approval is sufficient.

                                Yours Truly,

                                Sid Frankel
                                Thesis Advisor

Research Ethics Committee
Faculty of Social Work
University of Manitoba
Winnipeg, Manitoba
R3T 2N2

To: S. Frankel   December 14, 1995.

Dear Sid:

The Committee has agreed to accept S. Busca's ethics approval from the Faculty of Nursing. I
     would suggest that in the future the application to the Committee be initiated by the
     student.

                              Yours truly,

                              Grant Reid.
                              Chairperson.

                              ((   )

                              fax: (   ).

APPENDIX 7

PEDIATRIC RESEARCH COORDINATING
COMMITTEE APPROVAL

Health Sciences Centre

Pediatric Research
Coordinating Committee
820 Sherbrook Street
Winnipeg, Manitoba R3A 1R9
Dial Direct (204) -787-2455
Facsimile#: (204) 787-5040

November 8, 1995

Sonia Busca Owczar
Department of Social Work
FE330

RE: *"Parents' perceptions of family-centered care at Children's Hospital"*

Dear Ms. Busca Owczar,

Your study was reviewed by the PRCC on November 6, 1995. Please consider it **approved.**

Thank you for your submission. If you have any further concerns, please do not hesitate to contact ou office.

Sincerely yours,

Wade T.A. Watson, MD, FRCPC
Chair, Pediatric Research Coordinating Committee
Children's Hospital of Winnipeg

WTAW:ck

APPENDIX 8

SCREENING CALL TO POTENTIAL RESPONDENTS

Phone Call to Potential Respondents

Upon receiving the card, I will contact the interested persons by telephone. The purpose of this phone call is to thank respondents for their interest in the project, and to further establish their eligibility. The phone call will begin with introductions:

Hello, my name is Sonia Busca and I am calling you about the study about family-centered care at Children's Hospital. Is this a good time to talk? Thank-you very much for returning the card. Do you have any questions about the project?...I am trying to gather as great a variety of participants as possible, and also make sure that the people who responded are in fact eligible for the study. Do you mind if I ask you a few questions?....

In a conversational style, the following information will be sought: I understand that your child is diagnosed with _____. When was s/he diagnosed? How long have you been attending Children's Hospital with him/her? How often do you visit the hospital? With which services do you commonly interact? Do you consider yourself to be a member of a particular cultural or ethnic group?

I will be sensitive to the respondents' level of comprehension and will taylor the discussion accordingly. If the respondent is not eligible, I will clarify the purpose of the study and the reason that the selection criteria was established. I will thank him/her for their interest and apologize for not being able to interview them. If the respondent is eligible, I will arrange a mutually convenient appointment in their home or at the hospital.

APPENDIX 9

CONSENT FORM

CONSENT FORM

I understand that the purpose of this research is to explore the experiences of parents of children with special health needs in a hospital that offers Family-Centred Care. It is not intended to evaluate myself, nor my family.

I will be interviewed by the researcher, Sonia Busca Owczar (   ), at a mutually convenient location, either at the hospital, or in my home for no more that two hours.

The interview will be tape recorded to assist with data analysis. I may ask that the tape recorder be turned off at any point in the interview.

I will be asked questions that relate to my experiences in hospital with my child. These questions will be particularly geared to determine to what extent the hospital experience helps me to feel in charge of my child's health care.

Any information I give will be kept fully confidential. All identifying information will be changed or omitted from all reports. No one, other than the researcher will know that I participated in this study.

I understand that I can refuse to participate, withdraw from the study at any point, or refuse to answer any question in the interview. Doing so will have no effect on the treatment that I or my child receive at Children's Hospital.

Although there may be limited benefit to me or my family, participation in this study may help to improve services at Children's Hospital. Risk to me is minimal, unless I feel discomfort at expressing my views to Sonia Busca Owczar.

A written summary will be prepared at the end of the research and will be made available to me to inform me of the results of the study.

This study is being conducted towards a Master of Social Work degree, at the University of Manitoba, under the supervision of professor Sid Frankel who can be reached at   . The study has been approved by the University of Manitoba, Faculty of Nursing Ethical Review Committee.

Signed: _____

Date: _____

APPENDIX 10

SUMMARY OF INDIVIDUAL INTERVIEWS

Parents' Perceptions of Family Centered Care at Children's Hospital

The following is a short summary in my own words of some of your comments from the interview for the Family-Centered Care study. There are many things I left out, but I hope this represents some of your ideas. I appreciate your honesty. As it turned out, some of the most critical comments were the most helpful. I hope to be finished the study by early fall, and will send out a summary of the results when it's complete.
Thanks again for your time.

Principles of Family-Centered Care

1. Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate.

    -respondent feel that health care providers value parents' input as people who know their child best
    -this respect has been earned over time as the relationship between parents and providers evolves

2. Facilitation of parent/professional collaboration at all levels of health care

    -good partnership and team work between this family and providers
    -conflicts in the past have been adequately resolved
    -frustration exists in having to repeat history to changing staff
    -would appreciate more time with providers

3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner

    -plenty of information given, but sometimes it is too technical or quickly delivered
    -reassurance and interpretation would assist parent in fully benefitting from information
    -information from other sources besides staff, ie) journals would be appreciated but not freely offered

4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families

    -services to provide emotional support are available but not currently active
    -parent feels at home by being acknowledged by name

5.	Recognition of family strengths and individuality and respect for different methods of coping

	-would appreciate more positive reinforcement of even small gains to validate hard work of both parents and kids in keeping well

6.	Understanding and incorporating the developmental and emotional needs of infants, children and adolescents and their families into health care delivery systems

	-providers respect child as a growing person with different needs form when he was younger
	-providers direct medical questions to child vs to parent
	-staff take changing developmental needs into account, ie) distractions for toddlers, privacy for teens
	-as child gets older, more focus on child and less on family unit

7.	Encouragement and facilitation of parent to parent support

	-providers could have a greater role in linking compatible families but have seemed to move away from that function
	-better use could be made of clinic days and long waits to connect families

8.	Assurance that the design of health care delivery systems is flexible, accessible and responsive to family needs

	-family has negotiated a case manager role with MD
	Other resource people pulled in at his discretion. Saves repeating info to various team members
	-care is well coordinated by eliminating contact with various professionals
	-parent confident that external services would be offered if there were a need

9.	Honouring the racial, ethnic, cultural and socio-economic diversity in families

	-parent doesn't feel that culture/socio-economic issues pose personal barriers, however, can empathize with how the use of technical language or fast instructions can pose problems for some with limited education or language difficulties

General Comments
-fragmented family-centered care as staff deal only with the person
 accompanying child to hospital
-evening clinics would show commitment to accommodating more
 family members
-annual family/staff conference recommended

Parents' Perceptions of Family Centered Care at Children's Hospital

The following is a short summary in my own words of some of your comments from the interview for the Family-Centered Care study. There are many things I left out, but I hope this represents some of your ideas. I appreciate your honesty. As it turned out, some of the most critical comments were the most helpful. I hope to be finished the study by early fall, and will send out a summary of the results when it's complete.
Thanks again for your time.

Principles of Family-Centered Care

1. Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate

    -parent receives lots of encouragement for a job well done in caring for child
    -parent feels a part of decision making, but not left alone with decisions
    -feels valued and supported in child's care

2. Facilitation of parent/professional collaboration at all levels of health care

    -parent feels like a part of the team-good collaboration with providers
    -parent not asked to participate in meetings about care and treatment, but doesn't feel the need to be, as she trusts health care providers

3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner

    -parent receives lots of information (more then expected) without having to ask
    -not encouraged to receive info from other sources beyond health care staff but this is not seen as a problem
    -MD helps parent keep a written record on child's progress

4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families

    -parent not aware that mental health services are available and has not been encouraged to use them
    -parking is not easily available
    -staff try to accommodate more than one appointment per day

5.   Recognition of family strengths and individuality and respect for different methods of coping

-parent feels very valued and supported by staff

6.   Understanding and incorporating the developmental and emotional needs of infants, children and adolescents and their families into health care delivery systems

-child gets lots of attention from staff
-some concern expressed that level of support currently felt by staff can't be sustained over long term

7.   Encouragement and facilitation of parent to parent support

-parent would like to meet with other parents, but has not felt encouraged to do so by staff

8.   Assurance that the design of health care delivery systems is flexible, accessible and response to family needs

-child's care is well coordinated
-MD acts as very capable case manager
-parent confident that any needs related to caring for child would be met

9.   Honouring the racial, ethnic, cultural and socio-economic diversity in families

-parent wishes that providers knew more about other family issues so that open discussion could occur about other issues/problems
-help within family context not offered by staff

Parents' Perceptions of Family Centered Care at Children's Hospital

The following is a short summary in my own words of some of your comments from the interview for the Family-Centered Care study. There are many things I left out, but I hope this represents some of your ideas. I appreciate your honesty. As it turned out, some of the most critical comments were the most helpful. I hope to be finished the study by early fall, and will send out a summary of the results when it's complete. Thanks again for your time.

Principles of Family-Centered Care

1. Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate

    -parent feels that the best medical decisions are made for child through the treatment protocol and does not feel the need to make many medical decisions
    -health care providers value parents' input on how child reacts to protocol and try to accommodate accordingly

2. Facilitation of parent/professional collaboration at all levels of health care

    -parent enjoys good relationships with providers
    -parent participates in child's daily care while in hospital
    -family had a meeting with providers at diagnosis, but not formal meetings since
    -parent recommends that staff set up regularly scheduled meetings with parents to ensure that questions and concerns are addressed
    -nurses spend lots of time with family when they are able

3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner

    -social worker brought useful reading material written in layman's terms
    -parent not formally encouraged to seek outside information, but found providers to be open to discussing info found on alternative treatments

4.   Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families

     -family met social worker and chaplain as part of health care team
     -satisfied with developmental programs for child ie., hospital play room, clown
     -sleeping facilities are inadequate
     -hospital food not appealing to children, and alternative menu not freely offered
     -parking expensive
     -providers try to facilitate a quicker discharge by "hooking up" child as soon as possible
     -hospital services are easily accessed even when child is not in hospital

5.   Recognition of family strengths and individuality and respect for different methods of coping

     -generally feel respected by staff
     -critical of one nurse who shows disrespect by being noisy at night

6.   Understanding and incorporating the developmental and emotional needs of infants, children and adolescents and their families into health care delivery systems

     -staff make an effort to talk directly with the child to give information and ask questions
     -pleased with programs such as play room and clown

7.   Encouragement and facilitation of parent to parent support

     -ward staff has introduced parents to others in similar situations
     -staff have connected children with similar treatments as a teaching aid about treatment

8.   Assurance that the design of health care delivery systems is flexible, accessible and responsive to family needs

     -child's medical treatment is well known to all relevant providers
     -MD acts as very capable case manager
     -providers have suggested external resource, ie., Wish Foundation
     -providers have liaised with child's school

9. Honouring the racial, ethnic, cultural and socio-economic diversity in families

   -parent feels that as a member of the majority culture, and that shared by most providers, there are no cultural barriers
   -parent feels that family situation is known to providers and that needs of sibling are also considered

APPENDIX 11

SUMMARY OF PRELIMINARY FINDINGS

Parents' Perceptions of Family-Centered Care at Children's Hospital
Summary of a Research Project conducted in winter, 1996

A study was conducted during the winter and spring of 1996 to determine whether parents of children with special health needs perceived the services of Children's Hospital of Winnipeg to be family-centered. The following is a summary of the way in which the study was conducted, and of its findings.

Method

-a 90 minute interview was conducted with 10 mothers and 1 father of children who use the services of Children's Hospital

-the questions in the interview were based on each of the 9 principles of family-centered care as defined by the Association for the Care of Children's Health (ACCH)

-parents whose children represented a variety of diagnoses were interviewed to try to get a general picture of the services of Children's Hospital

Who Participated?

-parents whose children had on-going chronic illness who received services from the hospital from 3 to 53 times over the last 12 months

-10 mothers(including 2 foster mothers) and 1 father

-parents whose child had been diagnosed from 7 months to 12 years from the time of the study

-parents whose children ranged in age from 15 months to 16 years

-1 parent came from rural Manitoba

-1 parent was a member of a cultural or ethnic minority group

FINDINGS

The following is a summary of the preliminary findings for each of the principles of family-centered care.

1. **Recognition that the family is the constant in the child's life while the service systems and personnel within those systems fluctuate**

   -parents identified 3 ways in which they were encouraged to feel   by health care providers that they were the constant in their child's life: by a relationship of partnership with health care providers, by having real input into medical decisions affecting   their child, and by having control over the level of participation in care during their child's hospitalization

   -parents whose children had been diagnosed for a greater period of time (7-12 years) expected greater control and partnership in their children's health care than those that were newer to the system (less than 1 year to 3 years)

   -parents felt that respect in their ability to care for their children and partnership with health care providers grew over time as each party learned to work together

2. **Facilitation of parent/professional collaboration at all levels of health care**

   -effective collaboration is guided by trust, relationship and good conflict management. Most parents felt that this was achieved in their relationships with health care providers

   -parental participation in meetings other than those related to the diagnosis or discharge from hospital were not the norm among the group interviewed

   -some parents felt that they should have more participation in meetings about their child, others relied on staff to interpret the information from meetings for them

3.   **Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner**

-parents felt that the information they received from health care providers about their child's condition was available, thorough and patiently delivered
-health care providers were seen by parents as being in control of the information they gave by not actively encouraging exploration of other sources of information

-many parents believed that they should have access to the child's medical record. Lack of access caused some suspicion about what was being written and an imbalance in the relationship between parents and providers

4.   **Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families**

-parents were not aware that formal counselling services were available to them unless they worked with teams where a mental health professional would routinely make contact with them

-a high degree of satisfaction was expressed about the facility itself and its ability to help parents feel at home. The exception was lack of access to kitchens on the wards, expensive parking and noise at night

-providers attempt to coordinate appointments, admissions and discharges with families' personal demands within the confines of hospital organization

5.   **Recognition of family strengths and individuality and respect for different methods of coping**

-parents generally felt respected by health care providers with whom they worked closely

-respect was not automatically experienced by parents when interacting with new or different providers

-some experienced feeling judged, particularly during hospital admissions

-this finding leads to speculation that hospital admissions, already stressful events, place parents and providers in a more intimate relationship, thereby raising opportunity for judgments by either party to arise

6. **Understanding and incorporating the developmental and emotional needs of infants, children, adolescents, and their families into the health care delivery system**

-parents felt the providers showed genuine caring and respect for their children, and understood their unique developmental needs

-the non-medical programs such as the in-house t.v., play room and clown were applauded

-frustration was expressed by some about how hospital routines and procedures interfere with normal daily living for children in hospital

7. **Encouragement of parent to parent support**

-parents indicated an interest in meeting other parents in similar situations to be both helped by them and helpers to them
-health care providers do not routinely link parents with each other, thereby neglecting a possible resource for families

8. **Assurance that the design of health care delivery systems is flexible, accessible and responsive to family needs**

-coordination of internal services was generally found to be satisfactory to parents

-referrals to formal services outside hospital are made appropriately on an as needed basis

-coordination of all health, social and educational services involved with a given family could be improved

9. **Honouring the racial, ethnic, cultural and socioeconomic diversity in families**

-the use of technical language is seen as a barrier to effective interactions with families from non-English speaking cultures or with limited education

-people of some cultures may see the health care provider as a person of great authority and may not feel comfortable in engaging in a partnership with him/her

CONCLUSIONS

Although those parents that chose to participate in this study were generally satisfied with the services their families received at Children's Hospital, their comments suggest that the principles of family-centered care are not uniformly applied.

The greatest strengths in the system were related to direct patient care: medical treatment, supportive, informative relationships with parents and respectful care of children. Activities that were least in compliance with principles of family-centered care were those that required giving parents more control outside the sphere of traditional medical care: full participation at meetings, access to the medical record, linkages with other parents and external sources of information.

It should be noted that not all parents felt the same about the level of control that was appropriate. It was found that the concept of partnership developed over time, with parents more experienced in the system expressing more desire and confidence to take charge of their children's health care needs, feeling that they had earned the respect of providers. Newer families generally expressed greater satisfaction with services, and greater reliance on health care providers to provide the direction of care.

RECOMMENDATIONS

Although family-centered care is the guiding policy at Children's Hospital, its principles do not always trickle down to the actual service delivery. Health care providers need a greater understanding of these principles and what they mean in practice.

If strong partnerships regarding joint decision making and participation in care can evolve in time, strategies should be developed to aid that process for newer families. Parents must feel that it is their right to expect collaborative relationships with providers and gain the skills to negotiate services, get information, resolve conflicts, and determine their place in health care delivery

Mental health services are not routinely offered to all families of children with special needs, therefore programming alternatives must be found to best address families' emotional needs

As not all families have the same definition of family-centered care, negotiation should occur on an individual basis with parents about what level of involvement is suitable to them

ACKNOWLEDGEMENTS