

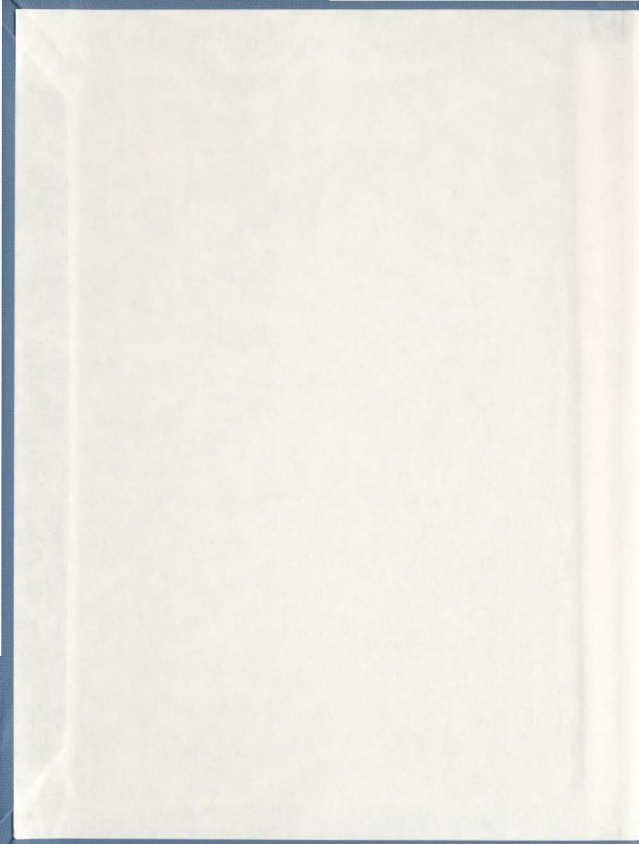
THE PATERNAL EXPERIENCE OF PARENTING
A CHILD WHO HAS DOWN SYNDROME

CENTRE FOR NEWFOUNDLAND STUDIES

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JANICE MARIE BROWN, B.S.N.



The Paternal Experience of Parenting
a Child who has Down Syndrome
by

Janice Marie Brown B.S.N.

A Thesis Submitted to the School of Graduate Studies
In Partial Fulfillment of the Requirements
for the Degree of
Master of Nursing

School of Nursing
Memorial University of Newfoundland
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ABSTRACT

The purpose of this study was to explore the parenting experiences of fathers who parent a young child affected by Down Syndrome. There has been relatively little exploration of the paternal experience in parenting and particularly in parenting a child with a disability.

The aims of this study were i) to describe how fathers of children with Down Syndrome describe their involvement with their child, ii) to identify critical events which have altered the fathers' experiences, and iii) to identify nursing strategies which were perceived by the father as beneficial in helping the fathers and their families.

The research was exploratory using qualitative data. A semi-structured interview guide was used to obtain tape recorded interviews with twelve fathers who had children in the age range of two to twelve years affected with Down Syndrome.

Data were then transcribed and coded into meaningful broad categories which captured important aspects of the fathers' experiences and critical events relating to these experiences. These categories were then clustered within three thematic categories entitled Paternal Roles, Paternal Tasks and Skills, and Processes Related to Parenting. Therapeutic nursing interventions

suggested by the data were identified.

Recommendations which arise from the findings of this study have significance for nurses practicing in the field of child and family nursing.

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The unfailing support of Keith Brown, and the sacrifice of a portion of my attention by my children, is gratefully acknowledged. This work is dedicated to my family, and with special affection and regard, to my nephew Jason, who knows much more than we have the wisdom to understand.

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Chapter 1

Although the importance of the paternal role in child development has gained greater recognition in the past two decades (Klaus & Kennell, 1982; Lamb, 1977), there is relatively little research related to the paternal experience of parenting a child affected by a disability. Research to explore parenting of children with or without disabilities has primarily dealt with maternal experiences, failing either to address paternal experiences, or, if they are addressed, to differentiate fathers' experiences from those of mothers (Damrosch & Perry, 1989; Johnson, 1986; Lamb, 1976). In light of the many differences in the experiences of men and women in other spheres of life (Smith, 1990), there is a possibility that mothers and fathers may have widely differing experiences in parenting a child, especially a disabled child.

Down Syndrome is a condition which occurs with relative frequency and is characterized by definite physical attributes (Berhman & Vaughan, 1987; Lane & Stratford, 1985). Fathers who have children who are affected by Down Syndrome may have unique experiences due to the relative ease with which the condition is recognized and the many potentially serious effects upon the child's health and development. In order to meet the

health needs of these fathers and their families, knowledge of fathers' experiences is relevant to nurses providing family-centered nursing care to families in which there is a child with Down Syndrome. Before effective nursing interventions can be developed we need to have a greater understanding of the fathers' experiences and their perceived needs. The purpose of this study was to explore the parenting experiences of fathers who have young children affected by Down Syndrome. The specific aims of the study were i) to describe how fathers of children with Down Syndrome describe their involvement with their child, ii) to identify critical events which have altered the fathers' experiences, and iii) to identify nursing strategies which were perceived by the father as beneficial in helping the fathers and their families. The questions for the research were: 1) what is the father's experience in parenting a young child who has Down Syndrome, 2) what are the family's nursing needs in relation to this experience, as described by the father, and 3) how do fathers view the role of nurses in meeting these needs?

Down Syndrome

The congenital syndrome of Down Syndrome is also referred to as "Down's Syndrome" and "Trisomy-21". The

overall incidence of Down Syndrome is approximately 1 case in 600-800 live births (Behrman & Vaughan, 1987). The rate of occurrence of Down Syndrome rises with each year of maternal age, from approximately 1 case in 1925 births at age 20 to 1 case in 12 births at age 49. The recurrence risk to chromosomally normal parents who have previously conceived a child with Down Syndrome is thought to be about 1% above the usual age-related risk for the general population.

In about 95% of diagnosed cases, a chromosome analysis yields a "regular trisomy" where 47 chromosomes with an extra chromosome 21 are found. In approximately 1% of cases a mix of normal cells and those with trisomy of chromosome 21 is believed to exist. The remaining 4% of cases are due to translocations; approximately half are directly inherited from a parent carrier (Behrman & Vaughan, 1987).

Down Syndrome results in a recognizable phenotype which varies in its expression in individuals. Characteristics include: mild to severe mental retardation; hypotonia; flat occiput; epicanthic folds; speckled irides; furrowed tongue; malformed ears; flat nasal bridge; decreased acetabular and iliac angles; cryptorchidism; simian crease; single crease on finger five; hypoplasia of middle phalanx of fifth finger; gap between 1st and 2nd toes; high-arched palate;

strabismus; and a broad, short neck. Congenital heart defects are found in 50% of children who have Down Syndrome (Behrman & Vaughan, 1987; Lane & Stratford, 1985). Atlantoaxial instability may occur in up to 30% of affected individuals, and of these 1 to 2% have pronounced muscle weakness. Males who have Down Syndrome are believed to be infertile, while females can reproduce (Pueschel, 1988).

Early intervention programs designed to promote development in early childhood are the main approach to developmentally delaying conditions such as Down Syndrome (Dmitriev, 1982). A key element in the provision of supports for developmentally delayed individuals is a philosophy of "normalization" or the promotion of life experiences which are normally experienced by the non-disabled (Wolfensberger, 1972).

Rationale for the Study

Since nurses frequently care for families affected by the occurrence of Down Syndrome both in the hospital and in the home setting, there is a need for a greater understanding of the experiences of these families. In clinical encounters with these clients, the needs of the mother and child have traditionally received more emphasis than those of fathers. While the philosophy of "family-centered care" which emerged in the past two decades has been credited with promoting much greater

inclusion of the father by health professionals, an article which appeared in 1985 in Canada's Mental Health cautions: "...health professionals have a strong tendency to forget the father after the birth and to confine him to the role of spectator" (de Courval & Goulet, 1985, p.9). The authors suggested that concrete action is required to ensure that fathers' needs are considered in planning and delivering care. In cases where a child has a disability, this action may assume even greater importance.

Research related to parenting and parent-child interaction has focused mainly on the mother. The volume of research involving maternal subjects is large in comparison to the amount of research which has included paternal subjects. Many comments are found in the literature regarding this discrepancy and also the tendency of researchers who do include fathers as subjects to report maternal and paternal findings together without comparison (Bristol & Gallagher, 1986; Damrosch & Perry, 1989; McConachie, 1986). In a review of the research completed on fatherhood, Boyd (1985) comments: "In recent years, the father's recognition as an integral and vital member of the child-rearing team has emerged, although the amount of research regarding the father and fathering remains small in comparison with the subject of mothers" (p. 112).

Considering the omissions which have generally existed in examining the paternal viewpoint, it is not that surprising information specifically related to the experience of fathers who have children affected by Down Syndrome has been largely absent in the literature. Due to the scarcity of research in this area, there may be important facets of their lives which remain unexplored or undiscovered. The findings of this study will yield new information to assist nurses in providing effective family nursing care.

Chapter 2

LITERATURE REVIEW

This chapter provides a review of relevant literature and research findings in three areas: parental reactions to the child who has a disability, the needs of parents who have a child with a disability, and parental influence and the developmentally delayed child, with an emphasis on those studies which included fathers.

There are three main limitations of the literature on the fathers' experiences of parenting a disabled child, especially a child with Down Syndrome. Firstly, a great deal of the literature describing the needs and responses of parents of children with disabilities is based on professional experience and opinion, rather than research findings. Secondly, there is a relatively small number of studies involving paternal subjects with disabled children. Thirdly, the literature review yielded few studies which specifically address fathers who have children affected by Down Syndrome. Because of the paucity of research on fathers of disabled children and conflation of the research findings of mothers and fathers, the literature on parents with disabled children was reviewed, highlighting any research dealing specifically with fathers.

Parental Reaction to the Child who has a Disability

Parental responses to the birth of a child with a congenital disability in children are frequently linked in the literature to the theoretical constructs of i) crisis intervention and ii) predictable grief reactions. Crisis intervention and grief theories, which were originally related to situations involving death, were later modified for application to other situations where a loss occurs, such as in the diagnosis of a disability (Bocian & Kaback, 1978; Drotar, Baskiewicz, Irvin, Kennel & Klaus, 1975).

It has been hypothesized in the literature that parents of a child with disabilities are vulnerable to at least two periods of crisis: an initial crisis which originates in mourning for the imagined "ideal" baby, and secondary crises as the day-to-day effects of the disabling condition are realized (Mori, 1983).

The concept of feeling grief for the loss of a fantasized "perfect" infant following the birth of one who possesses a disability was introduced by Solnit and Stark (1961). This theme was expanded by Olshansky (1962), who stated parents of a disabled child continue to experience grief over time. This experience was labeled "chronic sorrow".

The hypothesis that parental grieving normally occurs with the birth of a child with a congenital

disability, and may continue (or recur in cycles) over time, is widely applied in nursing literature. Feelings of guilt or responsibility for the condition are also frequently cited as a common characteristic in parents' reactions when a congenital disability occurs (Choi, 1978; Damrosch & Perry, 1989; Wacht, 1986; Wright & Leahey, 1987; Young, 1977).

Professionals frequently suggest the responses of parents who have a child with a disability follow a recognizable pattern (Drotar et al., 1975; Keele, 1987; Mori, 1983; Roos, 1963). Drotar and co-investigators (1975) interviewed 20 mothers and 5 fathers regarding their responses to the birth of a child with disabilities. Two children had Down Syndrome. Following a qualitative analysis, the researchers reported the subjects passed through five predictable stages: shock, withdrawal, an emotional reaction (ie: anger, sadness), adaptation, and reorganization (which includes planning for the future). The researchers appeared to generalize the results to a larger population although the small sample size and the failure to consider paternal findings separately from those of maternal subjects may well pose limitations to such generalizations.

Based on a review of the literature, a parental reaction which includes stages of denial, anger, bargaining, depression, and eventual acceptance was

outlined by Mori (1983). He cautioned however, that variables such as the severity of the disability, social acceptability of the disability, the manner in which parents are informed, and the age of the child when diagnosis is made, are important in influencing parental responses.

Keele (1987) stated parents of children with congenital disabilities typically experience anxiety, followed by stages of shock, denial, sadness, anger, adaptation, reorganization, and in most cases, a satisfactory adjustment. Furthermore, factors such as the severity of the disability, the parents' individual attributes, and the availability of family support played a part in parental response, according to Keele (1987). His comments however, are based on professional experience rather than research findings.

Another article (Roos, 1963) which was based on the professional experience of a psychologist, suggested parents of cognitively delayed children have greater difficulty coping with parenting demands, cannot develop as satisfying a relationship with their disabled versus non-disabled children, and experience a long-term depression as a result of realizing their inability to control life's events. In a later publication, Roos (1978) further supported these comments regarding parental needs from a new perspective, having become a

parent of a cognitively disabled child in the interim years. His position as a parent as well as professional lends credibility to the counselling needs and approaches he outlined.

In a discussion of parental reactions to a variety of congenital disabilities, Bocian and Kaback (1978) implied that it is expected that parents will experience strong negative emotions. They stated that physician-counsellors "must be aware of the profound disappointment and guilt of the parents" (p.643). They also suggested that marital conflict may result when the individual ability of partners to cope with the situation varies.

Fortier and Wanlass (1984), stated in a review of the literature on family reaction to having a disabled child, that the occurrence of grief responses with noticeable "stages" is well supported, although there is lack of consensus concerning their length and sequence. The majority of the articles they cited, however, are theoretical or based on professional records.

In contrast with the above, other authors contended that presently available research has been inadequate to justify an expectation by professionals that grief and guilt reactions will predictably emerge (Blacher, 1984; Bristol & Gallagher, 1986; Burden & Thomas, 1986; McConachie, 1986; MacKeith, 1973; Tritt & Esses, 1986).

Following a review of the evidence to support the occurrence of predictable "stages" and the experience of mourning in parental responses, Blacher (1984) concluded that available research used inadequate sample sizes, professional inference in reporting parental feelings, and that they also failed to consider the effects of specific disabilities.

McConachie (1986) remarked on the conclusions sometimes drawn by professionals that an underlying pathology, such as guilt, is linked to a particular parental response:

"...parental guilt has been postulated as identifiable in reactions of hostility to professionals, and in reactions to the child construed either as rejecting or as overcompensating. The danger in such reasoning lies in lack of appropriate action being taken, such as parents' anger with poor services being dismissed or parents' real need for respite care being ignored while professionals concentrate on 'guilt feelings' etc."(p.48).

Research specifically addressing the responses of fathers to parenting children with disabilities has resulted in findings which suggest adjustment difficulties (Cummings, 1976; Damrosch & Perry, 1989; Waisbren, 1980).

Psychological assessments of 240 fathers were completed by Cummings (1976), using a written questionnaire. Among the subject group, 60 fathers had cognitively delayed children, 60 had physically disabled children, 60 had chronically ill children, and 60 had healthy children. He reported that fathers of cognitively delayed children experienced significant stress, lowered self-esteem, depression, and fewer satisfactions from family life than did fathers of healthy children. The use of a written questionnaire could have limited the type of responses fathers made.

There have been attempts in the literature to compare maternal and paternal responses to parenting children with disabilities (Damrosch & Perry, 1989; Goldberg, Marcovitch, MacGregor, and Lojkasek, 1986; Waisbren, 1980). Findings in a survey conducted by Damrosch and Perry (1989) were analyzed for evidence of self-reported adjustment, chronic sorrow, and coping patterns of 22 mothers and 18 fathers who had children with Down Syndrome. Of the fathers included, 83% reported a steady, gradual re-adjustment period, while 68% of the mothers reported recurrent periods of crisis and a higher frequency of feelings of chronic sorrow, of being overwhelmed, gratitude for their child's positive traits, fear about others' opinions and for the future, and jealousy towards parents whose children are not

disabled. The researchers suggested sex-related socialization may have influenced the subjects' choices of coping strategies.

In a study completed by Waisbren (1980), 30 families of developmentally delayed infants were compared with 30 families who had normal infants. One half of each group of families lived in Denmark and one half in California. Parents in both cultures who had a developmentally disabled child saw themselves more negatively and expressed more negative comments about their child than did the parents of normal infants. Parents of disabled children evaluated themselves as personally changed in detrimental ways (ie: anxious and depressed). Comparisons between paternal and maternal reactions to their support sources suggested fathers who felt their own parents were highly supportive responded with greater positive feelings about their child, felt changed for the better, and made more plans for the future. Fathers were more negative than mothers about the impact of the disability on the marriage, and described more stress symptoms than did mothers.

The results of another study seem contradictory to the previous study, concerning paternal responses. Goldberg et al. (1986) interviewed the parents of 59 developmentally delayed preschoolers. The study group consisted of 18 sets of parents who had a child with

Down Syndrome, 19 who had a child with neurological problems, and 22 who had a child with developmental delays of unknown etiology. They found that fathers in all three groups reported having fewer stress effects, higher self-esteem, more internal locus of control, and less support than did the mothers. They stated it is inappropriate to make generalizations related to both parents if only mothers are studied, as there were significant differences between fathers' and mothers' experiences in the study sample. The attempt made to distinguish paternal and maternal findings and to group subjects in relation to different etiologies in children, is uncommon in the literature. However, other variables which were apparently not considered, such as child's age or additional health problems, may also potentially affect stress levels.

The possibility that different types of disabling conditions could evoke different types of parental response has also been given attention in the literature (Gallagher, Beckman, & Cross, 1983; Holroyd & McArthur, 1976). This may have implications for the results of many studies, because research designs frequently have grouped various physical and cognitive disabilities within broad categories, such as "developmentally delayed" or "handicapped".

From a review of the literature on sources of stress in families of disabled children, Gallagher et al. (1983) concluded that different diagnostic categories might be related to the appearance of specific stress factors. This conclusion would appear to be supported by findings from a study completed by Holroyd and McArthur (1976). They compared levels of stress reported by three subject groups; parents of autistic children, parents of children with Down Syndrome, and parents of children with psychiatric illness. There was a difference between the different groups regarding reported stress levels as well as parental responses to the disability. Families who had autistic children experienced the highest stress levels and poorer family integration; the subject group in which there were children with Down Syndrome appeared to have the lowest stress levels and fewer family problems.

Goldberg et al. (1986) also found differences in parental response which were related to the diagnostic category of the child's disability. Results of interviews with 59 parents whose children were affected by Down Syndrome, neurological problems, or an unknown etiology, revealed higher scores were obtained in the Down Syndrome group regarding positive child-parent experiences, helpful relationships with grandparents, and the support parents received. Their results suggest

that parental responses to a child's delayed development may not be generalized from one diagnostic group to another.

Needs of Parents who have a Child with a Disability

A number of sources cite specific needs of parents based on professional experience (Keele, 1987; Miola, 1987; Mori, 1983; Roos, 1978; Wacht, 1986). Mori (1983) identified major needs parents have which professionals should consider in their interaction with them: promotion of self-esteem, the need to refine parenting skills, the ability to overcome feelings of isolation, depression, and ambivalence, knowledge about their child and available treatments, and reality-based expectations for the future.

According to Miola (1987), parents of disabled infants need a well-thought out management program which includes medical interpretation of the diagnosis, assistance to understand what has happened and to deal with their feelings, promotion of emotional attachment and good parenting skills, exposure to community and school services, genetic counselling, and projection of the future. In order to reduce the potential for misinformation, the author stated that parents of children who have Down Syndrome require detailed information with planned repetitions of that

information, and a written summary of the information which is given to them.

Studies related to parental needs at the time of diagnosis have provided findings which have implications for healthcare providers (Cunningham, Morgan, & McGucken, 1984; Pueschel & Murphy, 1976). The perceptions of 414 parents were analyzed by Pueschel and Murphy (1976), concerning their experience at the birth of a child who had Down Syndrome. Their results suggested that tact, truthfulness, and empathetic guidance are needed by parents, along with prompt disclosure of the diagnosis, the use of appropriate terminology in explaining the condition, the support of the other parent at the time of diagnosis, and adequate follow-up and community supports. Those subjects who discovered the diagnosis indirectly or who were informed in a negative manner appeared to have lost trust in healthcare providers.

Cunningham et al. (1984) studied two groups of British parents of children who had Down Syndrome. One group served as a control group receiving typical diagnostic counselling, and the second group were the experimental group receiving "model" services. The "model" services consisted of both parents being told as soon as possible after the birth of the infant with the infant present, and time provided to answer any of the

parents' questions. The informing interview took place with the pediatrician and a British community health nurse with specialized experience present. The nurse provided supportive home follow-up care. Parents felt their needs were met better through the "model" service and expressed relative dissatisfaction with the variety of approaches used in the control group. A possible weakness in the design was the failure to provide one consistent form of management in the control group in order to have a better comparison for the experimental group.

Long-term support needs of parents of disabled children have also been given attention in the literature (Hayes & Knox, 1984; Miola, 1987; Wacht, 1986). Potential family needs outlined by Wacht (1986) included dealing with feelings of grief and guilt, dealing with relationship struggles and decisions related to adapting expectations, and providing training or education. Over time, the child's social needs and ability to live independently assume greater importance for parents. Wacht (1986) recommended nurses provide opportunities to foster the parent-child attachment, offer developmental and health teaching, counsel when difficulties arise, and include families in evaluation and planning for developmental intervention.

In describing the role of a Pediatric Nurse Practitioner on a multi-disciplinary treatment team for children who have Down Syndrome, Miola (1987) suggested the needs of families may include mediation and advocacy, as well as professional follow-up throughout hospitalizations and between clinic visits.

In a related area of study, the needs of parents experiencing hospitalization of children with long-term disabilities were identified. Hayes and Knox (1984) conducted open-ended interviews with 40 parents whose children were hospitalized with long-term disabilities and then they qualitatively analyzed the results. They found the parents needed to make sense of the experience, to familiarize themselves with a new environment, to adapt their relationship with the child and the other family members, and to learn how to negotiate directly with health professionals. The variability in the health status of the children and conflation of maternal and paternal responses are limitations in considering the results of this study. In fact, it is not clear if fathers were interviewed but the term parents is used throughout.

Needs which are specific to fathers have been identified by some researchers (Cummings, 1976; Damrosch & Perry, 1989; Goldberg et al., 1986). Following psychological assessments of 60 fathers who had

cognitively disabled children, Cummings (1976) concluded fathers need more opportunity to ventilate feelings of grief and anger with less pressure placed on them to be a support for other family members.

Damrosch and Perry (1989) conducted a recent survey of 18 fathers and 22 mothers of children who had Down Syndrome, and found significant differences in maternal and paternal experiences. The subjects were asked to evaluate the effectiveness of seven specified nursing actions. Mothers assigned significantly higher ratings than fathers to two nursing actions: encouraging expression of sadness, and allowing parents to be weak. Fathers rated the following actions as more supportive: assuming a cheerful attitude, encouraging parents not to dwell on the negatives, encouraging parents to be strong, and giving parents a chance for temporary escape. The results seem to indicate maternal and paternal support needs were very different. A replication of this study using a larger sample size would be of importance to see if these results hold.

Parental Influence and the Developmentally Delayed Child

The literature in this area relates to the outcome of early intervention programmes in which both parents have participated (Guralnick, 1988; Moxley-Haegert & Serbin, 1983), and the observation of parent-child

interactions (Levy-Shiff, 1986; McConachie & Mitchell, 1985).

Guralnick (1988) reviewed longitudinal studies which analyzed the efficacy of early intervention programs including parental participation. He supports the use of such programs with children who have Down Syndrome: "the well-documented decline in measured intelligence in Down syndrome children that occurs over the first few years of life can be prevented by early and continuous participation in early intervention programs " (p.78). There are conflicting opinions regarding the child's developmental outcomes and effects on the parent-child relationship when the parents assume formal teaching functions (Guralnick, 1988). A more informal relationship-focused teaching approach in which parents choose the additional resources and community support they need to assist with their child's development, has been promoted in recent years (Affleck, McGrade, McQueeney, & Allen, 1982).

Moxley-Haegert and Serbin (1983) studied the effectiveness of home-based treatment programs in which parents were given specific teaching tasks to complete with developmentally delayed children. A mixed group of etiologies was present. The families in the study were placed in one of three groups in which parents received developmental education, child management education, or

no education (lack of guidance in using materials). Child development was assessed using standardized developmental measures prior to and at 9-15 months after the introduction of the program. Greater strides in child development occurred in the group where developmental education was stressed. The researchers hypothesize this was the result of greater motivation on the part of parents, who had been taught to recognize learning as a sequential set of tasks and to place greater importance on small improvements. Fathers were not specifically addressed in this study.

Maternal and paternal styles of interaction were compared by Levy-Shiff (1986) in a naturalistic study in Israel. Mother-father-child interactions were observed for 90 minutes in 20 families in which there was a young cognitively delayed child and in a matched sample of 20 families with developmentally normal children. Although fourteen of the affected children had Down Syndrome findings from this sub-group did not differ significantly from the study group in total. Findings of written observational records indicated less verbal and physical contact, fewer teaching efforts, and less expressed affection in parental-child interactions in the families who had children who were developmentally delayed. Parents of cognitively delayed children spent a greater portion of communication on their childrens'

needs, with less sharing of other issues. Mothers exceeded fathers in caregiving tasks in both groups and elicited more laughing, smiling, and crying from children in both groups. Behavioral differences between the two groups were less evident in fathers than in mothers in regards to child-parent interaction, leading the researchers to conclude that fathers were less influenced by practical and emotional concerns about the children as they interacted with them. The researchers state their findings indicate "...fathers appear to be natural partners in any intervention aimed at bolstering the quantity and quality of child stimulation" (p.147). The rather unnatural "set-up" of the observational periods is a potential drawback in this study as it may have affected subjects' interactions with their children.

In contrast to the findings of the above study, McConachie and Mitchell (1985) found that fathers had more difficulty than mothers in a teaching session with developmentally delayed children. These researchers filmed interactions between parents and young children who were cognitively delayed children due to a variety of causes. The interactions were informal teaching tasks which took place in a naturalistic setting; the child's home. Their findings revealed that mothers responded more flexibly and used more verbal statements, whereas

fathers engaged in more physical demonstration or help, and elicited more negative responses from the child. The researchers pointed out that fathers may be less well attuned than mothers to the type of guidance which will teach their children successfully. This has implications for the kind of involvement and guidance fathers might require to be effective participants in early intervention. The authors stated fathers need to be directly involved in intervention programs, instead of relying on information passed on by other family members. Both fathers and mothers in this study, however displayed ineffective behaviors such as giving inconsistent and infrequent praise.

Summary

The concepts of stages of grief, chronic sorrow, and crisis reactions are widely accepted throughout the literature as typical components of parental responses to parenting a child with a disability. The criticism has been raised by some researchers that the expectation of such responses in all parents of disabled children is not adequately supported by research. The view that parental responses are unique and can be expected to vary, is more prominent in recent literature.

The findings of research suggest the presence of some degree of grief, depression, and adjustment problems in parents of children who have developmental

delays. Patterns of family interaction and paternal influence in families who have children with a disability is a relatively new area of research. Further research is needed to discover the needs and strengths of fathers who parent developmentally delayed children.

Chapter 3

METHOD

In order to explore the parenting experiences of fathers who have young children affected by Down Syndrome a qualitative, exploratory approach was used in the study. An exploratory approach is recommended when little is known about the phenomenon under study (Patton, 1980; Seaman, 1987). Boyd (1985) offered support for the use of exploratory approaches in studying aspects of fatherhood in her review of the literature on fatherhood: "Due to the current stage of development of research on fathers, it seems appropriate that the largest number of fathering studies are those attempting to gain familiarity with the subject area" (p.123). A similar research approach was used by McKeever (1981) to explore the experiences of ten fathers of chronically ill children and to develop categories within five broad areas of interest to nurses.

The limited amount of research which has been done regarding the paternal role in parenting has included very few attempts to look at fatherhood in relation to parenting a child with Down Syndrome. Included in this chapter is a discussion of the research approach, definition of parenting, criteria for subjects, data

collection, interview guide, data analysis, reliability and validity, and ethical considerations.

Research Approach

The study was qualitative and exploratory in nature, using qualitative data. The major emphasis was to gain greater understanding of the phenomenon of fathers' experiences in parenting a young child who has Down Syndrome.

An interview guide was designed from the literature review of related research (Appendix A). In-depth interviews were tape-recorded to gather data in the subjects' own words. Data were transcribed and coded into broad categories representing the major themes present which were somewhat shaped by the definition of parenting used by the researcher. These categories were later defined and developed and sub-categories formed.

This approach offers the advantage of allowing the subjects to describe their personal perspectives in detail and to expand on points which are exceptionally meaningful to them. The use of a flexible interview guide permits a deeper and more complete response than might be offered by other approaches.

The need for a research approach which allows the subjects this degree of freedom is supported in the literature. In 1981 Burden (cited in Burden & Thomas, 1986) reviewed 60 studies related to disabled children

and parents published between 1959 and 1979, and found little account had been taken of parents' own viewpoints; he recommended that parents of children with disabilities be interviewed and their experiences documented. Other researchers have noted the personal perspectives of such parents deserve further exploration (Hayes & Knox, 1984; Horner, Rawlins, & Giles, 1987; McKeever, 1981).

Definition of Parenting

Parenting is a multi-dimensional activity offering potential benefits of learning and development to both parent and child (Callahan, 1973; Hamner & Turner, 1985).

Horowitz, Hughes and Perdue (1982) consider parenting to be "a role, a process, a task, and a skill" (p.2). In the model they developed for nurses, the act of parenting contains complex dimensions which demand the use of knowledge, parental experience, and specific techniques. Parenting involves actions to fulfill the child's physical and emotional needs, as well as related activities such as planning events which promote the child's development and the creation of a growth-enhancing environment. Parents must utilize personal and external resources (Horowitz et al., 1982).

For the purposes of this study, parenting was viewed as an experience which can be described in terms

of roles, processes, and specific tasks and skills (Horowitz et al., 1982). Fathers have unique beliefs, knowledge, and abilities which they bring to the parenting relationship, and have learned through their participation in it. The process of parenting is a dynamic one, which alters and is in turn affected by the actions of others. In light of this, the subjects' perceptions of their relationships with friends, family members, and health professionals are explored.

Criteria for Subjects

The study population consisted of biological fathers who are parenting children between one and twelve years old who have Down Syndrome. It was decided the subjects might be too immersed in the initial reaction to the child's birth, prior to one year, to comment on all the areas the interviewer hoped to cover. The age of twelve was chosen as the upper age limit as the entry to adolescence is a developmental point at which parental concerns might begin to differ markedly from those related to younger children (Pueschel, 1988). Other criteria for fathers included:

- 1) good physical and mental health
- 2) ability to use and understand the English language
- 3) reside in an urban setting in a family unit where the mother and child also reside

completed a formal consent (see Appendix C) prior to collection of the data. Data was recorded through written notes and the use of a tape recorder, subject to the interviewee's permission. All subjects agreed to the taping of interviews. Subjects were told the audiotapes of the interviews would be destroyed following the completion of the thesis. The average length of time required for an interview was one hour.

All of the interviews were conducted in the homes of the subjects. Subjects were interviewed once. Due to the employment hours of the subjects, the majority of the interviews took place in the evening. Fathers were requested to choose a time for the interview when the immediate presence of other family members could be avoided. The intention in using a setting familiar to the subject and in giving the subject control of some aspects of the interview was to maximize his psychological and physical comfort during the interview process.

Interview Guide

An interview guide was designed after a review of related research (see Appendix A). Horowitz et al. (1982) describe six key aspects of parenting which include parental roles, rules and decision-making within the family, communication strategies, the use of physical and psychological space by family members, time

Data Collection

The subjects were recruited through two main sources: firstly, letters were distributed at two community-based events potential subjects might attend: a parent-organized playgroup for children with special needs and a conference sponsored by the Association for Community Living. The letters described the purpose of the research, criteria for subjects, and the background of the researcher (Appendix B). Three subjects were located when they responded to the letter by contacting the researcher. The second source of potential subjects was through professionals involved in community service or health professionals. These professionals suggested persons in the community who could act as a resource through their knowledge of fathers who might wish to participate. The researcher asked these resource persons to obtain permission from potential subjects to be contacted by the researcher. Once this was obtained, the researcher telephoned the potential subject, described the study, and provided a letter of introduction (Appendix B). Subjects then decided if they wished to participate. Nine subjects were obtained through this type of referral. One person who was contacted in this manner declined to participate in the study.

Interviews were conducted by the researcher at a time which was convenient to both parties. The subjects

and priority given to activities such as work and play, and how the family has coped and developed as stressors and changes emerge. The interview guide contains questions which pertain to these aspects of parenting, as well as other areas suggested by the literature review as important in exploring this experience: the effects upon family members, needs of family members, strategies and skills fathers utilized, and the use and impact of resources.

The interview guide also contained specific questions regarding the subjects' experiences with healthcare providers, and their ideas about the role of nurses in relation to meeting family needs. Basic demographic data was requested at the beginning of the interview. This included subject's age, occupation, and educational level, number of children in the family, birth order and ages of the children, and major health complications experienced by the affected child.

Data Analysis

Guidelines used for conducting the data analysis were those based on the suggestions of Corbin (1986) and Swanson (1986). The interviews were transcribed by the researcher and multiple hard copies of the data were produced. These copies were used to group and sort data into initial categories or "laundry lists" of categories as described by Swanson (1986). Breakdown and comparison

of data was completed through the process suggested by Corbin (1986). These "laundry list" categories were further collapsed and refined and then assigned to one of three broad thematic categories entitled Paternal Roles, Paternal Tasks and Skills, and Processes related to Parenting. Paternal Roles encompassed those categories which were related to fulfilling a highly visible function such as caregiving; Paternal Tasks and Skills contained categories outlining specific actions fathers employed to improve the outcome of parenting; and Processes related to Parenting contained categories describing internal and intrapersonal processes which evolved as the subjects parented.

The data in each category were examined for range and depth. Subjects' views regarding the role of nursing and the specific interventions they had described were also identified. Helpful interventions suggested by the fathers were outlined as well.

Reliability and Validity

If the research is to contribute new insights to a particular area of inquiry, the findings must be credible (LeCompte & Goetz, 1982). To have credible research findings the threats to the reliability and the validity of the findings must be addressed. In order to enhance the reliability and validity of the research the issues of i) sampling, ii) appropriateness of the

interview guide, and iii) possible effects of the researcher were addressed.

Since the researcher was interested in a detailed exploration into the experiences of fathers who have children with Down Syndrome a purposive or theoretical sampling method was used. One of the assumptions on which theoretical sampling is based is "that all actors in a setting are not equally informed about the knowledge sought by the investigator" (Morse, 1986, p. 183). Through the use of resource persons in the community who were familiar with the potential subjects, fathers who had experienced parenting a child with Down Syndrome and were willing and able to share their experiences were chosen. This helped ensure that good knowledgeable subjects would be chosen.

In order to ensure comprehensiveness and relevance of the data the interview guide was reviewed and critiqued for content and form by a father who has a child with Down Syndrome and a social worker who has experience in interviewing and counselling parents of handicapped children in a rehabilitation setting. In addition, the researcher continued theoretical sampling until the theoretical codes were saturated. A theoretical code is considered saturated when no new information is available which would suggest a new code or the expansion of existing codes. Finally, the thesis

committee members were provided with copies of the transcribed interview data and notes describing the data analysis process. These were reviewed by the committee members and their suggestions for revision and clarification were integrated into the interview and analysis process.

One of the threats to the internal validity of a study is the reactive effects of the researcher (Denzin, 1970). A semi-structured, open-ended interview that is conducted in a face-to-face situation, is naturally an interactive process. However, as Hammersley and Atkinson (1983) point out: "Rather than engaging in futile attempts to eliminate the effects of the researcher, we should set out understanding them" (p.17). Prior to beginning data collection the researcher attempted to make explicit the assumptions she held about parenting a child with Down Syndrome and to discuss these with members of the thesis committee in order to understand how these assumptions could bias the research process. In some instances the assumptions acted as sources of exploration with the subjects. A second effect of the researcher is the relationship between the researcher and subjects in a study. All the subjects were informed that the researcher was a nurse who had a special interest in children who had Down Syndrome and in their families. In order to separate the role of the

researcher and that of the nurse a debriefing session occurred only after the interviewing of a subject had been completed.

Ethical Considerations

Any research involving human subjects requires that certain procedures are followed in order to protect the rights of the individuals involved as subjects in the research. Participants were fully informed of the aims of the study and of their role as participants. Subjects were informed that they could withdraw from the study at any time, and were provided with debriefing time following the interviews. When specific needs were revealed by subjects, the researcher provided support in the debriefing period and encouraged subjects to follow up by contacting the appropriate resources.

Written consent for the use of the interview data was obtained from each subject (Appendix C). Confidentiality of information was protected by ensuring that no identifying information that could link specific comments to a particular subject was included in the text of the thesis. Subjects were informed the actual audiotapes would be destroyed following completion of the thesis. Ethical approval for the study was obtained from the Human Subjects Review Committee of the School of Nursing at Memorial University of Newfoundland.

Chapter 4

FINDINGS

The fathers' involvement with their children and critical events relating to the fathers' experience is presented under three main thematic categories. These thematic categories are entitled Paternal Roles, Paternal Tasks and Skills, and Processes Related to Parenting. Examples from the data are used to illustrate the range and depth of experiences and the events which were critical to the development of the role, task and skill, or process are described. Nursing interventions which the fathers identified will be summarized. In order to have a greater understanding of the subjects' experiences some limited demographic data of the subjects is included.

Demographic Data

A total of 12 subjects were interviewed. They ranged in age between 28 and 55 years of age. Their children who had Down Syndrome were between the ages of 2 and 12, with several in the age range of 3 to 6 years. One child had no siblings; four had one sibling; and the remainder had two siblings. Four of the children were the eldest in the family, and three children were the youngest. Two of the children were eight or more years younger than their siblings.

In addition to Down Syndrome, six of the children had additional developmental/health problems associated with respiratory and nutritional status, physical stature, coordination, and hearing problems. Speech difficulties were very common. At the time of the interview, none of the children were hospitalized.

Based on observation of the home setting and occupation of the father, the families' socioeconomic status ranged from low-income to high-income, with the majority in the middle class bracket. The educational levels and occupations of fathers varied greatly. Three fathers had received university-level education.

Thematic Category I: Paternal Roles

From an analysis of the descriptions that fathers gave of their involvement with their children both on a day-to-day basis and over time five main roles emerged. These roles were nurturer/caregiver, supporter, worker/provider, communicator, and advocate. Each of these roles will be described.

Nurturer/Caregiver

The subjects all saw themselves as strongly involved in a nurturer/caregiver role. Nurturance and caregiving are treated as one category rather than two separate categories because they were not viewed or fulfilled as separate functions by the subjects; when attending to various practical needs such as food

provision fathers' comments indicated they also strove to create a nurturant and loving atmosphere for the child or children in the family. The main features of this role are actions to meet basic needs and affectionate physical and emotional interactions with the child. Although nurturer and caregiver was the most common role identified by fathers and was played out on a day-to-day basis, the child's needs and issues related to the father's employment and usual style of parenting had an impact on how each subject enacted this role.

The birth of the child was a critical event from which the role of nurturer/caregiver flowed. All of the subjects had participated in providing aspects of nurturant care to their affected child from the time of birth. Three fathers reported they were given opportunities for physical contact with their child immediately after birth. Subjects stated close physical contact such as holding the baby in their arms was mutually comforting and helped them get to know their child and his or her needs. The affectionate parent-child bond was described by one subject:

S: We're very close. We watched a hockey game last night, and we lie in the bed and we hug each other, watching the hockey game...he likes that...his Dad hugging him, and watching the hockey game, and being excited, and so it's a good relationship that way, and I enjoy those moments....it's a very relaxing environment, for me, the bond that we have there.

As their children developed, fathers varied in the amount and type of participation they undertook in regard to their children and their caregiving and health needs. The pattern established in the division of caregiving responsibilities between the adults in the home varied. The majority of the subjects reported they fed, bathed, dressed, entertained, and supervised their children on a regular basis. Most of the subjects stated they spent less time providing childcare than did their partners, particularly in those cases where the children were below six years of age. The subjects attributed this to greater periods of time spent by themselves in employment out of the home and the mother having more time available to be with the children. One of the fathers describes the start of a usual day as:

S: Some days I make breakfast if I've got time. I might give him a bath. I at least put him in the tub before I leave, then [mother] takes over.... I'll change his pampers and dress him up or it just depends how much time I have, and then you know when I come home in the evening what I try to do is spend a little bit of time showing him a few things on the blackboard....

Health complications in the children were critical events which created an additional challenge in providing childcare for some subjects. When a child required medications, special feeding techniques, physical or oxygen therapy, this was incorporated into the daily caregiving routine by the parents. Concern

with maintaining their children's optimum health was emphasized by those subjects whose children had experienced health complications.

Subjects who had more than one child described the challenge of trying to meet the needs of all of their children for affection and care. The majority of the fathers felt they were successful in regards to this, given the amount of time they spent with their children. One father thought allocating greater attention to his child who had Down Syndrome was a factor which created difficulty in fulfilling the nurturer/caregiver role:

S: I pay quite a bit of attention to him [child with Down Syndrome]. The older one is the one who's not really getting as much attention as he should...I know I should be playing more with him, and I don't...I know.

Three subjects expressed the wish their employment outside of the home was less time and energy consuming, allowing them to contribute more to caregiving.

Supporter

All of the fathers felt they had a responsibility to support their partner and other family members including the affected child. The role of supporter encompassed actions fathers took to alleviate stress, particularly for their partner. Fathers described i) financial provision, ii) occasional mediation between health professionals and their wives, iii) the sharing of responsibility in childrearing and home maintenance

and iv) verbal encouragement as highly important actions they undertook in giving support to their partners.

In relation to the supporter role, critical events were the discovery of the diagnosis and later points in time when developmental or health issues intensified the needs of the family for support. Fathers described feeling very sensitive towards their partners' reactions and coping abilities at the time of diagnosis.

S: As soon as he [physician] told me [about the diagnosis], I knew...she's sitting there hoping that he would die...so she wouldn't have to tell everybody.

S: Oh I hurt, I hurt..but she was hurting so bad...

If their partners had previous positive experiences with children who had Down Syndrome fathers felt this enhanced their partners' ability to cope with the diagnosis. Subjects who felt they themselves had coped well with the diagnosis due to their own previous experiences described taking a strong initiative in engaging in positive behaviors towards the baby. They viewed their own positive attitude and actions as highly supportive to their partner and child.

Several of the subjects thought their partners were more emotionally affected at the time of diagnosis than they were, therefore requiring their protection and care. Other fathers described their partners as being overall more assertive and positive in coping with the

diagnosis and more likely to take the initiative in planning to meet the child's needs. Regardless of how they assessed their partners' coping skills, the majority of the subjects believed the ongoing demands in terms of practical management of the child's developmental needs or healthcare were more stressful for their partners than for themselves. This belief had the effect of reinforcing the importance of their role as a supporter to these subjects.

At the time of diagnosis, some fathers felt reluctant to reveal their own feelings of grief or disappointment because they believed this might have a detrimental effect on the coping ability of their partners.

S: I'd phoned everybody already, then the next day, I had to give them a phone and say...my mistake. I was [upset]. I don't think I showed it. I tried to keep it away from my wife.

Similar thoughts about the need to display calmness and emotional control were expressed by subjects in relation to supporting friends and family members. Some fathers revealed a belief that modeling such behavior might lessen or at least avoid escalating feelings of grief or worry about the family. Anticipating possible reactions of significant others was a highly stressful aspect of the role of supporter. Subjects worried about the best way to inform grandparents, and described

trying to "build up to it" or to deliver the news gently. Fathers described dealing with the grief of grandparents as emotionally taxing. Two subjects mentioned there was a long-term need to support grandparents who had difficulty understanding or accepting the effects of the syndrome on the child. This was an additional interpersonal challenge in fulfilling the role of supporter, particularly as the father's personal focus moved away from his own emotional responses to center on the developmental needs of his child.

Worker/Provider

All of the subjects expressed commitment towards the role of worker and provider. This role included practical work to maintain the home as well as work outside of the home environment which allowed subjects to contribute financially towards the home and the needs of the family members. A critical event affecting this role was the father's organization of his resources to meet demands which arose in the home as well as the external world.

In most cases fathers indicated that the female partners took the greatest responsibility for home management and housework, with outside employment as their chief responsibility. The arrangement created between the partners in dividing work responsibilities

both in and out of the home was attributed by the subjects to the individual abilities of the subjects and their partners, the specific needs of the family, and the parents' beliefs and values concerning their roles. The subjects described division of practical responsibilities between spouses as a mutually-acceptable arrangement. As one father said:

S: That's just sort of the way we live, that's just the way it works I guess, because having three kids it's just not financially possible for both of us to work.

Several subjects worked more than full-time hours in high-level positions. Fulfilling the work requirements of the external world as well as those within the home was a challenge in meeting the various demands of this role; the majority of the subjects indicated they were coping well with this. All but two fathers conveyed a high level of interest in and commitment to their employment outside of the home. Fathers' interest in establishing and maintaining an attractive and comfortable home setting for their families appeared to be universal in this group of subjects.

Communicator

For all of the subjects a very important paternal role was that of communicator. The role of communicator involved discussion with family members, relatives,

friends, health care professionals, educators, and occasionally the general public regarding the child's needs, abilities, and progress. The role involved both giving and seeking information, with an emphasis on the latter. Although the fathers were involved in this role quite frequently on a day-to-day basis, when critical events occurred this role was more salient. One of the critical periods was the postpartum phase. Many questions arose in the hours and days immediately after diagnosis. At the time of the initial diagnosis, eight fathers stated they had a very poor grasp of the developmental effects of Down Syndrome. This sparked a search for information.

S: I rushed around as much as I could to obtain whatever information I could find on Down Syndrome, and probably read the pamphlets and the articles, and the books, thirty times...trying to sort whatever information I could out of these, on Down Syndrome, and why it happened, and what we could expect.

As they gathered information, all of the subjects related feeling extremely sensitive to the attitude and philosophy they perceived in communication with healthcare providers. The content of the communication and how the information about their children was imparted to them made a difference as well. Using a compassionate approach, giving adequate information, and allowing enough time with the father, were professional

actions praised by fathers as promoting effective communication.

Some of the fathers were dissatisfied and frustrated with their attempts to communicate with healthcare personnel. Six subjects were unhappy with the initial information which was given and the communication styles of physicians and nurses. Several fathers complained that the first communication about Down Syndrome held very little meaning for them. The term "mongolism", for instance, was confusing to fathers and inhibited responses from them; it aroused fear and feelings of dread. The fathers that were unhappy with the communication styles of physicians and nurses in the postpartum period stated they acted brusque, matter of fact, and mechanical, cold, or unhopeful:

S: [Nurses] can be a little bit tough...they don't have any sympathy at the time. They've got a job to do and they're going to do it.

S: They [physicians and nurses] don't give you any hope.

In other instances, fathers stated information they needed about their children's conditions was withheld from them by healthcare personnel, resulting in miscommunication and incorrect assumptions. Three fathers who felt nurses had avoided giving them adequate information or bringing the baby to them, came to the conclusion their child had died.

Regarding the diagnosis, failure to receive information at the same time or prior to their partner was also upsetting to two fathers. Other subjects who had been informed of the diagnosis prior to their partners did not report any discomfort with separate telling. Those subjects who had been asked for their suggestions as to when and how their partner should be told felt it was appropriate they were included in communication plans. Three fathers who had told their wives of the diagnosis clearly viewed it as a responsibility they held in the communicator role, although a highly painful task; "that was probably the hardest thing I've ever had to do".

Regarding communication with genetic counsellors, the majority of the subjects were very satisfied with the opportunity it afforded them to contribute and receive information. Genetic counselling was a critical event for several of the fathers because it presented the first opportunity to the subjects to have their questions about Down Syndrome thoroughly answered. Subjects viewed communication with a genetic counsellor as extremely important for parents, along with early laboratory confirmation of the condition. In two cases, the subjects queried whether the results of genetic testing could have been provided more quickly, as their anxiety was increased by the waiting period. Two of the

subjects expressed some dissatisfaction with the information about genetics and Down Syndrome they received because they found it confusing initially.

Later points in time when the child's health or developmental status required more intensive communication with health professionals were also critical events in the communicator role. Some of the subjects experienced frustration in fulfilling their role during these events. Four fathers reported relying on their wife to obtain and communicate information from healthcare teams and therapists, an arrangement which was unsatisfactory at times because it did not afford them first-hand knowledge. This was primarily due to the scheduled times for therapy visits conflicting with the fathers' hours of work. During a hospitalization of his child, one father who sought information about his child during visits found the nurses most familiar with his child's care were almost invariably unavailable or on "breaks". The subject attributed this situation to poor organization on the part of nurses and a failure to consider his need for information as a high priority.

As part of their role as communicator, fathers also communicated information about Down Syndrome and their children's needs and progress to grandparents and acquaintances. Friends were often given basic information about Down Syndrome as the subjects became

more knowledgeable. The degree to which communication touched on family members' feelings and needs was dependent on the closeness of the relationship with a friend and also how the friend responded when initially told of the diagnosis. Another aspect of this role included communicating with their children's playmates and other parents about Down Syndrome in relation to their child's interests and abilities. Fathers considered this helpful in promoting opportunities for socialization and friendship for their children.

Advocate

The subjects acted as advocates on behalf of their own children and families as well as for other families affected by Down Syndrome. One aspect of this role included occasional mediation with school and community groups to promote opportunities for development for their child or to obtain specific services or programs.

Several subjects described a process of gradually becoming more involved in their role as an advocate as they developed stronger convictions or new ideas regarding their children's rights and needs. The father's incorporation of these deepening convictions into his actions was a critical event which promoted the advocacy role. The expectations the subjects held of society for the provision of educational, health-related, and supportive services varied. A few fathers

were engaged in a struggle to have policies changed or services expanded, which caused some frustration.

Fathers made comments which indicated they were active advocates for the services they viewed as appropriate:

S: I guess what I'd like to do is insure that there's services available...that he can you know, have those services; we had a speech therapist come in.

S: A lot of people have formed a group and they're trying to get something going with the education people [for integrated classrooms]; they're always worried about the green stuff, the money, because they have to have a special teacher, a special person in the classroom...but he's [child with Down Syndrome] entitled to an education.

Fathers also advocated in a more indirect way for their children by presenting a role model to friends, family members and other parents which illustrated the attitude and behavior they believed was appropriate towards their child. In doing so, fathers strove to promote an atmosphere in which their children's abilities and successful relationships were emphasized rather than focusing on developmental limitations.

Some subjects expanded their role as an advocate to include actions to support and ensure the rights of other families affected by Down Syndrome. Three fathers had offered information and support to new parents who had infants affected with Down Syndrome. An aspect of this included visiting new parents in the hospital at the request of nursing staff to provide information and

support to the parents. One father commented that nursing staff failed to make referrals in many cases, however, and he attributed this to lack of support by the attending physicians. Two fathers expressed a desire to advocate for greater access to peer support for new parents of children with Down Syndrome.

Thematic Category II: Paternal Tasks and Skills

This category is related to actions which the subjects consciously used to promote success in the outcome of parenting. It contains the subcategories of Promoting Child Development, Involving Siblings, Utilizing Social Support, and Utilizing Professional Services.

Promoting Child Development

Fathers made conscious efforts to promote their children's development, quality of life, and level of independence. The degree to which this was a concern varied in this subject group with some fathers describing more or less continuous anxiety and worry, while others coped through a "one day at a time" approach to their child's development which gave recognition to small gains.

A critical event which instigated the fathers to consciously promote developmental in their children was the recognition by the father that the child was developmentally delayed. All of the fathers in this

subject made comments which indicated they recognized developmental delay in their children. Two fathers mentioned they expected "plateaus" in learning where progress would lessen. Fathers made comments which reflected tenderness and dedication in helping their children progress, as well as some frustration with the pace or need for repetition.

Subjects used different types of interaction with their children in promoting development. Some fathers implemented activities which reflected a more formal "teacher" role, while others placed the emphasis on socialization through role modelling and companionship. Providing a strong male role model to his son was considered by one father to be very important. He felt he had developed a deep bond with his son through the "masculine" activities they share, as well as from physical affection in the form of "hugs and cuddles".

Three fathers stated they relied on their partners to give them suggestions for how they could promote their children's learning (with specific tasks in an early intervention program, for instance).

Fathers were aware of their children's developmental need for social learning, both with acquaintances and the public at large. Helping their children develop social skills was a strategy used to promote their children's acceptance, independence and

happiness. Social qualities which were seen as favorable by themselves and others, such as obedience or politeness, were a source of pride, whereas some subjects expressed unhappiness with individual behavioral traits such as overt physical friendliness, which they felt had negative social ramifications for the child. Fathers reported that parents planned and initiated many if not all of their children's activities, utilizing community, school, and church based activities to promote their children's social development.

In relation to moral guidance, all of the fathers reflected a personal philosophy that discipline and other treatment of their children should be fairly and consistently implemented. Six fathers thought the provision of parental discipline was a necessary ingredient in modifying child behavior; two of these subjects however indicated they found it difficult to discipline their children who had Down Syndrome because the child seemed too vulnerable. None of the fathers reflected beliefs which were highly authoritarian or punitive.

Involving Siblings in Promoting Child Development

Fathers viewed siblings as potential teachers, advocates, and companions to their developmentally delayed child. A key factor or critical event which

motivated fathers to involve siblings in promoting the affected child's development was the establishment of a cooperative and mutually enjoyable relationship between siblings and the child who had Down Syndrome.

Subjects whose children were young and similar in developmental ability noted their children played closely together. In this subject group one father whose children played closely together expressed concern his youngest child was learning undesirable types of behavior from an older sibling who had Down Syndrome. He also worried the siblings would be teased at school:

S: Not only will [child with Down Syndrome] have problems in school, possibly being picked on and teased, but [sibling] will, and so will the youngest one...you know, because 'you have a mentally retarded brother'.

The majority of the fathers thought the children obtained mutual benefit from their interactions and believed that siblings were an advantage in helping the affected child progress as he or she matured.

There was a range in the degree of sibling responsibility and involvement that the subjects thought was desirable or necessary. Formal arrangements to assist the child with Down Syndrome in adulthood through sibling involvement were considered to be a possibility by some subjects in this study, however most of the fathers in this subject group expressed worries about the effect of this responsibility on siblings. One

father felt strongly that long-term assistance of the child who had Down Syndrome should not be an expectation of a sibling, and was investigating other legal arrangements. Two fathers regarded some long-term sibling assistance very favorably but were unsure how this would occur. One subject expressed a firm expectation that the preschool sibling would act as a role-model, advocate, and companion to the affected child at present and in the future.

Utilizing Social Support

Fathers used social support to various degrees dependent upon the amount and type of social support they felt was desirable and the degree of support which was made available to them. The actions of others in the social network as they responded to the family's situation were critical events which influenced how social support was utilized.

Five fathers stated that they received helpful emotional and practical support from extended family. Grandparents were for the main part considered to be highly supportive, and those who developed an affectionate bond with the child were thought by subjects to be playing a highly significant role in his or her life. In two cases, grandparents were believed to have a negative attitude towards the child because of

the presence of Down Syndrome and their support was therefore not sought.

Three fathers placed high value on the support of friends who included their children in normal social events on a regular basis. Two subjects had developed the insight that friends who did not know how to respond and when to offer help just after the birth were more supportive if the parents communicated a positive attitude and verbalized their needs effectively. Initially, however, fathers were sometimes confused about how to respond to friends.

S: I was busy trying to figure out how I was going to get other people to deal with it. That [the diagnosis] was a shock to them. They were upset.

S: The friend who delivered [child with Down syndrome] was more hurt about it than I was at the start. I had to overcome him [his reaction], before I could go through my own [reaction].

One subject found the following words from friends were a source of encouragement:

S: When they came to the hospital, these friends of ours they said...that "you're very chosen people; you're very special people to have a child like this"...like wow, you know..."it's somebody special who can raise a child like this you know, and you must be the people"...it's great. Like, that's what we thought, you know.

Support available to fathers in the workplace was variable. One father had been given generous time away from work by his employer to help him deal with health

in ensuring their child's safety while out playing were considered supportive. In contrast, the failure of neighbors to help provide play opportunities and general supervision in the neighborhood accentuated a sense of aloneness in the parenting experience for one father.

Connecting with parent peers was beneficial for several subjects who felt such contact was supportive because it allowed them to observe an older child who had Down Syndrome and obtain information to help them in parenting effectively.

S: (We) met their family, and met their son, which I think was really a turning point for us.

S: A lot of families are a lot older than us and their children are a lot older too, so I thought it's good to find out what they're doing that you know I might be able to do, with my child being so young, and growing.

A critical event which affected how fathers connected with parent peers was the referral of parents to such resources. One subject was dismayed because he did not meet other parents who had children with Down Syndrome immediately; he expressed irritation towards the nurses in hospital whom he felt should have realized his need for an opportunity to connect with parent peers.

Another avenue for parent peer contact were groups organized through local rehabilitation services or by groups of parents in the community. Mixed opinions about

crises in his child and he felt this was highly supportive. Other fathers who felt they had to attend work when they were needed during healthcare crises described feeling highly stressed and "left out" of decisions at times. One father felt it was difficult to mention any aspect of his child's condition to co-workers because he perceived they were uncomfortable and unsure of how to respond to the situation.

On the other hand, being able to withdraw from the medical scene, even to a place of employment, was described as helpful in promoting coping by some subjects. Three fathers who stated their employment occupied much of their energy during the immediate postpartum period, viewed employment as a source of support at times. A subject stated time away from the hospital allowed him to "keep some mental stability" as he went through a period of disappointment and shock following the birth. Comments indicated that withdrawing emotionally or mentally, even when physically present, helped some fathers to cope.

Neighborhood support was considered helpful by three fathers who had lived for a long period of time in one location. All of the subjects verbalized a desire that their child have the same opportunities as any other child for social activities. Neighbors who interacted positively with their child and participated

the benefits and drawbacks of parent-run group meetings were encountered. Three fathers who had attended parent-run support groups thought they helped fathers feel less isolated and provided helpful information. A father commented that many parents of older children who had Down Syndrome were a source of advice and were just "waiting to share their experiences" with less experienced parents. Two other subjects were less enthusiastic however, as they felt when they entered such groups they "became involved in other people's problems", did not have enough in common with other parents in the group, and did not obtain enough useful information. One subject felt the aims of the group were unclear and this diminished its effectiveness and his desire to be a member.

Utilizing Professional Services

Fathers began to utilize professional services related to their family's needs prior to and at the time of birth. The services used as the child matured were a function of individual needs, the availability and knowledge of services, and the subject's view of the desirability of seeking professional intervention and support. Critical events influencing fathers' use of professional services were those times when the need for assistance with their child's health and educational

needs was greater, such as during hospitalization or at the beginning of formal schooling.

Fathers looked to local educational and habilitation services to help meet their children's need for education and social experience, and for the management of specific developmental goals. Availability of school or preschool services was important to the majority of the subjects, as well as services to promote lifeskills. Professional healthcare services to deal with medically-oriented complications were utilized through private office appointments, regular attendance at various clinics, during hospital admissions, and home-based nursing care.

This subject group were generally well informed about available therapy and healthcare services. Some of the fathers were perturbed about limited therapy resources in the areas of physiotherapy and speech development. Speech therapy was obtained privately by two of the subjects. Two fathers also identified opportunities for peer group meetings or information seminars as services they would consider using if they were made available to them.

Genetic counselling services were universally used. Contact with therapists, physicians, school nurses, and teachers, was either accomplished personally or by the mother. Local, national, and international organizations

who advocate for the mentally retarded were utilized to obtain reading materials and ideas related to parenting.

In regard to emotional support and counselling, the times in which subjects described seeking or needing professional support were the immediate post-partum period or during later medical crises in the child. At the time of diagnosis many subjects indicated they were apprehensive, acutely sensitive, and in some cases, confused. The fathers' assessments of how healthcare professionals responded to the needs of their family at this time tended to affect their expectations of professionals and how later services were utilized. Fathers who were satisfied with the support they received were relaxed and saw professionals as approachable and knowledgeable, whereas subjects who had assessed health professionals such as physicians and nurses as unhelpful at a past time made tense comments which indicated they did not view them as a current source of support.

Subjects who felt they had been well supported indicated it improved their coping ability when they were told their child was physically healthy, could have a reasonably long life span, or if other positive aspects of the child were stressed. Two subjects described these comments as supportive:

S: He [physician] said, 'you know these kids now are totally integrated, and you know,

they're just normal kids'...that made a big difference.

S: He [physician] said.. 'consider this, you and I who so-called live in a normal world...will have pressures on us, will have to strive to achieve certain things, where [child] will live a much happier life than we will...because she won't have the concerns'. I've remembered it, it put my mind at ease.

In contrast, other health professionals' statements or questions served to alienate some subjects. One father was baffled upon finding out the physician had asked his wife "if the father was Chinese" although the physician had met him previously and knew he was caucasian. Apparently this opening question was intended to introduce the subject of Down Syndrome. A second father recalled words he considered to be glaringly insensitive:

S: The doctor's advice was not even to bother, you know, following her, because she might not live...the doctor had indicated that it may be as well for the family if she didn't.

If there was an abrupt termination of support by healthcare providers after the diagnosis was given to the subject, these individuals were viewed as uncaring. At the time of the interview, one father continued to feel considerable anger about the effect of this on the coping and self-esteem of the parents:

S: What about us ? Like, we're sitting there with three hundred questions going through our mind...and you know, he [physician] comes and springs this on us, and then leaves, and leaves my wife and I by ourselves.

In other instances, stress was increased for fathers when an absence of information resulted in incorrect conclusions about their child's welfare.

S: They [hospital staff and wife] were in the delivery room, and I was waiting, and I was waiting, you know...and waiting...I could tell that she [nurse] knew something was wrong, and she wasn't telling me. I was already sort of building myself up, that something was wrong. I figured the baby probably died.

In relation to specific support from nursing staff, three fathers reported nurses were resources to them in the hospital for practical needs such as arranging for the mother to have a private room. Some subjects thought nurses who offered them simple comforts such as pillows or coffee were caring. None of the fathers described seeking emotional support from nurses, although several felt they were "there if you needed to talk". Fathers indicated they gained emotional support through their interactions with nurses who handled the child in caring ways and gave positive verbal feedback:

S:...coming into the room, and finding a nurse holding a baby, creating a nice environment to be in..[nurses] give you some nice warm fuzzies..."he's looking good".

Only two subjects reported that nurses were a source of emotional or practical support subsequent to the initial post-partum period. In one instance the child was visited in the home by nurses who assisted the

parents in meeting healthcare needs related to nutritional and respiratory status. Another subject identified a community nurse as helpful because she made an effort to communicate well with his child in the school setting. She was then able to act as a support to his son in that environment.

In two cases fathers had sought help with personal coping through governmental agencies. The local Social Services department provided a brief stint of respite care to enable one set of parents to vacation without their children. Another father utilized professional counselling to resolve difficulties arising in the postpartum period related to his role as a parent and a father. The counselling centered on greater use of short-term planning and marital communication.

Thematic Category III: Processes Related to Parenting

The third thematic category encompasses direct and indirect processes which enhance the parenting experience. Sub-categories include: Integrating the Initial Experience, Defining Beliefs and Values, Adjusting Expectations, Adjusting Aspects of the Partnership, and Meeting Personal Developmental Needs.

Integrating the Initial Experience

One of the processes that the fathers had to deal with was that of integrating the events surrounding two major critical events, the child's birth and receiving

the diagnosis of Down Syndrome. The fathers' recollections of the immediate period of time surrounding the diagnosis are starkly intense. One father summed up the impact with the comment "you never forget".

As part of this process, the subjects reviewed the events of the initial experience to develop a greater understanding how the experience unfolded for them and the effect it had on themselves and other family members. Some subjects described suddenly realizing at a later time that they had sensed something was "wrong" as soon as they saw their child. The majority of the fathers developed theories about why healthcare providers acted in a specific manner or why they themselves had responded in a particular way, as they reviewed the events surrounding their children's birth. Three fathers, for example, described how they believed miscommunication or lack of information from physicians and nurses had led them to conclude shortly after the birth that their child had died. A key point which fathers reflected upon included how and when the diagnosis was given to them and how they personally responded. The point at which fathers were informed of the diagnosis varied between immediately after birth, hours after birth, the day following birth, and five days after birth. The moment of finding out about their

children's disability was described as a blow, shock, or crisis by the majority of the subjects.

S: He [physician] just told me. He says, "do you know anything about Down Syndrome ?", and then it hit me. That's where the weight all of a sudden hit me.

S: If you lose a leg or something, you want to know who to go to; it's a similar type of thing...all of a sudden plunked into a crisis and you don't know who to turn to.

For many of the subjects, it was difficult to find words which they felt were adequate to convey the feelings they had at that time.

S: It just about destroyed me.

S: Disbelief. Shock. Terror. An experience that neither of us had ever had...

Subjects recalled how the initial shock was quickly followed by feelings of aloneness, anxiety, loss of energy, and dissatisfaction or grief:

S: When you first have a kid with Down's you figure that you're the only one in the world.

S: I think it's natural; everyone goes through the grieving process at a different speed...you are grieving, and you're grieving for the child you never had.

S: I was high, and yet there was a great dissatisfaction. There's the total load of "my God, what are we going to do now?". The responsibility of raising a child was enough.

Subjects varied in their estimation of the length of time these feelings were intense; citing hours, weeks, or up to several months. Several subjects also made remarks which indicated they did not expect

feelings of sadness or shock to ever completely abate.

As one subject remarked:

S: It took me a long time. I don't know if you ever do get over it.

An aspect of their own reaction which was commonly mentioned by fathers as important to them in integrating the experience involved feelings of "questioning" why the condition happened, and a sense of injustice.

S: Pride comes into the picture. Why did it happen to me ? It seemed like such an unfair thing to happen.

S: Why me ? All I want is two children.

In some instances the duration of such feelings was remembered as very brief, involving just hours or two or three days. Three fathers indicated they had quickly come to regard the syndrome as a chance phenomenon and a natural part of life. Two fathers decided in retrospect having such a view had helped them cope successfully:

S: There's nothing you can do, and you don't consider it's a problem, it's just one of those things in life that happened, and that you can't change, and so you carry on...I don't think it took very long to get over.

S: It hurts, it gets over [sic], and then you sit down and hopefully, start thinking about the situation that you're in, and get over the self-pity stuff fast, and move on.

Fathers also made comments which indicated reviewing the reactions of partners and families was a highly important element in integrating the initial

experience because it broadened their understanding of their own responses at the time.

S: You know, that was pretty difficult, telling your family that your daughter would not be normal.

S: Both of us knew. We never spoke about it. I knew in the back of my mind that there wasn't something quite right...in her eyes. There was something, and I thought she was mentally retarded. She [partner] thought right away the same thing.

Defining Beliefs and Values

The majority of the subjects indicated this parenting experience had an impact on the beliefs and values they held in relation to having a child with a disability and to life in general. As a result, they engaged in the process of affirming or reformulating these value systems. The arrival of new insights related to personal philosophy or spirituality on the basis of their experiences were critical events in this process.

When asked to identify differences in their view of life which may have developed as a result of having a child with special needs, the majority of the fathers felt the experience had enlightened them in terms of values, spiritual beliefs, and how they viewed or interacted with others; in particular with disabled individuals. The subjects varied in their estimation of how profoundly these different views affected their lives. Two fathers denied any change in outlook or belief system, stating the beliefs they held prior to

the birth were highly compatible with the experience; these subjects were noted to have firm beliefs in universal human rights. Other subjects felt the new insights they gained had motivated them to look at what was important in their lives and to change some of their priorities. As two subjects explained:

S: It changes us for life...you react a little different. You have more appreciation. You recognize there are difficulties all over, a lot of other things aren't important.

S: I've always been materialistic, up to then...all of a sudden BANG !...you realize it just means zip...you'd take everything you have and trade it if you could.

Some of the fathers could articulate specific factors in their lives that helped them to evaluate this parenting experience, such as spiritual beliefs or the values instilled by their parents in the family of origin. Fathers who had examined the experience from a spiritual perspective arrived at beliefs about "why" they have had this child.

S: I believe in God. If that's a punishment (having a child with Down Syndrome), I'll take that anytime. I think that's probably one of the nicest punishments I've ever had.

S: I believe in God. God gave him to you because he know'd darn well that you'd look after him. That makes a guy feel happy.

In describing how they defined their own values and beliefs, four fathers identified the philosophy that their own parents held towards other people and

disabilities as having a strong effect on the process. The comments of two fathers reveal the connection they saw between their own value systems and the examples given to them by their mothers:

S: My mother...would accept anybody for what they were...that was the philosophy she gave to us.

S: My mother; I had a very special mother...and she had a large house, and she looked after boys from the council for crippled children. We had a couple of Down's lived there...we saw the attention my mother gave to them.

Another area which fathers had considered was how they valued societal opinion concerning their children's participation in society, developmental ability, and needs. They indicated they had made firm decisions about the lifestyle and approach they believed would benefit their children and placed little importance on differing opinions they might encounter. Two fathers summarized their positions as:

S: Parents have to get a bit selfish. If these people don't like your kid, that's their problem.

S: If you spend all your time thinking about what society thought...what their opinion is, you'd never get anything done. I just say 'to H--- with that bullshit, let's go and do whatever we want to do.'

Adjusting Expectations

Parenting a child with a disability necessitated some adjustment in the expectations the fathers held for

the experience, especially if the child had additional health problems associated with Down Syndrome. Fathers went through a continuous process of adjusting their expectations both in terms of their children and their own parenting skills. Receiving the diagnosis of Down Syndrome was a critical event which motivated fathers to embark on a search for data with which they could adapt their vision of their child as he or she would be in the future. Subjects who had personal contact with older children who had Down Syndrome found this was useful in developing achievable goals for their younger children.

Although all the fathers had hopes and expectations for their children most of the subjects had a "wait and see" attitude in which short-term objectives were emphasized. One father stated that his philosophy of living "day by day" was a coping skill which prevented him from worrying excessively about the future and how capable his child would be at that time. Other subjects indicated they worried about this as well.

The fathers varied in their expectations of whether the child affected by Down Syndrome would eventually live apart from the family home. Subjects expressed difficulty in dealing with this question because the child's future abilities were unknown. Two fathers thought their affected child might continue living with them in adulthood, while two other subjects definitely

expected their children would be able to live apart from them in a supported environment. Other fathers expressed hope this could happen, but stopped short of stating it was a definite expectation. The contrast in fathers' expectations regarding their children's independence is starkly evident in these comments:

S: We have high expectation that he'll be able to be a part of society. Hopefully, he's got independent living skills someday.

S: She's going to be my child for life...it will always be that way.

Adapting expectations also required letting go of other ideals. One subject described the loss of "the perfect life" he had hoped for.

S: It still bothers me, what do you do in ten years? You like to plan for, for your child to grow up and do this and that...when you get married you hope that when you're thirty you're going to be wealthy, and have your own home, you're going to have kids and everything, the white picket fence thing...and it sort of makes you wake up to the fact that there's a lot of things that go wrong in the world.

Adjusting Aspects of the Partnership

The process of adjusting aspects of the partnership included addressing practical concerns in sharing responsibility for the home and family, as well as adapting to new emotional demands surrounding the birth and parenting a child who had developmental delays. Fathers participated in making the usual adjustments in running the household which follow enlargement of the

family. Changes in childcare household responsibilities were described as occurring through negotiation or had "just happened".

Critical events were interactions between the partners in which the emotional closeness and effectiveness of the partnership was significantly weakened or strengthened. The subjects were challenged to maintain a successful partnership throughout a time in which important changes were occurring in their lives and perhaps within themselves. The majority of the fathers revealed that they expended considerable personal energy and time adapting to situational demands and changes within themselves after their children were born. The degree to which subjects consulted with their partners concerning these changes varied greatly. Several subjects who had frequent discussions with their partners related to parenting experiences stated it had promoted their closeness to their partner. Crying was occasionally mentioned; a father who had cried with his partner felt that moment was the point at which he first felt the reality of his child's condition. Crying together was also related to intense feelings of shared grief for themselves and on their child's behalf, and to increased closeness to their partner.

Two subjects who had difficulty communicating with their partners in the initial period of time after the

birth attributed it to the situation. A father comments on how the relationship survived:

S: I don't know if we communicated, we probably didn't communicate enough verbally, but she had that determination and I...probably that was the sole thing that kept us going. She had such power to keep going. You can't give up on somebody else.

Fulfilling Personal Developmental Needs

The occurrence of Down Syndrome and its developmental or health effects were critical events affecting how fathers fulfilled their personal developmental needs. Social recognition and celebration of the birth which might normally be expected was dampened by the news of a disability in the child; participation in early caregiving was lessened if there were many medical interventions.

Fathers varied considerably in their response to finding out the diagnosis, and this influenced their decisions about the practice of social customs related to celebration of birth. Two subjects who chose to celebrate the birth of their child felt the response of health professionals did not take into consideration their feelings. In the words of one father:

S: They [nurses] found it a little difficult to see the enthusiasm we were showing, taking pictures of the baby, getting really excited...I don't know what their expectation was. I really didn't care.

In contrast, other fathers clearly did not hold any expectations of a celebratory mood:

S: It isn't necessarily a happy occasion. If they congratulate you... well, for what ? You know, like, you say, oh for what ? That's your reaction.

Some subjects whose children had medical complications were not able to be as involved in the child's care as they might have been had the child been physically healthy. Being asked to stay out of the delivery room after preparing for the birth experience, dealing with health crises, or having to obtain information about a child's health long-distance were secondary problems which interfered with parenting satisfaction. If health problems continued they created long-term demands on parental resources, complicating the role of the father and lessening the energy available for other endeavors.

Long-term goals such as the establishment of a home, expansion of the family, raising their children to mature independence, and the pursuit of personal interests and hobbies were affected for some of the subjects. There was variability in how much importance fathers placed on their affected children's needs in making decisions related to employment, situation of the family, and family size. Three subjects had either moved recently or were anticipating a move related to the

fathers' employment; the availability of suitable school programs and community support or services was also given consideration in planning such a move. One father who wanted to live in a rural setting hesitated to relocate the family because he was concerned about the resources available to meet his child's needs. In relation to career success, subjects who owned a business planned to include their children and to offer them employment; this may have encouraged them to succeed in these endeavours.

The birth of a child affected by Down Syndrome did not appear to be a deterrence to having more children for this subject group. In some cases it was considered to be a factor in support of the decision to have an additional child. Subjects who wanted more children felt it was desirable and beneficial for the entire family. Two fathers who didn't wish to have another child did not connect this to the occurrence of Down Syndrome. All of the fathers in this study indicated they had been told by geneticists the Down Syndrome was the result of an unknown cause rather than due to an identifiable chromosome abnormality in a parent.

All of the subjects conveyed a feeling of achievement in describing the rewards of parenting their children who had Down Syndrome. Subjects who had indicated they were distressed about their children's

developmental level or who had been very upset when the child was diagnosed made positive comments about parenting satisfaction as readily as fathers who described coping well with the diagnosis and feeling general optimism about the development of their children. Three fathers explained:

S: I think she's brought a lot of pleasure to our family; a lot of joy. It's been more of a struggle, it's been uphill for her...her achievements have been, I suppose, more dramatic and exciting for us than with the rest, with the other kids.

S: There's much more joy; more joy, more joy I'm positive, than [with] a normal child. You're so much more amazed...as to the things that she's able to accomplish.

S: He has given us more joy than we've ever given him...we're on the gain side.

In two families where older siblings were no longer at home, having a younger child with special needs had an impact on meeting personal developmental needs in relation to the personal freedom of the father. One father described the change in his life:

S: It's changed a number of the things I used to do. I used to sit at the computer for hours, and read quietly, and we used to go out to concerts, and all kinds of things, and now I can't do any of it now. But it doesn't bother me, it's not a negative thing.

Parenting a child for whom the eventual level of independence was unknown had implications for the future goals of the fathers in relation to lifestyle and the

completion of their role as a caregiver of their children. This unknown factor had motivated long-range planning by some of the subjects which might otherwise not have occurred at this stage of their lives.

Nursing Role and Interventions

The subjects in this study mainly had contact with nurses in the hospital setting at the time of birth. Four fathers reported subsequent hospital admissions for their children; one father had contact with a community health nurse in his child's school, and another father had experience with home-based nursing care for his child. Two fathers also described interactions with nurses in hospitals in other provinces.

In relation to how they viewed the nurses' role, the subjects provided a variety of observations about nurses' performance. There was variability in the level of professionalism fathers expected of nurses. Many seemed to regard nurses as workers who followed instructions as their highest priority, rather than professionals who were involved in making healthcare decisions. Others indicated that in their experiences, the nurses had a high degree of knowledge and ability. In some cases, fathers who had the expectation that nurses would perform in a professional and highly competent manner had been disappointed in their

interactions with nurses, leading them to modify their expectations of the role nurses fill.

Fathers had made positive and negative assessments of the nurses' clinical ability dependent on their experiences. Some comments indicating effective clinical skills included:

S: The nurses in the hospital have natural instincts when a mentally handicapped child is born. I think the nurses are doing a good job.

S: The staff that was there [out-of-province hospital], they watch for you to come in...and when you were there they told you exactly everything.

S: The nurses were super, just super. The people who are out there doing the work that you see ten times a day, are the nurses.

Several fathers emphasized the importance of nurses developing a genuine, caring, and professionally effective relationship with their children. They felt this was an essential ingredient in achieving healthcare goals for their child. One subject described his child's reaction to a nurse he did not know in a physician's office as uncooperative; the same child was highly cooperative with the school nurse where a warm and trusting relationship had developed. A father explained why one nurse was effective:

S: It was the way she handled things, handled the child, handled getting the baby; the baby was a baby... she loved her work.

The following nursing interventions were described as effective in promoting coping in families by the subjects. They are divided into those that are appropriate for use with parents and those for the children who had Down Syndrome.

Nursing Interventions - Parents

1. offered to contact peer parents for new parents and organized this if the parents wanted this support
2. referred parents to appropriate physicians or therapeutic services
3. offered or obtained appropriate written information about Down Syndrome
4. provided physical comforts to parents in clinical settings
5. monitored the mother's needs and provided personal care and support to the mother following birth
6. increased emotional comfort of father by making him "feel at home"
7. administered medications and treatments correctly
8. assisted with breastfeeding problems
9. called and assisted physicians in medical emergencies
10. welcomed parents who were new to the hospital and anticipated their needs
11. delivered nursing care to child in the home in conjunction with parents

12. included father in child's care
13. gave fathers verbal information about child's progress

Nursing Interventions - Children

1. assessed signs of Down Syndrome in the delivery room and alerted the physician to them
2. assessed ongoing health status of child
3. developed an effective care plan for the child
4. administered treatments such as medications and oxygen in hospital and home
5. assisted child in establishing breastfeeding
6. established a trusting relationship with the child
7. administered in-school health-screening to the child
8. communicated with and assisted physicians in medical emergencies
10. provided post-surgical care

Fathers also made negative assessments of the performance of nurses. Only one father identified a nurse in the postpartum setting as a good source of information about Down Syndrome. Subjects felt nurses needed to gain experience and knowledge so they could effectively answer questions parents had. Developmental patterns in children who have Down Syndrome and practical ways to deal with complications such as breastfeeding problems were areas fathers thought nurses should be familiar with. A father who had asked

nursing staff to obtain more information about Down Syndrome said: "We [parents] got them to act more professional". Fathers also thought nurses acted cold or "hardened", lacked time and had too many patients, placed priority on their own schedule rather than parental needs, mismanaged time, failed to disclose information parents needed, gave inconsistent advice, avoided parents or neglected requests, were mainly concerned with "getting the job done", and communicated an attitude of hopelessness to the parents in relation to Down Syndrome.

Interventions Recommended by Subjects

The subjects offered suggestions for programs and services they believed would benefit the family who has a child with Down Syndrome. These were not specifically related to nursing but rather to meeting the needs of fathers for information and peer support.

Two fathers suggested a program be developed to provide immediate and ongoing access to an "expert" who could relay health-related and developmental information to parents. It was proposed by the father that this could possibly be a nurse with appropriate knowledge and experience. It was considered desirable that such a service would automatically be offered to parents when a child is diagnosed with Down Syndrome.

S: I think providing a service, not only the healthcare aspect...but just to sit down and

say: "It may not happen [health complication] but it could be a possibility...these are some of the things that you should be looking for" - an educator.

Recommendations were made regarding the type of written information available in post-partum settings. Fathers suggested that simply stated and positively-oriented information, including pictures of active and happy children who have Down Syndrome, should be offered to fathers at the time of diagnosis. One subject felt the information he was given was not detailed enough to answer his questions. It was also important to the subjects that the information would reflect a modern viewpoint concerning developmental delay and promote a philosophy of normalizing the lives of children who have Down Syndrome.

Several fathers emphasized contact with other parents as an important source of information which should be made available to parents whenever needed. Two subjects thought nurses should routinely offer parents a referral to parent peers. One father suggested that nurses or a nurse specialist could play a role in organizing seminars for fathers which would fulfill support as well as informational needs.

Chapter 5

DISCUSSION

Discussion of the findings is presented in this chapter and is organized around the aims of the research: father's involvement with their child with Down Syndrome; critical events which have altered the fathers' experiences; and nursing role and interventions. The main findings of the study have been chosen to highlight important information from the data. These will be discussed in relationship to the literature.

Father's Involvement with Their Children with Down Syndrome

Paternal Roles

The fathers all experienced stress in their enactments of the paternal roles which were identified. Firstly, fathers were all cognizant of their children's needs and of the need to balance their attention in caring for all of their children. For the most part the fathers were satisfied with their efforts to fill the nurturer/caregiver role. Regardless of how they evaluated their own performance in this role, however, balancing time with their children when they had a child with special needs was recognized by the fathers as a potential problem area in the caregiving role.

needs at the time of diagnosis are similar to those arrived at by Pueschel and Murphy (1976,).

References by subjects to communication problems and communication blocks underscores the vulnerability of the father when his child requires healthcare treatment. Because he needs specific professional expertise with which to understand and address his child's needs, he often must depend on communication with professionals. At the same time, he may be experiencing great sensitivity to the conduct and attitude of the professionals (Mori, 1983) and considerable inner turmoil (Drotar et al., 1975; Keele, 1987). Many of the fathers in this study had negative perceptions about the motives and attitudes of healthcare providers. Hayes and Knox (1984) found parents had very different perceptions than professionals during hospitalization of their children, and needed to learn how to negotiate with health professionals. The degree of unhappiness this group of fathers expressed in relation to communication with health professionals would support the presence of differing perceptions about parental needs.

In respect to incidents where fathers were not included in communication about their child, several factors may have contributed. Adequate time and personnel is a real and critical obstacle to promoting

Secondly, stress was increased when fathers were required to expend energy supporting others when the father was also emotionally drained. The role of supporter was emphasized by this subject group. Subjects also minimized the importance of their own fears and concerns, although the data suggested these emotions were prevalent. The way in which the subjects fulfilled the supporter role was very likely in part related to the fathers' general beliefs concerning the male's role in a partnership, issues of strength versus vulnerability, and their expectations of their partners. Fathers were reticent to display their own feelings, which may have lessened the support which was offered to them.

Thirdly, stress was high when miscommunication with health providers occurred. Frustration, disappointment, and a perception of lack of caring were described by subjects who felt health professionals had failed to meet their information needs in the communicator role. The data arising from this subject group suggests failing to meet fathers' need for communication has the potential to increase isolation and lower self-esteem, with ramifications for the coping of fathers and in turn, for the rest of the family. Findings in this study in regards to how fathers described their communication

opportunities for dialogue between fathers and nurses in many clinical settings. The scheduling of teaching or treatment planning sessions in which parents wish to take part is not always geared to the availability of both parents but rather the availability of the appropriate healthcare personnel, although recommendations are frequently found in the literature supporting the inclusion of families in evaluation and planning (Wacht, 1986). The possibility that stereotypical beliefs about their role may make fathers appear reticent to participate in some aspects of parenting should also be considered. Stereotypical assumptions about fathers' roles may also lower the expectations nurses have of fathers' participation in some parenting tasks.

Lastly, fathers experienced stress in fulfilling the advocacy role, especially when the subject sought to make changes within a system. Fathers needed to maintain a high degree of motivation and confidence in the face of what appeared to be bureaucratic obstacles.

In conclusion, fathers described stress related to balancing their nurturing and caregiving attention among their children, maximizing the support they gave and minimizing their own support needs, communicating effectively with healthcare providers, and in obtaining the services they wished their children to have. The

tendency of fathers to avoid displaying their own feelings or to regard them as less significant than those of others has significant implications for fathers' coping and well-being. Fathers whose communication needs were not met were also at risk for less effective coping.

Paternal Tasks and Skills

The subjects used a circular problem-solving approach involving assessment, planning, the use of specific interventions, and evaluation or further assessment to modify plans in their parenting efforts. In relation to carrying out the tasks and skills which were identified, fathers frequently used assessment in the many examples they gave. Fathers assessed: their children's progress in many areas of life on a regular basis, how well their children were relating together and the impact of this on their development, the quality of social and professional support which was available to them, their own need for support, and the quality of their parenting ability. Subjects then promoted their children's development, involved siblings in this promotion, and utilized social and professional support on the basis of their assessments and the resources available to them.

They promoted specific areas of development in their children using specific interventions such as

reading to the child or doing exercises with him or her. The most effective teaching style for parents to use in promoting development is a point of controversy in the literature (Guralnick, 1988). A recent trend in the literature is the promotion of an informal "relationship-focused" teaching style by parents (Affleck et al., 1982) and this approach was more commonly used by the subjects in this study. Most of the subjects indicated they found it difficult to attend therapy sessions or preschools, and therefore relied on their partners to give them information about how they could help promote development.

Although the parenting style of the subjects in this study tended to be nurturant, democratic, and affectionate, a few areas of conflict within fathers arose as a result of fathers' problem-solving efforts. Fathers expressed some problems resolving how and when they should discipline the developmentally delayed child, whether their other children should be involved in long-term arrangements to support their sibling, and how to respond to others who seemed to be undermining their parenting efforts and self-esteem. Subjects expressed some conflict in relation to what they believed they should be doing as a parent to promote the child's development and how they evaluated their actual performance in this area.

The effort of some subjects in this study to provide for their child in the future reflects a need for long-term support and planning which is frequently referred to in the literature (Mori, 1983; Pueschel & Murphy, 1976). Fathers who were dealing with the question of whether to involve siblings in long-term arrangements for their affected child experienced some conflict which appeared to come from a desire to parent all their children equally well and fairly.

Assessments by two subjects that grandparents were not supportive of their children seemed to indicate a potential for relationship problems among family members. The majority of the subjects in this study felt the support of grandparents was highly beneficial and that they provided an extremely important relationship to their child who had Down Syndrome. Lack of availability of grandparents' support may have implications for self-esteem of fathers, child development, and the need for other supports for the family.

Data which emerged in this study regarding the type of comments fathers found to be supportive, document the presence of a need for positive feedback with resulting promotion of self-esteem in the subjects. The literature has referred to these needs in the parents of disabled children (Damrosch & Percy, 1989; Mori, 1983). The

benefits of an empathic, positively-oriented approach to parents in promoting coping are also frequently cited in the literature (Keele, 1987; Pueschel & Murphy, 1976). Fathers in this study expressed satisfaction with this type of professional approach.

In relation to support from the workplace, the findings suggest that continuation of a work routine can be either a support for coping or a hindering stressor for fathers. At times subjects felt burdened by work demands when family needs were high; other subjects clearly felt they benefited from "time away", especially during the initial time period following diagnosis. Opportunities for temporary escape were also identified as desirable and supportive by fathers of children who had Down Syndrome in a study completed by Damrosch and Perry (1989).

To summarize, a potential for personal conflict was revealed in relation to specific parenting areas, how the fathers viewed their own ability as a parent, and how this view was supported or challenged by others. When fathers received positive feedback and empathic support it appeared to promote coping; failure to meet fathers' needs for support had negative implications for the coping ability and self-esteem of fathers. Results obtained in this study suggest 1) promotion of self-esteem through positive feedback 2) freedom to attend

to family needs iii) the provision of opportunities to withdraw from family concerns and iv) grandparent support systems are factors which support coping in some fathers.

Critical Events Which Have Altered Fathers' Experiences
Processes Related to Parenting

The identified processes related to parenting were intimately connected to the emotional life and well-being of the fathers. Fathers who seemed to have progressed in resolving questions and issues related to their emotional experiences, their personal values and goals, and their relationship with their partners communicated greater contentment than did fathers who had many unresolved issues.

The birth of an affected infant was certainly a major critical event that had an impact on the majority of subjects' processes related to parenting. It was quite marked how vividly and with varying degrees of emotion these fathers could recall the early postpartum period when they first learned of their infant's condition. Most of the fathers did experience an initial crisis when they became aware of the child's diagnosis. This initial crisis is in keeping with that described in the literature on parental responses to the birth of an infant with a disability (Bocian & Kaback, 1978; Drotar et al., 1975; Mori, 1983). For some fathers a crisis

also occurred at a later stage, for example when signs of developmental delay became evident to the father or when the child approached the age of school entry. This finding is consistent with the concept of secondary crises, that is the realization of the day-to-day effects of the disability (Mori, 1983).

However, there was considerable variation in the fathers' initial reaction to the birth of their infants. These reactions ranged from quiet acceptance to intense grief and anger. Fathers' perceptions of this critical event seemed to be influenced by how they were permitted to interact with their infants after birth such as having close physical contact with the newly delivered infant, their previous life experiences regarding disabilities, and their partners' responses to the infant. The actions of health care providers at this critical period, particularly during the disclosure of the diagnosis, were also important in how fathers later evaluated the event.

Findings concerning the initial feelings of subjects in this study group are similar to descriptions which appear throughout the literature (Mori, 1983; Keele, 1987); parents are thought to experience shock, grief, depression, and various degrees of acceptance. There was no indication of a predictable pattern in the duration or intensity of emotions which were experienced

by this group of fathers. It is possible the previous experience and maturity level of a father, as well as other aspect of personality, affect the duration and intensity of emotions. Two subjects stated the period of initial depression and shock was extremely short, after which time they felt prepared to celebrate the birth. These findings seem contradictory to the literature in which strong grief reactions have been portrayed as a virtually universal experience for parents (Choi, 1978; Olshansky, 1962).

Searching for an explanation was a common response and at least three subjects continued to struggle with "why" at the time of interview. A similar period of struggle is described within the literature as a period of denial and anger (Drotar et al., 1975; Keele, 1987; Mori, 1983).

The phase following the initial shock, denial, and anger in which plans can be made is typically called the stage of adaptation (Keele, 1987) or acceptance (Mori, 1983). In this group of subjects, the majority had reached a stage where they were working towards goals with their child and had adapted their lives to whatever problems the condition created. The age of the child or the presence of additional health complications did not seem related to the father's ability to adapt to the disability. Continued despair and anger about the

diagnosis did seem to accompany poor adaptation, which would tend to support the hypothesis there is a set of stages through which parents may pass (Mori, 1983). Two subjects made comments which reflected more or less continuous distress and depression about the child's condition up to six years following birth. Unresolved anger about the actions of healthcare professionals at the time of diagnosis were also expressed by subjects who experienced long-term distress.

Several subjects made comments which indicated they had gained spiritual insights or developed new values which they felt were personally beneficial in relationship to this parenting experience. The proposition that a painful challenge can inspire personal change is not new in the literature (Mori, 1983; Roos, 1978).

Reactions of the subject's partner to the child were of great importance to the fathers and tended to affect how the subjects expressed their own feelings. However, the responses of other important individuals such as grandparents and close friends, were also critical events for the subjects. In some instances it was the anticipation of the possible reactions of family that proved to be most stressful. Siblings' responses to their brother or sister with a disability was important to some of the subjects. For these fathers the presence

of a cooperative and mutually enjoyable relationship between siblings was a positive and critical event. Friends also could provide comfort or increase the father's distress by their reactions; friends who included the affected child in normal social events helped the father in terms of social support.

Four subjects placed great importance on the examples they were given as children by their own parents concerning disabilities and human rights. Fathers' childhood experiences in their family of origin regarding the acceptance of disabilities may be a factor of particular significance in understanding paternal responses. Fathers who viewed such positive examples by their own parents as very important tended to focus almost exclusively on the attributes rather than limitations of their children.

The findings seem to indicate prompt disclosure of the diagnosis is highly desirable. Some subjects indicated they diagnosed the child's condition prior to the physician telling them about it. This suggests healthcare professionals would be wise not to underestimate the ability of parents to come to both correct and incorrect assumptions when they assess that "something is wrong". Fathers who reached such a conclusion indicated they felt unable to initiate communication about it or ask questions due to their

anxiety and fear about their children. The findings of this study suggest anticipating paternal needs for information and recognizing non-verbal signs of anxiety may be highly important nursing actions to reduce miscommunication and stress.

The scope of this thesis cannot address the experience of the mothers, but many references made by the subjects suggest they did not experience the same reactions at the same pace as their partners. These suggested differences have implications for communication within the relationship and for coping ability. Damrosch and Perry (1989) also found considerable difference in adjustment patterns between 17 pairs of husbands and wives of children with Down Syndrome. The existence of a greater potential for relationship breakdown between parents of children who have disabilities is mentioned in the literature (Bocian and Kaback, 1978; Damrosch & Perry, 1989).

Most of the subjects described feeling generally satisfied with their family life. This is at odds with the literature which presents a largely negative picture of family enjoyment. Cummings (1976), on the basis of results from a questionnaire comparing attitudes of groups of fathers, suggested fathers whose children had cognitive delays experienced more depression and fewer satisfactions within the family. There are researchers

who have questioned the applicability of such findings to all parents who have children with different forms of disability. Holroyd and McArthur (1976) found stress levels in families who had children with Down Syndrome were less than those in families with autistic or psychiatrically ill children. Goldberg and co-researchers (1986) compared three groups of parents who had children with Down Syndrome, neurological problems or diagnoses of unknown etiology causing developmental delay. They found higher scores in positive child-parent experiences in the group in which there were children with Down Syndrome, than those in groups in which the etiology was neurological or unknown. Findings from these studies suggest parents of children who have Down Syndrome may have different needs and experiences from other parents of disabled children.

In summary, the subjects engaged in a series of processes which helped them resolve questions and emotions, learn from their experiences, adjust their expectations, and reorganize their lives. The fathers in this study described emotions similar to those which are outlined in the literature, with many variations in the intensity and time spent within a certain phase. It is not clear any of the fathers passed through a definite set of stages. Positive examples towards disabilities which fathers were given by parents in their families of

origin may have an affect on their response as the father of a child who has a disability.

Overall, the parenting roles, skills, and processes which emerged from the experiences of the subjects in this study are also typical of fathers whose children are not affected by Down Syndrome. The resources used by the subjects in parenting were generally less related to meeting "different" needs than "more" of the same needs that all children have: the need for advocacy, instruction, pertinent healthcare, and recognition of individual worth from others both in and outside of the nuclear family. Parenting the child who has Down Syndrome appeared to demand greater time, energy, patience, personal sacrifice, skills, and economic provision than might be required to parent a child who does not have this disability.

Nursing Role and Interventions

The majority of the subjects seemed to relate nursing to a traditional role in which nurses were chiefly carrying out instructions from physicians and performing bedside care. It is difficult to know if this view of nursing was the result of their experiences or if their expectations of the nursing role had somehow altered the type of nursing interventions which the father experienced. In many cases subjects had little personal contact with nurses, which was perhaps the

greatest factor contributing to a vague or limited view of the nursing role. The majority of the subjects had virtually no contact with nurses after the postpartum period.

Comments made by some subjects in this study indicated they would have welcomed greater follow-up in the community to gain information. The findings of Cunningham et al. (1984), in which two groups of parents of children with Down Syndrome were surveyed, suggests a model for diagnosis and follow-up care in which a nurse with specialized training is a key player was overwhelmingly supported by parents. This is an area which could be explored further in providing nursing care to families.

Suggestions made by Wacht (1986) and Keele (1987) support the use of approaches which are both informational and emotionally supportive for families of developmentally delayed children. The approaches they describe would seem to offer the type of informational supports fathers in this study desired. Wacht (1986) recommends nurses offer developmental and health information, counsel if it is called for, and include families in care planning, intervention, and evaluation steps. Keele (1987) promoted emphasis on the positives in the situation, and stated physicians should give parents of children who have Down Syndrome detailed

information as well as a written summary of what they have been told. Professional follow-up with parents to reinforce information, allow for ventilation of feelings, discuss possibilities for the future, and promote involvement in community and school services were also suggested (Keele, 1987).

Fathers were upset with lack of action on the part of nurses in offering them peer parent supports. They did view this as a nursing responsibility. The findings of this study suggest offering to refer new parents to parent peers may be a valuable nursing intervention.

Chapter 6

LIMITATIONS AND CONCLUSIONS

This chapter presents a summary of the limitations of the study as well as recommendations for nursing practice and nursing research.

Limitations of the Study

Since this was a qualitative, exploratory study using purposive sampling the findings of this study are not generalizable to a larger population. However, it is not known if the findings have theoretical generalizability, that is "the extent to which the findings of the research may be applied to other situations or settings" (Field & Morse, 1985, p. 137). The experiences of this group may be unique to them. Further research with other fathers who have disabled children from other causes and of mothers' experiences would be a starting point in examining the issue of theoretical generalizability.

A further limitation exists in the fact that the subjects were asked to comment on past events. The passage of time may have an effect on what is remembered in terms of actual events as well as personal responses.

It was also noted that although the researcher attempted to separate the roles of researcher and nurse in pursuing this research, occasionally subjects seemed

to be focusing their comments on areas which they thought were of most interest to a nurse. This may have limited the information some of the fathers gave in responses to questions because many of them appeared to view the role of nurses in a rather task-oriented, traditional light. The researcher posed alternate questions to promote more expansive answers when she perceived this might be happening.

Recommendations for Nursing Practice

While acknowledging the variability which exists in fathers' responses, nurses can offer individualized, comprehensive, and effective care to fathers and other family members through the practice of sensitive assessment skills and participatory planning with both parents.

Nurses must go beyond traditional approaches to nursing practice to truly include fathers in family-centred care. The data which emerged in this study suggests nurses can assist fathers and families through clear communication, the provision of appropriate information, the communication of humanistic regard for the entire family, the establishment of opportunities for fathers to participate in all aspects of their child's care, and the availability of supports to enhance coping skills. Meeting such objectives has implications for individual nurses as well as

organizations, as personal and administrative willingness to spend time creating, locating, and using resources on behalf of families will be necessary.

Effective teaching materials for nurses as well as parents should be based on current information and address different levels of learning needs. If lack of knowledge concerning Down Syndrome exists among staff, nurse educators can arrange for inservicing and provide written material to prepare nursing staff to anticipate and deal with questions families may have.

Lack of personal experience with Down Syndrome and other developmentally delaying conditions can be partially addressed by inviting experienced parents to share their knowledge and experience. Nurses can also increase their effectiveness as caregivers by offering clients the opportunity for peer support from experienced parents.

As individuals, nurses can model and promote acceptance and regard for person with disabilities. The parents who participated in this study were very sensitive to professional attitudes and small signs of rejection and acceptance towards their children. It is of paramount importance that nurses confront their inner beliefs and values concerning the care and rights of children who face special challenges. Communicating pity and sadness when these are not the appropriate responses

required at the time, whether unintentional or well-meant, may not promote a therapeutic relationship with families.

Nurses can be influential in the promotion of program development which will maximize independence and quality of life for developmentally delayed individuals as they mature in our society. Such programming may take a giant step towards reducing stress and promoting coping within families who are looking at an uncertain future.

The findings of this study suggest the most important attribute a nurse may hold in the eyes of parents. The caring professional who can genuinely communicate a humanistic philosophy which inspires a positive approach towards the human imperfections we all possess, has a strong foundation for nursing practice with the families of children who have Down Syndrome.

A father said: "Every child is different no matter if they have Down's or if they don't have Down's; there are different variations...so you really know there is hope out there if you just want to work with it."

Recommendations for Nursing Research

Because of some of the differences noted between the findings in this study and the literature on parenting a child with a disability, further qualitative research is recommended. A grounded theory approach

might be helpful in developing a theory of parents' experiences with a child who has a disability and identifying core categories important to that parenting process. Parents who have children with different disabilities could be included in the research to establish theoretical generalizability. Since this study and others have suggested that men and women's experiences may differ, research with both parents is important.

Studies designed to identify the desirability of certain types of intervention might help in planning nursing care. For example, a survey which asks fathers to provide quantitative "priority" ratings to types of information they wanted most immediately after birth, could help provide a format for the development of resource materials for parents.

Comparative effectiveness of coping measures and the determination of which characteristics in fathers are related to more effective coping are also areas worthy of further study. For example, research could be designed to explore the possibility of correlations between the family of origin values and the father's response when a child with Down Syndrome is born.

The role of siblings and the characteristics of siblings is an area in which further study could be accomplished. Factors involving siblings could be

examined as elements of overall family dynamics, or independently in relation to sibling needs.

Supportive interventions which were suggested as helpful in this study's findings, such as parent-to-parent contacts, could be further explored to establish the actual benefits they provide and the degree of satisfaction parents receive.

Research which is designed to measure the effectiveness of specific nursing actions (ie: the incorporation of teaching plans or parent support resources) in terms of measurable satisfaction and/or outcomes could also be highly useful in providing support for the decisions which are made in planning nursing care. Studies designed to identify potential correlations between client satisfaction and well-being or aspects of family interaction or child development, and variables such as nursing staff preparation and experience, or nurses' professional and personal philosophy regarding the care of families who are coping with a congenital disability, could determine if significant relationships exist.

Conclusion

The findings of this study point to the need for nursing knowledge and skill in a variety of dimensions in providing care to families who have a child affected by Down Syndrome. One such skill is the ability to

create, recognize, and use opportunities to work as partners with parents in planning and delivering nursing care.

For many individuals, Down Syndrome remains a mystery until they are personally touched by it. Nurses can help families by developing a knowledge base and acting as a resource to help answer the questions of parents. They may be able to reduce stress and promote coping for fathers through the use of effective communication techniques, a positive and empathic approach, and the promotion of services which are seen as most useful by fathers. They can also join fathers in advocating for families who have Down Syndrome by promoting increased knowledge of the condition within the community at large.

The findings of this study will add to the knowledge nurses have acquired in their practice with parents and children. Learning more about the experiences of fathers will result in further research into paternal concerns and the development of nursing interventions to promote the well-being of fathers and their children.

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Appendix A
Interview Guide

A. Demographic data: father's age, number of children in family, age and sex of child who has Down Syndrome, paternal occupation and educational preparation. Presence of additional health problems in child with Down Syndrome (ie: cardiac defect) will also be noted.

B. Open-ended questions:

1. During a typical day at home, approximately how many hours of your own time is spent in direct care of your child ? Please describe the caring tasks you play a role in during a typical day. How were the tasks you take part in in caring for your child chosen ?
2. Are there other things you do which are not direct care tasks (ie: wage- earning) which you consider part of your job in the family as a father ? Please describe these additional tasks.
3. How would you describe your relationship with your child ? Do you see your relationship with this child as different from the one you have with your other child/children (if appropriate) ? If so, how is it different ?
4. How often do you go out alone with your child during

an average week ? What kinds of things do you do when you go out with your child ?

5. Do you think people you meet when you are out, or acquaintances, react to your child as special or different from other children ? If so, how do you feel about this ?

6. Do you remember when you first learned your child had Down Syndrome ? Can you describe the situation (who was there, if wife was told first, later, at same time, if child had been held by you).

7. Can you put into words your feelings during those first few days ? Can you recall discussing your feelings with health professionals, and if so, with whom ? (ie: doctor, nurse, social worker).

8. Were you given extra information about Down Syndrome during the first few days to help explain your child's condition ? Who gave you extra information (ie: doctors, nurses, social workers, other parents, etc.).

9. Can you recall any experiences with health professionals in the hospital, or since that time, that have been especially helpful to you as the parent of _____ ? That have made it harder for you ? Can you describe these experiences in a few words.

10. What do you think you needed or wanted most as a parent during the first few days after learning your child had Down Syndrome ? Is there any advice you could

give to doctors and nurses about the help they should give parents ?

11. Do you think being the father of (give child's name), has changed you as a person - for example, has your experience with your child changed your goals in life, your friendships, spiritual beliefs ? . Can you describe any changes in a few words ?

12. Do you think this experience has had any effect on your personal health ?

13. (if subject has had no children after this one at time of interview) Would you consider having another child ?

14. Now that your child is (give age), what are your major concerns about your child's development ? How do you see the future for your child ?

15. Is there any information you would like to have at this time in regards to your child's development or health ?

Appendix B

Dear parent:

I am a nurse who has a special interest in children and families who have experienced a congenital disability such as Down Syndrome. I am currently completing a Master's degree in Nursing from Memorial University of Newfoundland.

The research I have decided to undertake for my thesis is concerned with the experience of parenting a young child who has Down Syndrome, from the father's point of view. As so little attention has been paid to the viewpoint of fathers in the research which has been done to date, I plan to privately interview fathers who are willing to talk to me about some of their experiences in caring for their child and in dealing with health professionals. The overall aim of the study is to provide information which will help nurses to provide better and more appropriate assistance to families who have a child with the diagnosis of Down Syndrome. A second aim is to increase the general understanding nurses have of fathers' experiences, so that they can better act as advocates to increase the support of society to families who have developmentally delayed children.

An interview should take less than an hour to complete, and will be arranged at a time and place

convenient to the person being interviewed. All of the information which is obtained will be held in confidence and will not be reported in such a way to reveal the identities of those interviewed, their children, or the names of specific health professionals.

If you are a father (or know of a father) who:

- 1) has a child diagnosed with Down Syndrome in the age range of one to twelve years
 - 2) is generally healthy
 - 3) lives in a city in Saskatchewan with the mother and child
 - 4) would like to share your valuable experiences in a way that may help others,
- then I am eager to include your views in my research study.

Please contact me - collect if necessary - at the following telephone number in Saskatoon (if you live in a city other than Saskatoon, I would still like to hear from you). If you cannot reach me directly please leave a message with your name and telephone number so that I can be sure to contact you.

I wish to thank you in advance for your cooperation in making this study possible - and hope to hear from you soon.

Janice M. Brown

Appendix C

CONSENT FOR STUDY PARTICIPATION

I, _____
give permission to Janice Brown to utilize information
given to her by myself in confidential interview(s) for
the purposes of research. I agree to the use of a tape
recorder in order to assist the researcher in obtaining
an accurate record of the interview. I have been
informed of the aims of this research. I understand the
results of the study will be available to me following
its completion, that I may withdraw from the study at
any time, and that any tapes made will be disposed of or
erased following completion of the study.

Signature: _____

Date: _____

