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UNIVERSITY OF ALBERTA

PARENTAL PERCEPTIONS OF CARE, SATISFACTION AND GOAL ACHIEVEMENT

BY

JOSEPHINE LONGO KIMBER ©

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Abstract

This study examined parental perceptions of care and its relationship to parental satisfaction and goal achievement.

The sample consisted of 25 families who were enrolled in a program for children with behaviour and/or communication difficulties. The children ranged in age from 3.0 to 5.5 years. All of the children had behaviour difficulties and 36% also had speech and language difficulties. Four measures including the Measure of Processes of Care, the Client Satisfaction Questionnaire, a single goal achievement question, and the Canadian Occupational Performance Measure were administered.

The findings support the hypotheses that when parents perceive the program as being family centered they are more satisfied with the care they receive and more likely to perceive their goals as being met.

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Chapter I

Introduction

In the traditional focus of early childhood intervention it was the role of the therapist to identify the areas of difficulty for children with special needs and to develop a treatment strategy based on this information. While family participation was crucial to the success of such an endeavor, the family typically assumed a relatively passive role in the family-professional relationship. To address the imbalance in this relationship, family centered intervention is now being used by many health care professionals.

Family centered care focuses on the family that is described as comprising interdependent members (Dunst, Trivette & Deal, 1994). Dunst et al. state that if a family is strengthened and supported, they will be better able to meet their needs and their child's needs. The helpgiver takes a proactive approach that promotes and enhances already existing family strengths. In other words, a partnership is formed allowing the family to identify their needs, strengths and resources, and together the family and caregiver decide what is necessary to promote positive changes in family function and the care of the child.

Dunst, Trivette, Davis and Cornwell's (1988) study illustrated that if health care professionals use the attitudes, beliefs and behaviours that are consistent with family centered care, families will be empowered and positive outcomes will result from the care they receive. The families sensed more control over the care of their children and were able to engage in the therapeutic process more fully. Branspach (1986) found that when parents perceived control over their children's program activities, they felt more satisfied with the therapy programs. Bass and Leavitt (1963) and Latham and Locke (1979) showed that when professionals set goals collaboratively with clients, goals could be successfully met.

In this study I examined the relationship between parents' perceptions of the care they received, their level of satisfaction with the program, and their perceptions of program outcome. In terms of parental perceptions of the care they received I specifically looked at the extent to which parents perceived the program as being family centered. For perceptions of program outcome I specifically looked at whether the families felt that their goals had been met by the program.

CHAPTER II

Review of the Literature

Family Centered Care

The model of family centered intervention that is used in this paper is that of Dunst et al. (1994). Their model is based on two theoretical perspectives: human ecology theory and social systems theory. Bronfenbrenner's (1979) theory of human ecology stresses the importance of looking at the growing person, the changing environment and the interaction between the two. The family is seen as constituting the ecological context in which the child functions (Bailey & Simeonsson, 1988). Each family is embedded within other larger systems in society, such as neighbourhoods and social attitudes, and these systems are mutually interdependent and influence one another (Bailey, 1987). All of these systems need to be considered in order to understand the family's roles and their ability to function. The child is seen as a part of the family system and the child both influences and is influenced by the family (Bailey, 1988).

Social systems theorists postulate that "different social settings and their members are interdependent, and that events and changes in one unit reverberate and produce changes in other social units" (Dunst et al., 1994, p. 2). The family is viewed as a growing and always changing social unit that has its own structures, resources, functions and interactions (Bailey, 1987). Social systems theory sees the goal of intervention as being to identify family needs, to locate the resources and supports for meeting these needs and to help families use existing capabilities as well as learn new skills in order to mobilize needed resources (Dunst & Trivette, 1987) within the family's own system and social context (Bailey, 1987). This form of intervention helps a family to be more competent and better able to mobilize resources, which leads to family empowerment (Dunst et al.).

The major focus of family centered assessment and intervention is to empower families to make them more competent and better able to mobilize resources. Three conditions need to exist for empowerment to occur (Dunst et al., 1994). First, the health care giver must believe that people are competent or have the capacity to be competent. Second, enablement must be fostered, which refers to creating opportunities for competence to be learned or displayed. Third, family members must be able to attribute their behaviour change to their own actions in order to acquire a sense of control necessary to manage family affairs. Thus the empowered family will be able to exert influence on its social and environmental situation in a manner that will be beneficial.

Shelton and Stepanek (1995) list eight elements of family centered care which include:

- family is the constant
- coping and support is tailored to the family
- peer networking is encouraged and facilitated
- families are appreciated as families
- information is exchanged in a complete and unbiased manner
- family diversity is recognized (e.g., cultural)
- family-professional collaboration occurs at all levels of care
- services are supportive, flexible, accessible and comprehensive

A review of the literature conducted by McBride, Brotherson, Joanning, Whiddon, & Demitt (1993) revealed three major principles of family centered practice that are believed to encompass current values and practice. These are:

- establishing the family as the focus of services. The concerns of all family members should be the basis for establishing intervention outcomes, and the strengths of all family members should be considered as resources for implementing interventions.
- empowering families to make decisions regarding their child and family. This fosters their sense of control and provides a basis for partnership in parent-professional relationships.
- providing services that strengthen the family's ability to meet their needs and those of their child. This is accomplished by providing support that enhances and promotes family capabilities and family functioning.

Implementation of a family centered intervention model has been found to result in high levels of parental satisfaction, accelerated rates of progress by children with moderate or severe disabilities, and acquisition of skills by families (Caro & Derevensky, 1991). Outcomes of empowering individuals and families include a positive self-concept, personal satisfaction, self-efficacy, a sense of mastery, a sense of control, a sense of connectedness, self-development, a feeling of hope, social justice, and improved quality of life (Gibson, 1991). Empowering families to make decisions fosters a sense of control and provides a good basis for partnership in parent-professional relationships (McBride et al., 1993).

Families have stated their preference for family centered practices (Able-Boone, Sandall, Loughry & Frederick, 1990); however, the family centered model is not widely used. On a questionnaire that consisted of 22 components of care, Rosenbaum, King and Cadman (1992) found that although family centered care was highly rated by parents, it was rated much lower and infrequently offered by health care professionals. Brotherson and Goldstein (1992) conducted focus groups with 21 family members who were involved in early intervention programs in Kentucky. The families indicated that they would like professionals to consider their unique family environments and routines, as well as to be respected as competent, contributing members of the team with knowledge to share. They also found that the more family centered intervention services mothers received, the more they perceived their intervention programs as benefiting their families and their children. In looking at a sample of 503 mothers who had handicapped children who were enrolled in intervention programs throughout the United States, Mahoney, O'Sullivan and Dennebaum (1990) found that families had greater needs for family centered services than they were currently receiving. These findings are consistent with those of Mahoney and associates (Mahoney & Sullivan, 1990; Mahoney, O'Sullivan & Fors, 1989). They found that the most predominant model used was the family allied model, where professionals develop goals and interventions for parent feedback and approval. Mahoney, O'Sullivan and Dennebaum (1990) also found that the most common services provided in family centered early intervention programs involved providing families with information about their children and helping parents and families become involved in the early intervention system. They found that different types of care were provided depending on the age of the children and whether there was a home based component. Mothers of children age birth to 3 years and programs with home based components that have Individualized Family Service Plans tended to have a greater family centered orientation. In a qualitative study on parent- professional relationships in early intervention, Minke and Scott (1995) found a higher degree of staff control than parent driven intervention in three early intervention programs even though theses were described by the staff as being family centered. For example, staff tended to reserve decisions regarding estimation of progress on goals and the design of intervention strategies for themselves.

The use of family centered practice is supported by theory and research (Turnbull, Summers & Brotherson, 1984). Parents have also stated their preference for family centered practice (Mahoney & O'Sullivan, 1990; Mahoney, O'Sullivan & Fors, 1989; Rosenbaum et al., 1992). Evaluation of family centered outcomes as perceived by parents seems to be the logical next step in the provision of family centered services (Washington & Schwartz, 1996).

Perceptions of Care

Parent involvement is a key component in empowering parents and returning to them a sense of control over the outcome of their child's life (Dunst et al., 1988). To actively involve parents it is necessary to understand and respond to their needs. Parents and families have needs and resources that directly affect the functioning of their children (Mahoney et al., 1990). When programs provide services that deal directly with family needs and resources, children and families benefit the most from the program (Dunst, 1985). Parents need to be given the opportunity to give feedback on all aspects of program delivery.

Maddison (1977) stressed the importance of seeking the opinions of health care consumers and believed that parental opinion is important since it reflects the care that their child received. Ledwith (1988) stated that consumer surveys are useful and emphasized looking at more than just consumer satisfaction. King, Rosenbaum, and King (1995) also supported consumer input and felt that measuring parents' perceptions of caregiving is a useful method of evaluating activities to improve services. Bailey et al. (1992) also stated that perceptions of consumers are essential and they explored two barriers to consumer involvement. First, many professionals may resent parental viewpoints since they feel that decisions related to programming are ultimately theirs. Secondly, health care professionals may feel that consumers have inadequate knowledge to participate in this process.

The shift to a family centered approach warrants the assessment of parental perspectives on services for their child and their family (Able-Boone et al., 1990). Able-Bonne et al. provide two rationales for acquiring parental perspectives on early intervention services. First, they state that studies have shown that parents want to share their perceptions of services rather than have professionals make assumptions about whether their families' needs were met. Second, they state that parents' views on the best implementation strategies are required to ensure that effective services are offered.

Several studies have examined parental perceptions of intervention programs, four of which used qualitative methodologies. Chisten (1991) explored the perceptions of 8 parents in Arizona using interviews, participant observations and document analyses. Parents identified communication across the program, comprehensive program services, and caring qualities of the staff, as being of critical importance to them and their children. Able-Boone et al. (1990) interviewed 30 families in Colorado. Parents emphasized their need to become knowledgeable about their child and about available services as well as the importance of professionals' relaying information and empowering families to become their own decision makers. Summers and associates (1990) examined family preferences of how services are delivered and how practitioners interact with families in early intervention using nine consumer focus groups. The results showed the need for practitioners to be sensitive to parents' needs and perceptions, including giving positive feedback, being flexible and being responsive to rapid changes in the family. Summers emphasized the importance of acknowledging the family as the ultimate decision-maker and the family's desire to be more actively involved in setting goals and designing the intervention program. Katz and Scarpati (1995) used an ethnographic approach to determine how members of an early intervention team in New England State involved nine families in the development of Individual Family Services Plans. Parents perceived early intervention programs as being more child-focused than family focused even though there was a significant degree of family involvement. In this program the professionals maintained the belief that they were the primary decision- makers, responsible for the final development of goals and the source of professional judgment.

Other studies used quantitative research methodologies to examine parental perceptions of care in early intervention programs. Mahoney, O'Sullivan and Dennebaum (1990) used the Family Focused Intervention Scale with 503 mothers who had handicapped children ranging in age from birth to 6 years. Mothers who received high levels of family centered care reported significantly greater benefits from the intervention. The findings also indicated that programs with home based components had a substantially greater family orientation than programs that were primarily center based. Parents expressed their greatest needs as learning how to utilize the early intervention system and identifying other community resources to assist them in the care of their children. Trivette, Dunst, Boyd and Hamby (1996) found that sources of variation in 208 American parents' assessment of helpgiving practices and their personal control appraisals were related to differences in program models and not parent or family characteristics. Rating scales were used to identify the program model used. Program models included professionally centered, family allied, family focused and family centered. The family centered model was considered to be more effective and resulted in more parental control of their children's care.

Similar results have been found by studies examining parental perceptions of care received while their children were in hospital- based programs and habilitation centers. Ball, Glasper and Yerrell (1988) used a questionnaire to look at many aspects of pediatric nursing care. They showed that parents' perceptions of receiving adequate information and evaluating staff as being competent related strongly to their respect for clinical staff. Similarly, Baine, Rosenbaum and King (1995) measured 22 components of care perceived as important by 213 Canadian parents of children with long term disabilities. The components of care covered a broad range of activities conducted by health care professionals, organizational features of treatment facilities, and philosophical approaches to caregiving. All of the components of care were ranked as important; however, the parents ranked parent involvement, education/information, treatment, accessible and available care, continuity, consistency, coordination, and family centered care as being most important. Bjorck-Akesson and Granlund (1995) studied parents' perceptions of family involvement in the habilitation process. The sample consisted of 73 Swedish parents. Using rating scales, parents ranked 4 dimensions of family involvement. They found that parents perceived substantial discrepancies between how they are currently involved in early intervention and how they think that they should ideally be involved. Parents wanted to be more involved in decisions regarding their child's assessments, team meetings, and the generation of family goals and services.

In the family centered model of providing care, practices are consumer driven, in that families' needs and desires determine all aspects of service delivery and resource provision (Dunst, Johanson, Trivette & Hamby, 1991). The aims of programs are to promote family decision making and competencies, and to strengthen a family's capacity to build both informal and formal networks of resources to meet their needs. Although the studies that have been cited have been conducted with different populations (e.g., different disabilities, age groups, countries), different programs (e.g., early intervention programs, habilitation centers, hospital based) and different methodologies (e.g., qualitative, quantitative), several common elements have emerged. Parents want to be involved (Baine et al., 1995; Bjorck et al., 1995; Summers et al., 1990). This involvement is reflected in their desire for more information (Able-Boone et al., 1990; Baine et al., 1995; Ball et al., 1988; Mahoney et al., 1990), and to be the primary decision makers in their children's care (Able-Boone et al., 1990; Bjorck et al., 1995; Katz et al.,1995; Summers et al., 1990). The parents also want comprehensive and consistent care (Able-Boone et al.1990; Baine et al., 1995; Chisten et al., 1991; Summers et al., 1990), and health care providers who are caring and respectful (Chisten et al., 1991; Summers et al., 1990). These studies suggest that when parents perceive programs as having the characteristics of family centered care, then parents perceive the programs as being more effective and in turn provide them with the control they need to ensure that their family's needs are met (Mahoney et al., 1990; Trivette et al., 1996)..

Satisfaction

Client Satisfaction

One measure of the effectiveness of health care services is the extent to which the consumers are satisfied (McWilliams et al., 1995). Client satisfaction is an important indicator of the quality of treatment received and is also an important goal of service providers (Hill, Bird, Hopkins, Lawton & Wright, 1992; Kopec-Schrader et al., 1993). Client satisfaction surveys provide very useful information. They provide information about the acceptability of different interventions (Sabourin, Bourgeois, Gendreau and Morval, 1989). They are a good predictor of the client's compliance with treatment, premature termination of services and future helpseeking behaviour (Kaplan & Ware, 1989; Sabourin et al., 1989; Ware & Davies, 1983). They are also moderately related to the client's view of treatment outcome (Sabourin et al., 1989; Ware et al., 1983).

Research on client satisfaction has been hampered by a lack of awareness that users of the service may have suggestions which could improve service delivery, by a lack of standardized measures for collecting this information, by low response rates to satisfaction surveys (Kopec-Schrader et al., 1993), by poor psychometric properties in existing satisfaction surveys (Sabourin, Laferriere et al., 1989) and by the high levels of reported satisfaction (Larsen, Attkisson, Hargreaves & Nguyen, 1979). High levels of reported satisfaction can be explained in several ways (Larsen et al.). These ratings may be due to the client's desire to give positive comments to avoid repercussions or these ratings can be accepted at face value. It is difficult to find a meaningful comparative basis for interpreting client satisfaction findings since levels of satisfaction in absolute terms and in isolation from other data are meaningless. The sample may not be a representative sample of the client population due to low return rates, patient drop out from programs, and perhaps only satisfied persons reply. Another influence is the halo effect, which refers to the tendency to rate people one likes positively (Tuckman, 1994). This causes the scales to simply measure the general positiveness of the rater's perceptions of the staff rather than satisfaction with the program. Despite the fact that concerns have been identified with client satisfaction surveys, it is still important to measure client satisfaction. If the client's perspective is not taken into account the evaluation of services is incomplete and biased towards the provider's perspective (Larsen et al.).

Consumer satisfaction has been found to be related to factors that include: client sociodemographics, physical and psychological status of the client, client attitudes and expectations concerning medical care (Cleary, 1988), characteristics of the provider or organization that made the care more 'personal' such as good communication skills, empathy and caring (Cleary; Kaplan & Ware, 1989), and the structure, process and outcome of care (Cleary). Structure refers to the physical setting and resources available and includes accessibility and continuity of care. Process refers to the way in which the service is delivered and includes technical and interpersonal aspects of care, and outcome is the end product of the process.

Client dissatisfaction is usually related to concerns regarding communication, empathy, time, accessibility, and the attitudes of health professionals towards care their clients (Hill et al., 1992). Plapp and Rey (1989) stated that satisfaction and dissatisfaction are not mutually exclusive since it is possible that a person may be generally satisfied with something but still have a number of specific dissatisfactions with it.

Parent Satisfaction

Though similarities exist between client and parent satisfaction it is important to examine parent satisfaction as a separate concept. Measuring parent satisfaction is an essential component of the evaluation of early intervention programs (Bailey and Simeonsson, 1988). Parents have the major responsibility of their child's development and their decisions concerning success and failure should have primacy (McNaughton, 1994). Parent satisfaction measures are important because they give families a sense of ownership and control over the services made available to them, and may increase parent participation in programs (McNaughton). Information about parent satisfaction and dissatisfaction can be used to develop better services for families (Bailey et al., 1986; McNaughton). Data collected regarding parent satisfaction may also be used to convince people of the usefulness of a particular program (McNaughton).

Bailey and Simeonsson (1988) noted that the measurement of parental satisfaction has received limited attention in the past and therefore little information exists to guide the collection and interpretation of satisfaction data. In a review of 20 early intervention studies published between 1975 and 1983, Marfo and Kysela (1985) reported that only 2 studies included a measure of parent satisfaction within the early intervention program. However, as the emphasis on client empowerment and family centered care in health care is growing, parent satisfaction is gaining credibility as an important outcome measure (Unwin & Sheppard, 1995).

Where attempts have been made to identify correlations between reported satisfaction measures and objective measures of achievement, the focus has been on the child receiving the services (McNaughton, 1994). Marfo, Browne, Gallant, Smyth and Corbett (1991) reported a low correlation (r=.20) between parent satisfaction and child progress as measured by the rate of the child's development during intervention. Upshur (1991) observed a low correlation between fathers' satisfaction and their children's development of cognitive skills (r=.22) and no relationship was found between mothers' satisfaction and measures of children's progress. Plapp and Rey (1989) found that 70% of parents were satisfied with the treatment their child received and a similar proportion reported improvement in their children's skills. Kopec-Schrader et al. (1993) conducted a study in a private hospital for children with eating disorders and found that most parents were satisfied with the services provided and about the same proportion reported that their child was functioning better yet felt that they were not given enough information and support. These studies suggest that there may be a weak relationship between parental satisfaction and their child's development of skills.

The literature also suggests an important link between parental perceptions of participation in programs and satisfaction with the care received (Cleary & McNeil, 1988). In a survey of parental satisfaction of parents who were fully involved in all aspects of their child's stay in hospital, Jackson, Bradham and Burwell (1978), found that all parents reported that they were satisfied with the care their child received. Similarly, Styba, Elaschuk, Jesse and Cote (1992) confirmed that parents expressed a high degree of satisfaction with being able to be completely involved in all aspects of their child's care. Caro and Derevensky (1991) evaluated a family centered home based intervention model with 16 families having infants with moderate or severe disabilities and found high levels of parental satisfaction. These studies suggest that when a program has the characteristics of being family centered parents report that they are satisfied with the care their children received.

Parental perceptions of the characteristics of the staff providing the program are also related to feeling satisfied with the care provided. Similar to the literature on client satisfaction, interpersonal elements of care – such as understanding, warmth and sincerity – were identified as being valued by consumers of health care. A number of authors have found these qualities to be related to parental satisfaction with care (DiMatteo, 1979; Doyle & Ware, 1977; King, Rosenbaum & King, 1995). Similarly, in a study looking at parental satisfaction with the transition from early intervention programs to kindergarten, it was found that parents who felt supported and had explanations provided to them felt more satisfied (Hamblin-Wilson et al., 1990).

McWilliams et al. (1995) found that parents' satisfaction was related to their perceptions of having access to services, developing individualized family service plans and coordinating services. However, they also found that priorities vary for different families. For example, Latino families included information and support, socialization for the child and help with separation from their children as goals. Philadelphia families wanted to be well educated about their children and prepared for transitioning to school. They also found that fathers and mothers have differences in their perceptions of satisfaction but both agree on what is beneficial to their child and family.

The potential benefits of collecting information on parents' satisfaction with early intervention services are frequently cited in the literature (Bailey & Simeonsson, 1988; Mahoney et al., 1990). Information on parent satisfaction with early intervention services can help develop better services (Upshur, 1991; Wolery, 1987), enhance parental participation in programs, and provide support for the usefulness of a program (McNaughton, 1994). The literature reviewed also suggests that there may be a relationship between parent perceptions of being involved in programs that are family centered and their level of satisfaction with the program. The characteristics most cited as linked to satisfaction include feeling supported, receiving clear explanations of care, being fully involved in all aspects of care, and the feeling that the staff are being understanding and sincere. These characteristics are all part of the model of family centered care.

Goal Achievement

Reviews of research conducted on setting goals have concluded that parents are typically passive recipients of information rather than active decision-makers (Brinckerhoff & Vincent, 1986). Witt, Miller, McIntyre and Smith (1984) stated that the parental role preferred by most professional team members is of a passive participant. Salisbury (1992) reported that goals have often been completed by staff prior to meetings with parents, and that participation has meant listening to professionals and approving the goals already prepared for their review. Katz and Scarpati (1995) found that staff use their professional roles and influence to change family goals by redirecting, suggesting and encouraging families to adopt certain interventions.

In order to set goals that are meaningful and important to the child and family, it is necessary to work together with them. A team approach is necessary in early intervention and families are essential members of the team (McGonigel & Garland, 1988). Studies have found that parents who want to be involved in all aspects of their child's program have the ability to develop and implement goals when encouraged by staff (Katz & Scarpati, 1995). Bass and Leavitt (1963) and Latham and Locke (1979) support that "ownership" of goals, which is only possible when a person is meaningfully involved in setting their own goals, is the most effective way to ensure that goals are successfully met. By focusing on needs that are of direct concern to families, interventionists can develop a trusting and collaborative relationship with families and assist them in achieving their goals (Bailey et al., 1986; Garshelis & McConnel, 1993).

Several studies have documented the frequent incongruence between the priorities of families and those of professionals (Bailey, 1987; Blackard & Barsh, 1982; McGonigel & Garland, 1988). Hare (1982) showed that while interdisciplinary teams are more accurate in identifying parental perceptions of needs than individual professionals, they still did not do well in assessing family needs. Salisbury (1992) identified two sources of disagreements over chosen goals. First, the situation where parents place a priority on a goal that a professional sees as being minimally related to their child's program; and second, when conflicts over time lines for goal achievement arise, including time frames that are thought to be too long or too short.

There is some research that demonstrates that parents can be reliable sources of information and that they can be accurate assessors of their child's abilities (Beckman, 1984). Models that stress enabling and empowering families and respect for their beliefs and values are based on the assumption that family priorities are paramount and are to be respected (Minke & Scott, 1995). These models stress that disagreements should be resolved through negotiation and families must retain final control over decisions.

Several studies have illustrated the benefits that result when families set the goals for intervention. Adubato, Adams and Budd (1981) studied aspects of training a mother and father in child management techniques with their six year old severely developmentally delayed son. The parents chose the goal of improving their child's dressing skills, and a partnership was formed between the therapist and the mother to work collaboratively. There were four significant results from this study: the mother learned to implement the training procedures and communicate them successfully to the father; parents showed generalization of skills; child improved with dressing skills; and a two year follow up indicated that parents retained their knowledge of skills taught, continued to use the procedures and rated the training as helpful to teach self-help skills. Schriebman, O'Neill and Koegel (1983) conducted a study to investigate the effectiveness of a generalized training program for siblings of autistic children. The goal of improving the child's behaviour was generated by the family and then the therapist worked together with the siblings to improve the behaviour of the child with autism. The results showed that the siblings learned to use the behavioural procedures proficiently, and developed a more positive attitude towards their sibling with autism. The behaviour of the children with autism also improved. These studies illustrate the benefits that result when parents generate treatment goals that are important to them and their families. In these two situations the therapists used the family centered model of care to achieve the outcomes that resulted.

The literature suggests that when partnerships are formed between professionals and parents so that the goals of intervention are collaboratively set, positive outcomes will result. Working towards goals that are important to the family and the child are characteristics of the family centered care model.

Rationale

The use of the family centered care model in programs designed to help families with children who have special needs has been associated with outcomes such as accelerated rates of progress by children, acquisition of skills by parents (Caro & Derevensky, 1991), and empowerment of families (McBride et al., 1993) as well as increased parental satisfaction (Cleary & McNeil, 1988; Styba et al., 1992). The family centered model of intervention includes focusing on needs that are of direct concern to families. By taking this focus, interventionists can develop a trusting and collaborative relationship with families and assist them in achieving their goals (Bailey et al., 1986; Garshelis and McConnel, 1993). The literature suggests that when the family centered care model is used family goals can be successfully achieved (Adubato, Adams & Budd, 1981; Dunst & Trivette, 1987; Schriebman et al., 1983).

In this study I looked at the relationships between three variables: parent's perceptions of the extent to which the care they receive is family centered; parental satisfaction with the program; and parents' perceptions of their goals being met while in the program. The literature suggests a positive relationship between the family centeredness of a program, parental satisfaction, and goal achievement. None of these relationships has been studied extensively but the literature supports continuing research in this area.

Research Questions

1. Will parental perceptions of care received while attending the Communication Behaviour (CB) program as measured by the Measure of Processes of Care (MPOC) be positively correlated with the level of satisfaction with the CB program as reported by the parents using the Client Satisfaction Questionnaire (CSQ)?
2. Will parental perceptions of care received while attending the CB program as measured by the MPOC be positively correlated with parental perceptions of goal achievement as measured by a single question using a 7 point rating scale of goal achievement?
3. Will parental perceptions of care received while attending the CB program as measured by the MPOC be positively correlated with parental perceptions of goal achievement as measured by change scores on the Canadian Occupational Performance Measure (COPM)?

CHAPTER III

Method

Participants

A convenience sample of twenty-five families who participated in the Communication Behaviour Program (CB) at the Glenrose Rehabilitation Hospital from October 1996 to March 1997 was studied. There were 15 families enrolled in the program that was conducted from October to December 1996. All 15 of these families agreed to participate in the study. Twelve out of 13 families attending the program from January to March 1997 agreed to participate in the study. One set of parents was unable to attend the educational components of the program and was not approached to participate in this study. Twenty-seven sets of questionnaires were received, but two were excluded due to missing data. Questionnaires were completed by 18 mothers and 7 were completed by the parents together.

Demographic characteristics of the families are shown in Table 1. This information was obtained by reviewing the children's medical files. All of the children had behaviour difficulties. It is interesting to note that 80% of the children in the program were male. Most of the children came from two-parent homes. Forty-three percent of fathers and 32% of mothers had post-secondary education, and the majority of parents held jobs that required skilled work (e.g., bank customer representative, skilled labourer). Almost half of the mothers were homemakers.

Table 1

Demographic Characteristics of the Sample (n=25)

CHILDREN

Age (years)	
Mean	4.1
Median	4.3
Range	3.0-5.5
Standard Deviation	.7
Sex	
Male	20
Female	5
Diagnoses	
Behavioural Difficulties	25
Speech/Language Difficulties	9
Attention Deficit, Hyperactivity Disorder	7
Sleep Disorders	3
Oppositional Defiant Symptoms	2
Asperger's Disorder	2
Attention Deficit Disorder	2
Tourette's Syndrome	2
Pervasive Developmental Disorder	1

PARENTS

Marital Status

Single mother	4
Married(biological parents)	16
Married (biological mother, step father)	4
Married (foster parents)	1

Education

	Father	Mother
University graduate	2	2
College graduate	7	6
High School graduate	9	11
Partial high school	3	6

Occupation

	Father	Mother
Foster parent	1	1
Homemaker	0	12
Professional	2	2
Skilled work	17	6
Semi-skilled work	0	3
Unemployed	1	1
Disability Pension	1	0

NUMBER OF CHILDREN IN FAMILY

Mean	1.5
Median	2.0
Range	0-6
Standard Deviation	1.2

The Communication Behaviour (CB) Program

The CB program is a multidisciplinary program that provides intensive, short term diagnostic and treatment services for preschool children who have been identified as having significant behavioural and/or communication disorders. The program provides intensive classroom diagnostic and treatment services for children and active teaching of appropriate strategies to parents and other caregivers both at the Glenrose Hospital and in the community. The CB program is for children who are between the ages of 3 and 6 years (but not in grade 1). Children must be ambulatory. Children who have a diagnosis of mental handicap are not accepted into this program.

The CB program provides a language enriched, behaviourally structured and emotionally supportive environment. Strategies are developed that will maximize the independence, social adjustment and verbal competence of the child. These strategies are based on the principles derived from Social Learning Theory (Patterson, 1977). Clear expectations and consistency are integral parts of the philosophy. It is believed that effective communication skills and appropriate social interaction skills have a complementary effect on each other and therefore both aspects are integrated into program activities. Staff focus on normal child development to ensure the same expectations for the child as they will encounter in the community.

Active involvement by the family is strongly encouraged in order to facilitate better understanding of the child's strengths and special needs and to promote family empowerment. Treatment and diagnostic goals are prioritized in consultation with the family.

Integration is a strong focus of the program and therefore community contact is important. In order to achieve generalization of treatment gains, active consultation with the community is emphasized. The program staff spend time working directly in the community with the child and caregiver. This feature is a vital component in the generalization of behaviour change across settings.

The core staff in this program consist of two psychologists, one speech-language pathologist, one educational therapist and one program assistant. Consultant staff to the program are from occupational therapy, social work, nursing, medicine, psychiatry, and audiology.

The CB program runs for 2 ½ hours either in the morning or afternoon, three days per week for 10 weeks. Three sessions of the program with approximately 15 children per session are offered per year. The program in the morning is for children between 3 and 4 ½ years of age and they tend to present with more diagnostic questions than the afternoon group. Children ages 4 ½ to 6 years are in the afternoon program and often attend concurrent community programs.

The program includes formal parent training in the form of weekly parent groups to discuss pertinent behavioural and developmental issues, supervised practice of effective strategies within the Glenrose classroom and the child's home, regular individual meetings with the psychologist and other members of the team, and supervised practice of effective strategies in public places. The training is augmented by a variety of written handouts and readings. These services are also available to staff from the child's community placement program and other professionals in the community. Formal inservices and workshops to community agencies are an integral part of the training program.

Instruments

The Measure of Processes of Care (MPOC)

The MPOC is a 56-item questionnaire that was developed to assess parental perceptions of the services received for parents and their child with a chronic health problem (King et al., 1995). This measure is based on the components of caregiving valued by families who have children with neurodevelopmental disorders. Approximately 2000 parents in Ontario participated in various stages of its development and testing to ensure that the concepts, format and language were applicable and accessible to parents. Due to the extensiveness of the parental contributions the MPOC is thought to capture aspects of care and services most important to parents, and provides a means to evaluate the family centeredness of a program. This questionnaire was used to measure perceptions of the family centeredness of the CB program.

The MPOC consists of 5 scales derived from theory and factor analysis which are highly intercorrelated with Pearson correlation coefficients ranging from .33 to .73. The Enabling and Partnership scale has 16 items that reflect parents' involvement in the care process, particularly decision making. The Providing General Information scale consists of 9 items that focus on activities that meet parent general information needs. The third scale, Providing Specific Information About the Child, contains 5 items that highlight behaviours by which parents are provided with information about their child. The Coordinated and Comprehensive Care for the Child and Family has 17 items that cover whether care was provided consistently for the entire family. The fifth scale, Respectful and Supportive Care, has 9 items about the parents being treated with respect and receiving support. Each item begins with a question that has the same beginning, "To what extent do the people who work with your child...." This is followed by a specific behaviour of a health care professional. The parents respond using a 7-point scale with 1 being "never" and 7 being "to a great extent". A section for comments is contained at the end of the questionnaire. The authors report that the questionnaire is at a grade 8 reading level. The questionnaire was slightly revised for this study with permission from the authors. Hospital and Treatment Center were deleted and replaced with a blank space so that the CB Program could be written in and "in the past year" was deleted from all pages since the CB program is 10 weeks in duration.

Cronbach's alphas for the MPOC subscales range from .81 to .96 (N=653), indicating that the measure has good internal consistency. The measure is reported to have good stability with test retest reliability coefficients ranging from .78 to .88 over a 28 day period. To assess the construct validity of this measure, the authors correlated the scale scores with the Client Satisfaction Questionnaire (CSQ) (r=.40 to .64) and parental stress (one question stress scale) (r=.23 to .35). The authors hypothesized a positive correlation between the MPOC scale scores and satisfaction as measured by the CSQ since they believed that parents who perceived that care is better would have higher satisfaction with a program that delivered these services.

Client Satisfaction Questionnaire (CSQ)

The CSQ is a standardized scale used to assess client's satisfaction with a program (Larsen, Attkisson, Hargreaves & Nguyen, 1979). It consists of 8 questions with a 4-point response scale. The questions ask about various aspects of the program. The response scale scores vary with 4 representing high satisfaction and 1 representing low satisfaction. A comments section is included at the end of the questionnaire. This questionnaire has a reading level of grade 7. Cronbach's alpha for the CSQ was .93 indicating that the measure has high internal consistency. No information is available on test retest reliability. Therapists' estimates of how satisfied they believed their client to be were correlated at .56 (p<.01) with client's CSQ scores illustrating adequate concurrent validity.

The CSQ has been used in the CB program for 5 years. The scores obtained on this questionnaire are always very high.

The Canadian Occupational Performance Model (COPM)

The COPM is an individualized outcome measure of occupational performance (Law et al., 1994) used to assess changes in client's self-perceptions of outcomes in the areas of self-care, productivity and leisure. This measure is based on the occupational performance model (Law et al.) which is consistent with the beliefs of family centered care.

The second edition of the COPM was used in my study to determine goal achievement. Performance refers to how parents rate the way their family does the goal now. Performance ratings range from 1 (not able to do it) to 10 (able to do it extremely well). Satisfaction refers to how satisfied they are with the way they do this goal now. Satisfaction ratings range from 1 (not satisfied at all) to 10 (extremely satisfied). Change scores for performance and satisfaction were calculated with a score of 2 or more indicating that the goals had been achieved.

To determine the test retest reliability of the COPM, the COPM was administered twice with a two week interval (Law et aL, 1994). The sample consisted of 27 senior citizens with a variety of disabilities including arthritis and stroke who attended a rehabilitation day program. The test retest reliabilities for the performance and satisfaction scores of the COPM were .63 for performance and .84 for satisfaction (inter-class correlations).

Several studies have examined the responsiveness of the COPM. In one study of adult clients, differences in the means between initial and reassessment scores for both performance and satisfaction scores were statistically significant ($p<.001$) (Law et aL, 1994). In a study of 30 clients in an Outpatient Day Center over a 3 month period, Law et al. reported that the initial and final scores for performance and satisfaction changed by 1.0 and 1.1 points, respectively. These differences were statistically significant ($p < .001$). To evaluate whether these changes were similar to changes in overall function as perceived by clients, therapists, and caregivers, each of these groups were asked to independently rate changes in function over the three month period of time using a 7-point Likert scale. When the change scores on the COPM were compared with these ratings, a low to moderate correlation was obtained. Law et al. stated that the correlations obtained provided evidence that the COPM is responsive to changes in global function as perceived by clients, families and therapists.

Validity of the COPM was examined by Chan (1995). He examined the content-related validity of the COPM. A nine-member panel consisting of 7 clinical specialists, 1 clinical measurement specialist and one specialist in occupational therapy was used to gather information on performance. Comments from the expert panel revealed that the

COPM was good in incorporating clients' considerations of their own performance in all three areas of occupational performance and fair in measuring the performance components of clients. Chan also had the COPM and three other instruments administered by occupational therapists to 39 adult orthopedic and stroke clients. The three instruments were the Klein-Bell Activity of Daily Living Scales (KBADL), the Satisfaction with Performance Scaled Questionnaire (SPSQ) and the Functional Independence Measure (FIM). However, Chan did not find the anticipated pattern of correlations between the COPM and these other measures.

All of the studies conducted to look at the reliability and validity of the COPM were conducted with the first edition of the COPM. The second edition of the COPM includes changes in administration and scoring, but does not change the nature of the scales. There have been no studies conducted to date using the second edition of the COPM.

Since the COPM is reported to have fair to good test retest reliability it should be an adequate measure to use in looking at changes in parental perceptions of goal achievement at the beginning and then at the end of the CB program. The results of Law et al.'s studies of responsiveness suggest that the COPM can detect changes in function as perceived by families. Chan's results revealed that the COPM has fair to good content related validity and lend support to using the COPM to gather families' perceptions of goal achievement. The results of Chan's study indicating that the COPM does not have good criterion validity is less relevant in this study because the emphasis is on parental perceptions rather than on actual performance.

Question on Goal Achievement

One item using a 7 point rating scale was used to determine parental perceptions of goal achievement. It was: "Did the Communication Behaviour Program meet your goals?" The scale scores consisted of 1 - none, 2 -very few, 3 - few, 4 - some, 5 - quite a few, 6 – most, and 7 - all.

Procedures

The CB team used the COPM as a part of standard program procedures for 1996 - 1997. The CB team did a home visit to gather information and to set goals prior to the families starting in the program. The COPM was administered at this time by the program psychologist to the parent who was present during the visit. An interview format was used to assist parents with identifying and ranking goals in order of importance. The top 5 goals were rated by the parents on performance and satisfaction using a 10-point scale. If both parents were present, then the parents came to agreement on their goals and the ranking assigned to the goals. The researcher met with the families during the first week of the program to describe the study, answer any questions and sign consent forms. Consent was given for the researcher to examine the data obtained from the COPM and the CSQ, as well as to administer two additional measures, the MPOC and the one question on goal achievement during the last week of the program. The psychologist readministered the COPM during the last week of the program to enable parents to assess goal achievement. The parent(s) who initially ranked the goals reranked them without reference to their previous ratings of the goals. The goals were again rated on performance and satisfaction so that a change score could be calculated to determine if the goals have been achieved. Changes of two or more points on the COPM are considered clinically important (Law et al., 1990). Therefore, an increase of two or more points on the performance or satisfaction scores was used to indicate that goals had been met. The CSQ was also part of the standard program procedures and the CB team administered this questionnaire during the last week of the program. This questionnaire was completed by the parent(s) who completed the COPM. The investigator met with families during the last week and was available to answer questions while the parent(s) completed the MPOC and the single goal achievement question. The parent(s) who completed the COPM and CSQ completed these questionnaires. These forms were collected by the investigator and kept confidential.

Data Analysis

Mean scores and standard deviations were calculated for each of the five scales of the MPOC. Thematic analysis was conducted on the comments that were made by the parents on the MPOC. Comments were clustered into similar topic areas and then grouped into themes. For the CSQ, a total mean score and standard deviation were obtained. Total COPM performance scores were calculated by adding all of the rankings that the parent(s) assigned to their five most important goals and then dividing by the total number of goals. Total satisfaction scores were calculated using the same method. This was done pre and post program. Then the pre program performance total score was subtracted from the post program performance total score to calculate the change in performance score. The same method was used to calculate the change in satisfaction scores. Means and standard deviations were also calculated for performance and satisfaction scores, pre and post program. Paired t-tests were conducted to determine the statistical significance of differences. A single score was obtained for the single question on goal achievement. The mean value for the entire sample was calculated for the single question on goal achievement. Pearson correlation coefficients were calculated to look at the relationships among the scores obtained on the COPM, the MPOC scales, the CSQ and the single question on goal achievement.

Ethical Considerations

Approval to conduct this study was obtained from the Glenrose Rehabilitation Hospital's Ethical Review Committee. Families were provided with written information about the study (Appendix A). A group session was conducted to inform the families of the details of the study and to answer any questions. Written consent was obtained from all families who were interested in being involved in the study (Appendix B). The information and the consent letter have a grade 8 reading level. Families were identified through a number system to ensure confidentiality and all data was reported on a group basis.

CHAPTER IV

Results

<u>The Measure of Processes of Care (MPOC)</u>. Descriptive data obtained on the MPOC are given in Table 2. The scale entitled Providing General Information received the lowest mean value and the largest range in scores. A mean score of 4 refers to parents feeling that the program provided general information to them "sometimes". The large standard deviation indicates that people varied considerably in their perceptions of this scale. The Providing Respectful and Supportive Care scale received the highest mean score. A score of 7 indicates that parents felt that they were always treated with respect and given support. This scale was ranked highly by all parents as indicated by the narrow spread of scores.

The MPOC questionnaire contains a section where parents are able to provide comments about their perspectives of the care they received and 52% of parents made comments. Using thematic analysis, three themes emerged . First, all of the parents felt that their child's behaviour had improved; however, 24% reported that the improvement was greater in the program than at home. These parents reported that they did not feel that the child's behaviour was easy to manage at home and feared that their child would regress upon discharge from the program.

A second theme was that parents wished the program could be longer. Thirty-two percent of the parents reported that they wanted more time to learn and practice the various behavioural strategies. They commented that they were just beginning to learn and understand and then the program ended.

The third theme centered on their disappointment with follow up programs. Twenty-eight percent of the parents reported that they had to wait up to 6 months to begin another program or they had no program to turn to. The concern regarding possible regression in their child's behaviour was reiterated here.

The Client Satisfaction Questionnaire (CSQ). A mean score of 3.52 (S.D. = .44) was obtained on the CSQ indicating high parental satisfaction with the program. Means scores ranged from 2.13 to 4.00 on the 4 -point scale indicating that most parents were generally satisfied with the program. It is also interesting to note that even though the parents rated providing general and specific information lower on the MPOC, they were still very satisfied with the care they had received.

Correlation Between MPOC and CSQ. The mean scores obtained on each of the five scales of the MPOC were correlated with the mean score obtained on the CSQ. The correlation coefficients ranged from .46 to .76 (Table 3) and were all statistically significant. The highest correlation coefficient was between satisfaction and the MPOC scale, Providing Specific Information. The lowest correlation coefficient was between satisfaction and the MPOC scale, Providing General Information. The results indicate that the MPOC scales correlate positively with the CSQ. That is, parental perceptions of care received while attending the CB program are positively related to parental satisfaction with the CB program.

Table 2

Descriptive Data Obtained on the Five Scales of the Measure of Processes of Care (MPOC)

MPOC Scales	Mean	Standard Deviation	Range
General Information	4.64	1.60	1.89-6.89
Specific Information	5.71	1.17	2.20-7.00
Enabling and Partnership	5.99	.76	4.31-6.88
Coordinated Care	6.01	.66	4.88-7.00
Respect and Support	6.40	.58	5.11-7.00

Single question on goal achievement. This question had a mean value of 5.12 (SD= .97). A value of 5 indicates that parents, on average, perceived "quite a few" of their goals as being met during the program. This question had a wide range of scores from 3 indicating that "few" goals were met to 7 referring to "all" goals being met.

Correlation between MPOC and single question on goal achievement. When the mean scores obtained on the five scales of the MPOC were correlated with the mean score obtained on the specific goal achievement question (Table 3), correlation coefficients ranged from .37 to .59. Only the General Information subscale of the MPOC failed to correlate with the single goal achievement question at a statistically significant level. Overall, there seems to be a positive relationship between parental perceptions

Table 3

Correlational Analysis Between Mean Scores of the Five Scales of the MPOC, the Mean Score of the CSQ, the Mean Score of the Single Goal Achievement Question, and the COPM

	Enablement/ Partnership	General Info	Specific Info	Coord. Care	Respect and support	CSQ	Meet Goal	Perf. Post Program	Satisfaction Post Program	Perf. Change Score	Satisfaction Change Score
Enablement/ Partnership	---	.71***	.77***	.91***	.86***	.71***	.59**	.40*	.43*	.38	.29
General Info		---	.63**	.71***	.51**	.46*	.37	.43*	.48*	.34	.19
Specific Info			---	.75***	.57**	.77***	.51*	.36	.26	.43*	.10
Coord. Care				---	.83***	.65***	.55**	.34	.31	.29	.19
Respect and Support					---	.64**	.55**	.43*	.41*	.43*	.39
CSQ						---	.78***	.57**	.48*	.51**	.31
Meet Goal							---	.51*	.39	.42*	.23
Perf. Post Program								---	.91***	.79***	.66***
Satisfaction Post Program									---	.72***	.81***
Perf. Change Score										---	.75***

Note. General Info = General Information; Specific Info = Specific Information; Coord. Care = Coordinated Care; CSQ = Client Satisfaction Questionnaire; Perf. Post Program = Performance Post Program; Perf. Change Score = Performance Change Score.
***p<.001. **p<.01. *p<.05.

of care and parental perceptions of goal achievement with the CB program.

Canadian Occupational Performance Measure (COPM). Table 4 provides descriptive data obtained on the COPM. The mean number of goals identified by parents was 4.4 and were primarily child focused; however, some family focused goals were present. Examples of child focused goals included: decreasing aggression, improving compliance, and improving social skills. Family goals included having more time for recreation, having more couple time, increasing parental understanding of child's areas of difficulty, and increasing parental knowledge in strategies to help the child with areas of difficulty. The scores on pretest were low as expected. A score of 3 indicates poor performance of the goal area and dissatisfaction with current performance of the goal. The mean ratings on performance and satisfaction with goals on posttest increased. A score of 5 indicates perceptions of moderate goal achievement and moderate satisfaction with goal achievement. A score of 10 indicates perceptions of high goal achievement and high levels of satisfaction with this goal achievement. A change score of 2 or greater indicates that a clinically important change has occurred in perceptions of performance and satisfaction with the goal area (Law et al., 1990). The change scores obtained for both performance and satisfaction indicated that parents perceived a clinically important change in their performance of the goal area and their satisfaction with their performance in the goal area. Sixty-eight percent of parents perceived a clinically important change in goal performance and 64% of parents perceived a clinically important change in satisfaction with goal performance. Examples of goals that parents ranked as not being achieved included: improving communication skills, improving compliance, improving listening, decreasing temper tantrums, and improving social skills.

Table 4

Descriptive Data on the Canadian Occupational Performance Measure (COPM) (N=25)

	Pre	Post	Change	t
Performance				
Mean	3.69	5.90	2.21	-7.67**
Standard Deviation	0.99	1.57	1.44	
Range	2.25-5.80	1.50-8.60	-0.75-5.20	
Satisfaction				
Mean	3.29	6.13	2.84	-7.93**
Standard Deviation	1.22	2.09	1.79	
Range	1.0-6.60	1.50-10.00	-.40-6.25	

Note. Df=24; **$p < .001$

The results of the T –tests indicate that a statistically significant difference exists in the performance scores. This finding means that parents perceived an important change in their performance of the goal by the end of the program. The results also indicate that a statistically significant difference exists in the satisfaction scores. This finding can be interpreted as meaning that parental satisfaction with their ability to perform the goal changed greatly from pretest to post test.

Correlational analysis between MPOC and COPM. The 5 scales of the MPOC were correlated with performance and satisfaction post program scores of the COPM (Table 3). For performance scores, coefficients ranged from .34 to .43. A statistically significant relationship was found with performance scores post program and three scales of the MPOC: Enablement and Partnership, Providing General Information, and Providing Respect and Support. Coefficients ranged from .26 to .48 for the satisfaction scores post program and the five scales of the MPOC. The same three scales that were found to have a statistically significant relationship with performance were identified for satisfaction.

The change scores obtained on the COPM were also correlated with the mean scores obtained on the five MPOC scales. For change in performance, correlations ranged from .29 to .43 with a statistically significant relationship only for Providing Specific Information, and Providing Respect and Support. Correlations with change in satisfaction were lower, with a range of .10 to .39.

Chapter V

Discussion of Findings

On the perceptions of care measure, the CB program was rated very highly on three scales. These were: Providing Respectful and Supportive Care which includes treating each client as an individual rather than as a case and providing enough time to talk so that clients do not feel rushed; Partnership and Enablement which includes explaining reasons for treatments, explaining treatment choices fully, and enabling clients to choose when to receive information, the type of information they would prefer and which treatment they want; and Providing Coordinated and Comprehensive Care which refers to having a continuous relationship conducive to the expression and resolution of needs, and valuing continuity in services and the individuals providing these services.

Providing Specific Information About the Child and Providing General Information were given lower ratings by the parents indicating that parents felt that the program provided information sometimes (King et al., 1995). The items in the Providing General Information scale consider providing parents with information, both spontaneously and in response to questions, providing advice on how to get information, and providing information about services available in the community. For the scale, Providing Specific Information, the range of scores was from 2.2 to 7.0, indicating that some parents ranked the items very low. The items in this scale specifically relate to the provision of verbal and written information on the child's assessment and treatment sessions. The results on these two scales are surprising in that the program provides information specific to the child by encouraging all parents to observe assessment and treatment sessions, and the provision of written handouts and reports. General information is also provided in the weekly parent group and through written handouts. However, some parents evidently felt that not enough information was provided.

The results of the thematic analysis of the parents' comments may help to understand the lower ratings on these two scales. Many parents felt that their child's behaviour had improved more in the program than at home and parents wished the program could be longer so that they could have more time to learn and practice the various behavioural strategies. These results suggest that the parents may not have received enough specific and general information because of the short- term nature of the program, and the fact that the majority of the program was center based rather than home based. Therefore, even though the staff may perceive that they provide a great deal of information, the parents are asking for much more information or for information to be delivered in another format.

The comments that the parents made regarding having more home based intervention and a longer program have been reported by others. Mahoney et al. (1990) found a strong relationship between mothers' perceptions of the family centeredness of a program and the effectiveness of intervention services received. They also found that programs with home based components tended to have a greater family centered orientation. Yoshikawa (1994) reported that successful programs for children with behaviour problems must be at least 2 years in length, and involve both home based family support and center based educational daycare and preschool.

As hypothesized, perceptions of the program as family centered were significantly positively correlated with satisfaction scores. The CB program received high ratings by the parents on satisfaction. This positive relationship is in keeping with the theoretical literature and previous research. Caro and Derevensky (1991) found a similar positive relationship for a home based intervention for families who had children with moderate or severe disabilities. Jackson et al. (1978) and Styba et al. (1992) also found a positive relationship between parental satisfaction and parents being involved in all aspects of their child's care. Dunst, Trivette, et al. (1988) reported that if health care providers used the behaviours that are consistent with family centered care, families would be empowered and positive outcomes would result from the care that they received including satisfaction with care. Branspach (1986) also found that when parents perceived control over their child's program, they felt more satisfied with the program.

Other factors may be involved in the relationship between the family centeredness of a program and satisfaction. It may be important that parents have finally found a program that will listen and address their concerns. Many of these parents have been seeking help for an extensive period of time, being told that nothing is wrong or that their children will outgrow their difficulties. Another factor may be the parents' perceptions that their children have improved while attending the program. Parental satisfaction could be linked to child's development of skills as suggested by Kopec-Schrader et al. (1993) and Plapp and Rey (1989). A study that compares child -centered to family centered care is needed to examine these additional factors. Also incorporating qualitative methodologies such as interviews rather than rating scales to measure satisfaction would provide more information on the high satisfaction ratings received. Satisfaction questionnaires must be interpreted with caution due to the high levels of reported satisfaction caused by factors such as the halo effect (Tuckman, 1994) and social desirability (Lebow, 1983). The CB program has collected satisfaction information for the past few years and report that their ratings are always high. A factor that may be linked to satisfaction is that perhaps the parents are grateful for any services that they receive. Looking more closely at satisfaction might be beneficial.

As hypothesized, parental perceptions of care were also positively correlated with parental perceptions of goal achievement. In looking at the results obtained on the single question on goal achievement all parents felt that quite a few of their goals had been met. The results illustrate that there is a moderate relationship between goal achievement and enablement and partnership, providing specific information, providing coordinated care, and providing respect and support. When looking at the relationship between perceptions of care and goal achievement as indicated by the COPM post program satisfaction scores, a moderate relationship exists with goal achievement. The qualities most strongly related included enablement and partnership, providing general information and providing respect and support. The results suggest that there are two common qualities of family centeredness that are most consistently related to goal achievement. These two qualities are enablement and partnership, and providing respect and support, and these were also the ones most highly associated with satisfaction.

Enablement and partnership, and respect and support are linked to empowerment which is a key concept in family centered care. Dunst et al. (1994) list two characteristics of the health care provider that help to promote empowerment in the client or the family. The first, is the belief that people are competent or have the capacity to be competent. This characteristic is congruent with the quality of providing the client with respect and support. If you feel that someone is competent then you will most likely treat them with respect. The second characteristic is enablement, which refers to creating opportunities for competence to be learned or displayed. This is consistent with the findings here that the two qualities of care most associated with goal achievement in this study were providing respect and support, and enablement and partnership. Since these are two significant factors that lead to empowerment then it makes sense for them to be linked to goal achievement. The family that is empowered will be able to ensure that their goals are met. McBride et al.'s (1993) principles of family centered care also highlight the concepts of respect, support and partnership.

The positive relationships between goal achievement, partnership, and providing support are in keeping with the theoretical and research literature. Adubato et al. (1981) and Schriebman et al. (1983) both conducted studies which demonstrated that partnerships formed between therapists and families supported them in successfully working towards achieving their goals. Minke and Scott (1995) reported that models that stress enablement of families are based on the philosophy that family goals take priority and must be respected. In this study the CB parents set the goals, priorized them and then ranked them to measure achievement. Bass and Leavitt (1963) and Latham and Locke (1979) reported that goals are more likely to be successfully achieved when a person sets their own goals. Further studies are required to look more closely at this relationship to determine if other factors may be contributing to this relationship.

Conclusions

From the preceding discussion, the following conclusions are drawn:

1. Parental perceptions of care, specifically the extent to which a program is perceived to be family centered, are positively correlated with parental satisfaction in the Communication Behaviour Preschool Program.

2. Parental perceptions of care are positively correlated with parental perceptions of goal achievement in the Communication Behaviour Program. The qualities most highly related are enablement and partnership, and providing respect and support.

Limitations of the Study

The limitations of the study are as follows:

1. Care must be taken when generalizing these results to other situations because they are based on a single program.
2. The sample is small.
3. Since only self-report instruments were used to measure the variables studied the results are representative of the cognitive and emotional state of the subjects at the time of completion of the measures.
4. This is a correlational study so that only descriptions of relationships can be made. No causal inferences can be made.
5. The COPM has moderate interrater reliability. It would have been advantageous to do an interrater reliability study between the two psychologists who administered the COPM.

Implications of the Study

In this study, positive relationships were found between the family centeredness of a program and satisfaction with the program. A statistically significant positive relationship was also found between providing support and respect, enablement and partnership, and goal achievement. These findings suggest that there is a positive association between the CB program staff adopting the characteristics of a family centered model and enhanced parental satisfaction. The findings also suggest that it is two particular characteristics of family centered care that the CB program staff should consider adopting that are associated with goal achievement. These include providing the families with support and respect, and providing the families with the opportunities for enablement and partnership to occur. The parents who participated in this study indicated that the program provided information, both general and specific, sometimes. The CB team need to reexamine what information they provide and how they provide it.

The parents also identified three issues that are important to them and their families. First, they identified the need for more home based intervention to help them to generalize the strategies that they learned in the center based component of the program. Second, they identified the need for a longer program. Finally, parents identified the need for good follow up programs. These are three issues that the CB program teams need to consider in order to ensure that the needs of families are met.

Parental input is essential in understanding aspects of caregiving that they value and that will empower them in meeting their child and family's needs. To provide effective intervention to families who have children with behaviour difficulties it is essential to provide them with respect and support throughout the program. It is also essential to believe that they have the skills and the abilities to acquire the knowledge they require to help their families meet their needs and priorities.

Implications for Further Research

Further research is required to clarify parental perceptions of care that are associated with parental satisfaction and parental perceptions of goal achievement.

Replication and refinement of the present study would strengthen the results obtained. Recommendations for refinement include:

1. Increasing the size of the sample would add to the validity of the results. Also incorporating subjects from other programs would aid in the generalization of the results.
2. Collecting more comprehensive demographic characteristics on the sample would allow statistical analyses to see if there is a relationship between certain demographic characteristics and qualities of family centered care. Examples of characteristics that may be important include socioeconomic status, and support systems that presently exist.
3. It would be interesting to include the perceptions of the program staff and then to compare the family and program staff's perceptions of the family centeredness of the program and goal achievement.
4. Qualitative methods can be used to gather more in-depth information from the parents. For example, individual interviews or focus groups could be used to gather more comprehensive feedback from the parents.
5. The use of a comparison group based on another theoretical model would permit the evaluation of the independence of the family centered model by controlling for factors such as parent perceptions of their child's performance or the availability of a team willing to address their concerns.

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Appendix A

Information Letter

Dear Parent/Guardian,

I am interested in studying how you feel about the care you and your child receive while you are in the Communication Behavior Program(CB). I am also interested in knowing how satisfied you are with the care you received and how well you feel your goals were met while in this program. I hope that this information will help us to provide better treatment programs for children and their families.

During the home visit that you had prior to starting in the CB program you determined and ranked goals with the CB team. During the last week of the program the CB team will have you rerank your goals. They will also ask you to complete an eight item questionnaire that measures how satisfied you were with the program. These two measures are a standard part of the CB program. I am asking you to complete one additional questionnaire during the last week of the program. This questionnaire consists of 56 questions that measure how you feel about the care you received while in the program. This questionnaire takes about 20 minutes to complete. I am also asking for your permission to look at the goal measure and the satisfaction measure that you complete with the CB team.

If you are interested in participating in this study, please read and sign the attached consent form.

If you have any questions please feel free to contact me at 471-2262 ext. 2547.

Yours truly,

Josephine Longo Kimber BScOT
Occupational Therapist

Appendix B

Consent Form

Project Title: Parental Perceptions of Care Received, Satisfaction and Goal Achievement

Investigator: Josephine Longo Kimber BScOT
Occupational Therapist
Dr. G. Kysela Ph.D.
Professor, Educational Psychology, University of Alberta

Purpose:

1. To find out how parents feel about the care they received while in the Communication Behavior (CB) program
2. To look at how satisfied parents are with the care they received while in the CB program
3. To look at whether parents felt that their goals were met while in the CB program

Procedures:

During the last week of the program you will be asked to complete a questionnaire that measures how you felt about the care you received while in the CB program. This will take about 20 minutes. I will be looking at your completed goal and satisfaction measures that are a standard part of the CB program.

Risks/Benefits

The results of this study will help us to provide better care for future children and their families. There will be no direct benefits for participants. There are no known risks involved in participating.

Confidentiality

Records from this study will be kept confidential. No names or other identifying information will be released. All data will be stored in a secure location. Any report published about this study will not identify your child or yourself by name.

I voluntarily agree to participate. I may refuse to answer any questions. I am free to withdraw my consent and stop my participation at any time. If I decide not to participate or I withdraw from the study, this will not affect present or future care for myself or my family.

I have read this form and this project has been discussed with me. All of my questions about this study have been answered to my satisfaction. I understand my involvement in this study. I have been given a copy of this consent form.

If I have any further questions I can contact Josephine Longo Kimber at 471-2262, ext. 2547. If I have concerns about how this research is being done, I can contact the office of Research Services at 471-2262, ext. 2500.

Signature of Participant(s) Date   Signature of Witness Date

The person signing this form appears to understand what is involved in the study and voluntarily agrees to participate.

Signature of Investigator Date