

ISOLATED BUT NOT ALONE: EXAMING AN INTERNET-BASED  
SELF-HELP FORUM FOR FAMILIES OF PREMATURE INFANTS

by

ELIZABETH T. KENNEDY

(Under the direction of Cynthia O. Vail)

On-line support groups have become an accepted place for families to seek support concerning their children with special needs. Recently, an increased survival rate of the premature infant has been associated with stresses and disruptions in the lifestyles of families. Research evidence is almost non-existent with regards to studying the characteristics of online support groups for parents of children with chronic health problems and for understanding the families' point of view with regards to prematurity. The purpose of this qualitative study, using an ethnographic design, was to describe and understand the lived experiences of families who participate in the Premie-L Internet support group for families with premature children. The theoretical framework for analysis used a symbolic interactionist theoretical perspective. The presented findings provide evidence that these virtual communities produce global, intercultural commonalties that cannot be neatly separated into offline and online realities. The stories that the family members told, as observed through computer-mediated communication, confirmed that there are long-term implications that effect the well-being of the families as related to on-going health problems, forced relationships with professionals, and an overlay of on-going psychological stress. Positive resources gained from the online support group were informational and social support. Themes that arose from the data show that meaningful interaction on the listserv provided opportunities to problem solve

from collective experience that influenced the development of self-efficacy and control over their individual situation. Educational implications stress the importance of professionals understanding the families' perspective and to understand the benefits of online support groups as a positive coping resource. Outcomes provide evidence to assist with the development of public, educational, and health policy to support the families in a life-span approach. The need to follow these children and families into the later school years and young adulthood was implicated.

INDEX WORDS: Preterm infants, Low birthweight outcomes, Online support groups, Family perceptions, Family resources and adaptation, Professional-family relations, Family well-being, Human agency, Advocacy, Symbolic interactionism, Model of family stress and adaptation

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ELIZABETH T. KENNEDY

B.S., Georgia State University, 1978

M.M.Sc., Emory University, 1991

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ELIZABETH T. KENNEDY

Major Professor: Cynthia O. Vail

Committee: John Langone  
Claire Hamilton  
William Quinn

Electronic Version Approved:

Maureen Grasso  
Dean of the Graduate School  
The University of Georgia  
May 2004

## DEDICATION

In loving memory, this study is dedicated to my mother, Corinne Edwards Templeton

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## CHAPTER 1

### INTRODUCTION

Rapid evolution of medical technology in the past decade has led to increased survival of premature infants, especially those with lower birth weights or increased prematurity ENRfu(Goldson, 1997). There are approximately 400,000 premature births each year in the United States ENRfu(Statistics, 2002). Numerous medical problems occur as secondary complications of prematurity ENRfu(Dusick, 1997). The complications effect respiratory outcome, growth and physical development, hearing, and vision. Some of the problems are short term and others have longer lasting effects. The increased survival rates of the extremely premature infant have not been without cost. A sub-population of vulnerable children is now evident. These children have been referred to as “the new survivors” of the 90’s ENRfu(Kaplan & Mayes, 1997).

Caring for these infants is associated with unavoidable stresses and disruption in relationships and lifestyle of the family. The success of current healthcare has been said to be primarily based on the ability of family members to provide care for these infants ENRfu(Hilbert, Walker, & Rinehart, 2000). The enormous responsibility assumed by the family for the physical well being of their infant is often detrimental financially, psychologically, socially, and physically to the family. Over the past several years, health professionals are becomingly increasingly involved with families who suffer the emotional toil of coping with prolonged care of their premature infant.

The information we have available regarding caregivers and children is primarily based on research from families with children with developmental disabilities not requiring skilled medical care, illness requiring lengthy hospitalizations, or acquired

trauma not related to birth ENRfu(Beresford, 1993; Day & Alston, 1988; Hilbert et al., 2000; Horn, Feldman, & Ploof, 1995; Melnyk, 2000; Sherman, 1995). The perception of stress and the ability to successfully adapt are closely intertwined because a family member's perception of stress directly affects the well-being of the family. The paucity of existing research regarding the individual family's perception of stress related to prematurity supports the need for qualitative research that seeks to portray the viewpoint of the families. Knowledge gained from this type of study may be used to develop more effective support systems for these families.

Increasingly, families with children with special needs are seeking guidance and relief from self-help support groups ENRfu(King, Stewart, King, & Law, 2000). Regardless of age, disability-related self-help groups have become so popular that approximately 25 million people in the United States are estimated to have used these groups in their lifetime ENRfu(Kessler & Mickelson, 1997). The literature provides evidence that groups that seem to be the most successful are the ones that utilize the leadership of peers that have experienced similar circumstances ENRfu(Braithwaite, 1999). Recent advancements in medical care and changes in healthcare philosophy, producing high anxiety related to diagnosis, medical intervention, and unclear prognosis, are further propelling people to seek help from these groups. Self-help groups for parents with children with special needs have been shown to be quite successful in providing basic support, information, shared experience of camaraderie, and advocacy ENRfu(King et al., 2000).

Specific to prematurity, the parent-to-parent support group model is a widely accepted model by neonatal intensive care units (NICU) professionals ENRfu(Lindsay, 1993). These groups are traditionally held in a face to face (FTF) format that is held within the hospital that the NICU is housed. The problem with these groups is that the FTF format is not flexible to meet the individual needs of families who have difficulties related to transportation, distance, time, family, or work.

With the rise in the use of the Internet, families with children with special needs have begun to network with other families through the Internet and have formed support groups ENRfu(Han & Belcher, 2001). These parent led Internet support groups mirror the philosophy of the typical FTF parent to parent support groups that have flourished since the 1970's ENRfu(Santelli, Poyadue, & Young, 2001). The benefits of these online groups are that they are able to transcend the difficulties of distance, time, and the need for childcare.

An example of one of these Internet support groups is Parents of Premature Babies, Inc. (Preemie-L). This group is " a nonprofit foundation that provides support for families with children born six weeks or more before due date." ENRfu(Casey, 2002). The uniqueness of this Internet community is that it began as an Internet discussion site but quickly expanded into a community of resources that transcends the online and offline experiences of these families. Through this Internet support organization, a family is able to participate in a discussion forum, to obtain a mentor, to receive newsletters, to attend offline reunions sponsored by the organization, to obtain answers to frequently asked questions, and to access medical and information related to prematurity.

The active nature of online disability-related peer support groups serves as a reminder that there has been a change in the disability paradigm over the past 20 years ENRfu(O'Day & Killleen, 2002).The focus used to be that disability model entailed a diagnosis of limited function. Now, the model has changed and recognizes the complexity of disability and embraces the paradigm that there is an interaction between the individual and their environment. This is much more of an ecological approach rather than the total focus on the limitations of the disability of the person. Alternative models of disability are being proposed that stress the necessity of understanding the experience of disability from the family's perspective (Brett, 2002). Current healthcare philosophy is compelling consumers to assume more responsibility for their outcome. This change has resulted in families looking for support outside the traditional professional network.

Historically, paradigms were based on the assumptions of the disability or medical model that believed that the goal of rehabilitation was to "fix" the individual with the disability. The current disability paradigm, basing assumptions on functional outcomes, recognizes the complexity of disability and focuses on an individual's need to function competently within the world. The variables that have been shown to effect an individual's ability to function well in society are "... interdependence of human interaction, cultural attitudes, institutional processes, and public policies ENRfu(O'Day & Killleen, 2002)(p 2 of 9). As the disability paradigm continues to evolve, we are becoming more aware that the paradigm includes the whole family as a system and not just the individual with the disability.

Research lending clear specific insight into specific needs and characteristics of the families of premature infants, especially the extremely low birthweight infant, is sparse because of the recent rise in the survival rate of the very low birthweight infant. Prior to this proposed study, I subscribed to the Premie-L Discussion Forum to gain a better understanding of the family's point of view. The computer-mediated communication (CMC) fascinated me and the power of parents helping parents was evident. There was evidence that this was a "real world" community of people with connections on-line and offline. Messages from group members underscored an important function of the list that was to bring isolated families together with others to discuss similar concerns. I observed information being exchanged, an outlet for emotional expression, encouragement that was provided during difficult times, and an arena to tell their stories to those who really care. There seemed to be a genuine caring atmosphere for each other on the list. Reading the messages on the Premie-L peaked my interest to learn more about this Internet community of families. I sensed that a wealth of specific information about the characteristics and perceived needs of the online members could be obtained through an qualitative ethnographic study of this web site. My curiosity led me to the implementation of a pilot study whose primary purpose was to

discover how an on-line support group for families with premature infants was able to support an individual family in ways that enhanced their caregiving abilities and the well-being of their child and family.

Qualitative research is well suited to address the complexities of prematurity and the well-being of the family. The strength of qualitative research is that it provides a mechanism to capture perspectives of individuals affected by disability ENRfu(O'Day & Killleen, 2002). This type of research seeks to understand multiple realities and most importantly captures the perspectives of the 'stakeholders'. Ethnography, a specific qualitative design, provides a thoughtful method for understanding what is going on within a specific social system or culture ENRfu(Wolcott, 1999). Ethnography embraces the values, the beliefs, and the daily experiences of those who interact within the culture.

Finally, computer-mediated communication (CMC) has changed the world's view of social interaction and cannot be ignored as a powerful context for ethnographic research ENRfu(Hine, 2000). Now, the Internet is rapidly becoming accepted as a place "... where culture is formed and reformed." (p. 9). Contemporary researchers and sociologists understand that the culture of the Internet cannot be neatly separated into offline and online context ENRfu(Miller & Slater, 2001). Traditional ethnographic research has provided evidence that social interaction within a culture facilitates changes in perceptions that ultimately lead to acquired new identities and changes in behavior ENRfu(Spradley, 1970). Those family members who are participants of the Premie-L seem to be empowered to assume a greater role in the outcome of their family and child.

An ethnographical cultural interpretation will provide insight into the culture of families with premature infants that participate in an Internet support group. In summary, the increase in the survival rate of very premature infants over the past decade has created an atmosphere of uncertainty that has led to anxiety and turmoil in the lives of many of these families. There is a need to understand the complexities of the prematurity experience from the families' perspective because of the limitation in available research

in this area. Effective programs and policies to support these families cannot be developed without understanding the perceptions of the family. The Preemie-L, an Internet support group for families with premature children, seems to be filling the needs for some of these families. Findings from the pilot study are integrated into the study that follows to provide a more complete understanding of these families.

## **Conceptual Framework**

### **Topic and Research Problem**

The topic of interest is families with premature infants and the challenges that they face. There is a lack of knowledge and understanding of the complexity of these families' lives and their actual needs by professionals who work with them.

### **Purpose**

The purpose of this study, using an ethnographic design, is to describe and understand the lived experiences of families who participate in an Internet support group for families with premature children. The outcome of this study will result in rich cultural descriptions of these families' lives through the use of computer-mediated communication. The intended audience is professionals who work with these families who have premature children.

### **Significance**

Limited research exists on this topic because of the relative newness of the issue ENRfu(McCaleb & Luther, 1996). What we have realized is that the growing number of premature children dependent on medical technology to sustain life is challenging the social, economic, and political systems of our society ENRfu(Palfrey et al., 1991). Ethical issues have been raised about quality of life and the need to provide support for these families ENRfu(Noyes, Hartmann, Samuels, & Southall, 1999; Palfrey et al., 1991; Thyen, Terres, Yazdgerdi, & Perrin, 1998). The information that we have regarding caregivers and children is primarily based on research regarding families with children with developmental disabilities ENRfu(Beresford, 1993; Day & Alston, 1988; Hilbert et

al., 2000; Horn et al., 1995; Melnyk, 2000; Sherman, 1995). The children in these studies typically did not require skilled medical care; did not require lengthy hospitalizations; and did not have a disability related to birth. A possible benefit of this study may include improvement in quality of life for parents and families.

The outcome of this study should provide information for professionals, especially early interventionists, regarding the benefit of online support groups for families with premature infants. Specifically, the study should provide knowledge regarding the online participant's values and needs for their families to promote genuine collaboration between families and professionals, to improve delivery of support services for these families, and to inform decision-makers regarding policy in education and healthcare.

### **Research Questions**

The expectations of this study are that the beliefs, values, and the needs of families who are participants of an online support group for families with premature children will be captured through the implementation of a descriptive cultural study.

Specific research questions raised for this study are:

- 1) What is the community and culture of the online support group?
  - a) How does the online support group function (e.g. norms, rules, etc.)?
  - b) Who actively participates in the online support group (e.g. audience, sense of identity and association)?
  - c) What relationships, themes, symbols, behaviors, and interactions are observed in the online support group?
- 2) What patterns of content emerge within the messages of the group?
  - a) What impact has the premature birth experience had on the families from the online support group members' point of view?

- b) What are the perceived needs from the point of view of the members?
  - c) What types of support are available to the members of the online group?
- 3) What are members' perceptions regarding the role of the Preemie-L to enhance the family's caregiving ability for their child and well-being of the their child and family?

### **Assumptions**

My assumptions are (a) that families with premature infants are under stress that affect their ability to care for their child and their quality of life; (b) there is a gap between standard of medical care provided and what the families perceive they need; (c) there is a lack of specific knowledge regarding what families need; and (d) the Preemie-L discussion provides the vehicle to empower families that results in improved coping skills and quality of life for both child and family.

### **Theoretical Framework**

Theory is a "cluster of ideas" that provides us with an explanation or a general way of thinking ENRfu(Klein & White, 1996). Theories are subjected to rules of organization as they attempt to explain relationships in family development, including functioning and process. Research, based on various theoretical and conceptual frameworks, is present in the literature with regards to the adaptation and feelings of well-being of parents in response to their children's disabilities ENRfu(Beresford, 1993; Caldwell, 1988; Day & Alston, 1988; Deardorff, 1992; Horn et al., 1995; Hunfel, Tempels, Passcheir, Hazebroek, & Tibboel, 1999; Lavee et al., 1985; May & Alston, 1988; McCaleb & Luther, 1996; Noyes et al., 1999; Sherman, 1995; Smith, 1991; Stephenson, 1999; Sterling et al., 1996; Thyen et al., 1998). Most of the research relates to general disability and stress and not particularly to the aspects of prematurity. A theoretical model that provides a framework to support an explanation of how individual

families adapt to the strain of on-going stress related to a single crisis event is The Double ABC-X Model of Family Stress and Adaptation ENRfu(McCubbin & Patterson, 1983). An understanding of the original family stress model is necessary to have a full understanding of the later model. Prior to the Double ABC-X, the original family stress theory model provided the framework to explain a family's ability to cope and respond when challenged by a single stressful event ENRfu(Hill, 1965). This theory, simply known as the ABC-X model, established X as the outcome variable; with the combined interaction of A (the stressor), B (family resources), and C (family's perception of the events) having an influence on the outcome. McCubbin and Patterson (1983) revised the original theory and developed the Double ABC-X to describe a family's response to the cumulative effect of stressors over time. This theory added the variable, aA, to describe the pile-up of stressors experienced by families after the original stressor. An additional resource variable, bB, was added to the theory to describe existing and new resources needed by the family to successfully cope with the pile-up of stressors. The term, cC, was added to the model to describe the family's perception of events that included the pile-up of stressors, existing and new resources, and the response to the initial crisis. As in the original model, xX, the outcome variable for the Double ABC-X Model, describes the psychological well-being of the family as influenced by the interaction of the stressors, the acquisition of new resources, and the coping skills of the family. Family adaptation is seen as a continuous variable with a family striving to achieve balance over time ENRfu(Lavee et al., 1985).

Concepts from the Double ABC-X Model of Family Adjustment and Adaptation have been used in previous research to explain the relationships between stressors, coping, and psychological well-being in families with children that are technology-dependent ENRfu(Stephenson, 1999). The initial stressor (a) is the birth of a child and the transition to parenthood that places a strain on a family's structure. Resources, may include financial resources, social support, family resources that help cope with the birth

of the infant. The birth of a premature infant with medical complications is more complex. A pile-up of stresses (aA) occurs over time as the family strives to adapt to parenting a child with special needs. The family must seek new resources (bB) to adapt to the on-going stresses related to the child. Online self-help groups may serve as new resources to help the family positively adapt to the changes within the family. The online support group has the capacity to provide new resources of social support, information, and practical wisdom of collective experience that may serve to increase the competency of the caretaking skills of the family and the well-being of the family. The model is dynamic and allows for the changing needs of the family. The online support group is also dynamic. The virtual community has the availability of different resources for a family and has the capacity to change over time as needs arise from the members. The family adaptation model is a narrowly focused model of framework. A limitation of the Double ABC-X Model of Family Adaptation is that that the theory is more relevant to explain the adaptation of an individual family but does not adequately explain the success or sustaining power of the virtual community. The use of the family adaptation model to explain how an individual uses the online group as a new resource assumes that an individual has Internet access and is Internet savvy.

In addition to the Double ABC-X Model of Family Adaptation, the theoretical model of Symbolic Interaction Theory (SIT) may be used to support the group dynamics that apply to the listserv model. SIT embraces an interpretive approach to understand the family and allows for the uniqueness of individuals and families in a well-functioning family ENRfu(Klein & White, 1996; LaRossa & Reitzes, 1993). The model does not have a definition for deviancy and assumes a measure of normalcy in every family. The foundation of SIT is not value laden but is based on the primary assumption that individuals construct meaning through communication with the goal of interaction to create shared meaning. The model embraces the assumption that meaningful interaction occurs when people share common interpretations of symbols that they exchange in

interaction. These meanings are assumed to change over time as interpreted through the interactive communication process. Examples of symbols or rituals/traditions on the listserv are: introducing self to the group, describing the child's birth story, announcement of milestones (i.e. first birthdays, first time off oxygen), abbreviations that denote aspects of disability, requests for prayer, and sharing of concern for others). This theoretical model acknowledges multiple realities and is based on assumptions that allow for an individual to use an online support group to develop roles through communication that best fit the reality of their family. SIT assumes that the future is not pre-determined. This assumption provides an explanation for the concept of resiliency and the diversity of responses in families with premature infants along with the changing dynamics of the listserv. Symbolic interaction and the Double ABC-X are similar because both theories take into context the multifactorial subjective and objective variables that work together to explain a family's behaviors.

Critics of SIT state the theory is too vague and places too much value on the subjective perceptions and understandings of those being studied. Critics feel that SIT lacks quantitative testing of key concepts that define the theory ENRfu(LaRossa & Reitzes, 1993). Traditionally, symbolic interactionists have been resistant to developing a formal framework with specific operational terms because the model is founded on an interpretive model. This type of theory is most applicable to qualitative family research that seeks to understand how families interpret and make meaning of their lives ENRfu (Rosenblatt & Fisher, 1993).

## CHAPTER 2

### REVIEW OF THE LITERATURE

This review of literature will begin with current knowledge related to associated stresses of prematurity on the family and the how families have been shown to cope with these challenges. Next, a relationship will be demonstrated between the different types of resources available to a family and a family's ability to cope with a difficult situation. As part of the review of coping strategies, the discussion will provide a basis for understanding the importance of online support groups as a resource related to the well-being of the families. Studies included for review were selected from data base searches using ERIC, CINAHL, MEDLINE, PsychINFO, and Google. Manual searches of related literature in the areas of prematurity, computer-mediated communication, qualitative research, and family development were also performed.

#### **Associated Stresses for Families with Premature Infants**

Health-related needs. Major issues are related to family life after discharge from the neonatal intensive care unit; with research showing that discharge is a point of significant stress and dysfunction in families ENRfu(Robinson, Piarak, & Morell, 1999). Numerous guidelines exist to prepare the family to manage the care of their child after discharge but concerns are now being raised by professionals that the family is not obtaining the type of support they truly need or desire ENRfu(Cavendish & Jackson, 1999; Davis, Logsdon, & Birkmer, 1996; Hill, 1993; Lemons et al., 1998; Swanson & Naber, 1999). Because of the timeliness of this issue in our society, there have been calls for further research to discover the genuine needs of these families ENRfu(Sokol, 1995).

Coping with multiple, health-related issues creates enormous stress on the families as they juggle the provision of skilled medical care with the everyday demands of life ENRfu(Palfrey et al., 1991). The integrity of the family system is at risk because of high medical expenses, the loss of employment or career goals to care for the child at home, psychological risks related to the stressful situation, and limited time to spend with spouse, other children in the family, or in leisure activities ENRfu(Deihl, Moffitt, & Wade, 1991; McCaleb & Luther, 1996; Miller, Rice, DeVoe, & Fos, 1998; Sherman, 1995). Isolated from typical social structure in society, many families express feelings of helplessness and hopelessness ENRfu(Miles & Holditch-Davis, 1997; Smith, 1991).

The complexity of the child's condition requires the families to be comfortable with a variety of related medical conditions and medical equipment ENRfu(Stephenson, 1999). Examples of equipment are heart and breathing monitors, oxygen and ventilation equipment, and feeding tubes. Families report stress directly related to the use of the equipment ENRfu(Stephenson, 1999). The equipment is often complicated and the families feel that they are not adequately trained and lack technical assistance to operate or troubleshoot when problems occur ENRfu(Deihl et al., 1991; McCaleb & Luther, 1996; Stephenson, 1999). A fear commonly reported by parents is that of not hearing the alarms on the equipment ENRfu(Stephenson, 1999). In addition, the caregivers report fatigue from the constant attention that must be paid to operating the technical equipment ENRfu(Stephenson, 1999). The families experience a lack of mobility, as most of the equipment is difficult to manage outside of the home. This mobility problem further perpetuates the problem of social isolation in families.

Health problems have been linked to the strain of caregiving for these children. Mothers have been shown to have an increased risk for health problems secondary to the stress and anxiety of dealing with the medical technology ENRfu(McCaleb & Luther, 1996). Thyen et al, (1998) examined the health outcomes of 54 mothers with children who were chronically dependent on technology. These mothers were matched with a

control group of 54 mothers who had infants who were hospitalized for acute illnesses. Dependent measures analyzed in this study were maternal health, emotional well-being, severity of the child's condition, family functioning, social support and socioeconomic indicators. The mothers with technology-dependent children had statistically more health and emotional problems. Almost half of the mothers exhibited clinical depression. The quality of life was affected in the families of the chronically ill children because these families had significantly fewer opportunities for recreational and cultural activities.

Collaboration with professional healthcare providers. The relationship between the family caregiver and professional care provider is often a source of strain for families ENRfu(Fitton, 1994; Stephenson, 1999). Managing complex medical problems requires families to collaborate with professionals from different disciplines in their homes ENRfu(Deihl et al., 1991; Sterling, Jones, Johnson, & Bowen, 1996; Thyen et al., 1998). In their research of the perspectives of pediatric healthcare professionals, Latourneau and Elliot (1996) found that the philosophy of family-centered care is accepted as the standard for healthcare practice but actual implementation of the philosophy by service providers is lacking in many situations. Their research studying the implementation of family-centered care provided evidence that family-centered care seems to be more highly valued by the families than the formal healthcare providers. The discrepancy between the standard of care and actual care provided has been blamed on the fact that professional healthcare providers make decisions based on the perceived needs of the child and family and do not involve the families in the decision making process ENRfu(Wesley & Buysse, 2001). The professional is observed to be acting in the best interest of the family because they feel that the family does not have adequate knowledge to make informed decisions. In reality, the family caregiver seemingly has the support of professional caregivers yet may feel socially isolated and frustrated. As a result, the family seeks additional support to compensate for the narrowly focused emphasis on the infant and not the wider needs of the family ENRfu(Pickel, 1991).

Financial costs. The direct and indirect costs of providing care for the technology-dependent child places a financial burden on the family and society ENRfu(Miller et al., 1998). Direct costs are related to hospital billings, outpatient medical follow-up, home health care, equipment, medications, special diets, transportation, lodging during clinic visits and hospitalizations. The indirect costs involve missed days of work and changes in employment. Financial ability of the family to manage medical costs has been shown to be a strong predictor of stress in the family ENRfu(Stephenson, 1999). The financial plights of these families have not totally gone unnoticed by government funding agencies. Medicaid programs that previously provided medical assistance only to children with low income have had to adjust eligibility requirements to serve children with developmental disabilities who incur high medical costs ENRfu(Conway, Jacobson, & Stoneman, 1998). Often it is very tedious to obtain eligibility for these programs and this adds to the stress of the families.

Financial issues are universal but may have specific problems related to geographic region. The previous discussion provided an insight into financial problems primarily encountered by American families ENRfu(Conway et al., 1998; Miller et al., 1998; Stephenson, 1999). Research projects looking at families' reports of stress caring for technology-dependent children under national healthcare systems overseas found that these families did not report financial cost as a stressor ENRfu(Kolk, Schipper, Hannewalk, Casari, & Fantino, 2000; Noyes et al., 1999). The existence of a national healthcare system is thought to explain the difference ENRfu(Kolk et al., 2000). Though not expressing financial cost as a major concern under a national healthcare system, a study from the United Kingdom found that families did express concern about the lack of autonomy concerning medical decisions and long-range implications ENRfu(Noyes et al., 1999). These studies show that economic strain is not just an issue unique to the United States and demonstrates the universality of financial issues for families caring for children with special needs.

Family management demands. Management of these complicated medical issues creates enormous stress on the family structure. The difficulties associated with family management were first illustrated in a focus group interview with parents of children, ages birth to 21, that required 24-hour medical care at home. ENRfu(Deihl et al., 1991). Deterioration of the family structure was one of the greatest concerns to these families. The comments from the families illustrated that caregiving impacts all family relationships. Performing routine errands, such as grocery shopping, were not possible unless someone was at home to care for the child. The spouses spoke of having little time alone together and when they were alone they found that they were unable to talk about anything but their child. Divorce rates among parents of children with disabilities are higher than that of the population of parents with typical children ENRfu(Beresford, 1993).

This section highlights the on-going responsibilities that must be managed to successfully function as a family when caring for a child with medically complex needs. The preceding section described the associated health-related stressors that a family encounters and provides the background to understand the need for resources and coping strategies. The next section will focus on the relationship between a family's ability to cope under stress as mediated by resources available to them ENRfu(Beresford, 1993; Deardorff, 1992; Lavee, McCubbin, & Patterson, 1985; Stephenson, 1999).

### **Family Resources and Adaptation**

Research has shown that resources are a determinant of how well a family will cope in response to a stressful situation and which strategies that family will use in adaptation ENRfu(Beresford, 1993). These resources refer not only to existing resources but also to new resources that the family acquires in response to on-going stress. Resources may be categorized into internal personal resources and family system resources or social support ENRfu(Beresford, 1993; Deardorff, 1992; Lavee et al., 1985). Coping is defined as the process that one goes through to mediate the effects of stress.

Coping should be considered as a management process and not a mastery process since a person or family cannot possibly master all problems in life ENRfu(Beresford, 1993).

Overall, coping includes a complex interaction between an individual and the environment that ultimately affects the sense of well-being of the individual and the entire family.

Personal resources. Personal resources include both physical and psychological variables ENRfu(Beresford, 1993). Examples of personal resources are physical health of the caregiver, educational level, beliefs and ideologies, personality traits, previous coping experiences, competency in caregiving, marital satisfaction, satisfaction with life, and parenting skills. Personality variables such as optimism and humor are regarded as important defense mechanisms in positively adapting to a stressful situation. This category of resources includes a person's overall approach to life. For example, people that sought positive aspects in their child have been shown to have an easier adjustment to their child's disability. During the time surrounding a crisis birth event, families may be particularly vulnerable to guilt and self-blame regarding the child's condition. This vulnerability is not considered pathological but may hinder the process of coping with the stressful event. Resources do not always have the same mediating effect. For instance, families have been shown to use the support of prayer and their religious belief system to interpret and define the birth experience of their child. In contrast, other families have been observed to question their belief system that would allow the birth of an infant with a disability. The wide range in available personal resources explains the adjustment variability as observed in families as they attempt to mediate stress in their lives. This discussion highlights the importance of examining personal resources in the context of the individual family and demonstrates the "one-size fits all" mentality regarding provision of family-centered care is not appropriate.

Social support. The second category of coping resources is located within the social context of the family. Social support includes marriage partners, extended family

and friends, economic resources, and community support services ENRfu(Beresford, 1993). The availability of social support has been shown to be a coping resource in families with children with disabilities ENRfu(Beresford, 1993; Miles & Holditch-Davis, 1997). Types of social support are categorized into levels of support that help define the intimacy of support from within the family to the environment outside the family. The first level is considered to be close family members and friends with the second level including neighbors and more distant friends. The third level of support includes formal and institutional support that is considered infrequent support.

Positive social support is observed in families that have higher perceived life satisfaction levels within the family, have a cohesive family structure, are adaptable to a variety of situations, and have the ability to express emotions within their families ENRfu(Beresford, 1993; Hawley, 2000; Stephenson, 1999). A strong marriage relationship assists a family in coping with stress but the on-going stress of caregiving for the child causes marriages to be vulnerable. The build up of demands within a family has been shown to increase relational strain within a family ENRfu(Stephenson, 1999). Families that are able to develop strong intimate social supports are more likely to withstand pressure within the family.

Another source of stress in marriages may arise from differences of opinion related to change within the family. Assuming the responsibility for care of a chronically ill family member forces change within a family ENRfu(Deardorff, 1992). The initial change is unsettling as the family is at first thrown off balance with the new demands placed upon the family. This change is dynamic and continues as a process of adaptation over time as the family seeks to restore balance. As a process of restoring order, one family member is generally designated the primary caregiver ENRfu(Day & Alston, 1988). The decision to assume the role of family caregiver is typically “unplanned, unexpected, and not by choice” ENRfu(Seltzer & Li, 2000).

Much of what we know regarding caregiver stress is based on the outcome of research from caregivers caring for elderly relatives with chronic illness, such as Alzheimer's Disease ENRfu(Hughes, Giobbie-Hurder, Weaver, Kubal, & Henderson, 1999; McConnell & Gallant, 1999). A hierarchy of caregiving, influenced by family structure, has been documented to exist within families ENRfu(Seltzer & Li, 2000). This hierarchy appears to be influenced by family structure. Though multiple family members may provide caregiving assistance, one family member typically assumes most of the responsibility for caregiving. This primary caregiver is often the only caregiver ENRfu(Day & Alston, 1988). Doty and colleagues (1998) surveyed informal primary caregivers providing eldercare. As other researchers had found, female members of a family typically assume this role of primary caregiver ENRfu(Beresford, 1993; Day & Alston, 1988; Seltzer & Li, 2000). Employment status did not seem to effect the hierarchy of caregiving status though women in this study were older (ages 65 and older) and more likely to have left the work force. A working age male primary caregiver was rarely found ENRfu(Doty, Jackson, & Crown, 1998). The women in the study, though aware and questioning of the fairness of assigned gender roles, were still strongly committed to the role of caregiving ENRfu(Doty et al., 1998). These conclusions may not generalize to younger women who are mothers since most of the women in the study were ages 65 and older and were more likely to leave the work force.

Supports from formal agencies are valuable resources but services not tailored to the individual needs of the family are not beneficial ENRfu(Noyes et al., 1999). As previously discussed in the topic of associated stress, formal support that emphasizes development of family-professional partnerships can be a powerful resource for the family ENRfu(Fitton, 1994; Stephenson, 1999; Turnbull, Turbiville, & Turnbull, 2000). This support includes quality communication between the family and professional caregivers that has been shown to be a positive indicator for reducing stress in families ENRfu(Fitton, 1994). Noyes (1999) et al. studied social support from a multidimensional

construct with parents who cared for ventilator-dependent children. The results of this study found that social support was found to have a general positive effect on maternal well-being but maternal appraisal of the support was observed to differ according to the individual family. This means that the support did not adequately meet the need for all families. Recently, there has been criticism of the public policy of social support. Critics are saying that blanket institutional support does not provide adequate resources to meet all the complexities of individual family requirements ENRfu(Sherman, 1995). There is an implied challenge to further examine individual families' *perceived* needs for social support to be able to develop quality support programs that meet the *individual* needs of the family.

The information we have regarding caregivers and children is primarily based on research from families with children with developmental disabilities not requiring skilled medical care, who don't have illness requiring lengthy hospitalizations, or acquired trauma not related to birth ENRfu(Beresford, 1993; Day & Alston, 1988; Hilbert et al., 2000; Horn et al., 1995; Melnyk, 2000; Sherman, 1995). We cannot assume that families with premature infants have the same resource needs. Personal experience with an online group for families of premature infants has provided me with insight that the stressors presented in the review of literature are very applicable to today's families. Future research is indicated to study the needs of families with premature infants with complex medical needs.

### **Perception of Stress and Adaptation**

Perception of stress is related to more than one variable. The impact of caregiving is partially objective and partially subjective ENRfu(Goldson, 1997). Variables that have been shown to impact the caregiver's perception of stress are caregiver age, race, and gender ENRfu(Cain & Wicks, 2000; Hughes et al., 1999).

Also, preexisting problems in the family appear to influence a family's perception of caring for a child with disabilities ENRfu(Miles & Holditch-Davis, 1997). These

preexisting problems may relate to personal and family issues, ethnicity, socioeconomic issues, personality traits, social support, previous history with disability, and birth history of the child born with disability. The resilience of a family to cope with stress has been characterized by a family's ability to withstand and grow under stressful conditions, to have the ability to emphasize strengths and resources, and to recognize the importance of having positive perceptions about adversity ENRfu(Hawley, 2000). The resiliency variable does help explain the variability in family outcome to stress.

Perception of support may not always be obvious to the outsider. An example is that mothers of children with illnesses that have large support networks sometimes report feeling lonely ENRfu(Beresford, 1993). There is a tendency for professionals to base assessments of the quality of support resources for families on accessibility to support systems without assessing the perception of the resources by the family. For example, a pre-existing resource system that does not include individuals who have experienced having a child with disabilities may not be able to provide adequate support. Finally, social pressures appear to have an influence on perceived stress ENRfu(Rogers, 1999). Social pressures seem to place strain on the family caregiver to be "good" caregivers. The added pressure, whether self-induced or not, causes further stress because the family caregiver often perceives that they are never measuring up to the level of societal or health professional expectation.

During the past decade, several studies have focused specifically on the perception of needs and well-being of the primary caregiver of the child with assisted or technology dependence ENRfu(Deihl et al., 1991; Noyes et al., 1999; Stephenson, 1999; Thyen et al., 1998). Stephenson (1999) compared the well-being of families (n = 172) of healthy infants (n = 87) with infants that were technology-assisted in the home (n = 85). The conceptual framework of this study was based on the Double ABCX Model of Family Adjustment and Adaptations ENRfu(McCubbin & Patterson, 1983). The following self-report assessment tools were used to quantify family well-being: Family

Inventory Life Events (FILE) ENRfu(McCubbin, Patterson, & Wilson, 1983) measured pile-up of family stressors and strains; The Family Crisis Oriented Personal Evaluation Scale (F – COPE) ENRfu(Caldwell, 1988) identified problem solving strategies in 7 different situations; and The Family Well-being Assessment Scale (FWB) ENRfu(Caldwell, 1988) was used to measure family life, role function, and vulnerability. The outcome of this study showed the families with children that were technology-assisted had statistically higher scores in pile up of stressors and higher scores in coping scores as compared to the families with healthy infants. An interesting outcome was that levels of coping and levels of pile-up were not significantly correlated in either group. Primary caregivers with the same levels of stress seemed to vary in their self-perception of well-being. This finding continues to emphasize the need for intervention and research to be directed towards perceived individual family needs.

From the United Kingdom, another study researched the individual needs of family members ENRfu(Noyes et al., 1999). They performed a pilot study to examine the experiences of seven parents that were caring for ventilator-dependent children in their homes. The children in this study were diagnosed with Central Hypoventilation Syndrome. Qualitative information obtained from a questionnaire revealed that these families had similar complaints as previously discussed in this review of literature. The families felt inadequately trained and socially supported to manage the equipment and had concerns regarding the competency of the professional healthcare provider.

This pilot study highlighted other issues than have not been as readily discussed in the literature. One issue discussed was the interruption of traditional family gatherings during holidays. Some families were able to adapt their lifestyles to accommodate equipment and medical needs to travel during holiday seasons to be with family. The families did state that they preferred caring for the child in the home versus having their child experience prolonged hospitalization because the developmental needs of the child were felt to be better met in the home. Parents expressed concerns about the coordination

of care with professional caregivers. These children, though receiving medical financial support under the National Healthcare System in the United Kingdom, had similar concerns as families in the United States. A universal concern of families seems to be that there is a lack of coordination in services, goal planning for the future, and attention to individual family needs ENRfu(Deihl et al., 1991; Noyes et al., 1999; Stephenson, 1999). Finally, one parent raised the ethical issue of quality of life for the child and the family. This family member stated that their family had met with mixed feelings from professionals towards their child. Some health providers seem to question whether or not their infant should have been resuscitated and technologically supported to live. This small descriptive study was an attempt to provide and understanding of the individual needs of families in order to develop a more effective support system.

Sterling (1996) examined the relationship of family resources to family feelings of anxiety with 100 primary caregivers managing care of chronically ill infants at home. The Spielberger State-Trait Anxiety Inventory (STAI) ENRfu(Spielberger, 1983) was used to measure feelings of apprehension, tension, nervousness, and worry at the time of the testing. The researchers developed The Home Care Resources Inventory (HCRI) to measure family resources. The HCRI is an instrument based on the ABCX Model of Family Adaptation theoretical framework. The outcome of the study showed that the major strength of resource for families was the availability of a support network of family and friends. The results of the study supported earlier research with other caregiving populations that religious beliefs were meaningful resources. Many of the participants reported that prayer was an effective coping strategy. The caregiver participants in this study showed deficits in personal resources related to fatigue, lack of sleep, and not enough respite care resources. These findings support the concerns reported by earlier focus group members ENRfu(Deihl et al., 1991). The outcomes of the studies underscore the importance of each family to be able to obtain meaningful resources for their own unique needs.

The perception of stress and the ability to successfully adapt are closely intertwined because a family member's perception of stress directly affects the well-being of the family. The gap that occurs between an individual's perception of stress and society's perception of stress supports the need for qualitative research that seeks to interpret the viewpoint of the families. This gap in understanding provides an explanation why people would seek support from others going through similar circumstances, such as a peer-mediated online support group.

### **Adaptation Strategies**

Adaptation strategies also involve an integration of family resources and perceptions of the stressful situation. A family must develop effective coping strategies to be able to restore balance and to manage on-going associated stresses ENRfu(Deardorff, 1992). People tend to react in two different ways in response to stress. These two methods are emotion-focused strategies or problem-focused strategies. Both strategies involve “actions, behaviors, and thoughts used to deal with a stress” ENRfu(Beresford, 1993), p 190. Even though people are driven by different coping strategies, the strategies may still include sharing stories with others, relying on religious beliefs, seeking information, and seeking advice from family, friends or health professionals ENRfu(Sterling et al., 1996). Specifically, actively seeking advice and information about their child’s disability is observed to be an early beneficial coping strategy. Other studies have found that families that seek information and advice were more realistic about their future and were better able to cope than families that denied the problem or were too optimistic about the future ENRfu(Beresford, 1993). Self-help groups will be discussed as a strategy used by families to mediate the stress and to help them care for their children with special needs.

Self-help groups. Families are actively seeking help by joining support groups ENRfu(King et al., 2000). The traditional support group, established by professionals, was formed with the purpose of helping members cope with illness in a face to face

(FTF) format ENRfu(Davison, Pennebaker, & Dickerson, 2000b; Lindsay, 1993). One criticism is that these FTF groups do not facilitate a comprehensive understanding of how the small group of members are actually part of a much larger group of people with the same issues ENRfu(Davison, Pennebaker, & Dickerson, 2000a). Over the past few decades, a societal change has occurred within support group structure. Self-help support groups have established their beneficial role for their members and have moved away from the sole professional led groups ENRfu(Humphreys, 1997). Approximately 25 million are estimated to have used self-help groups in their lifetime ENRfu(Kessler & Mickelson, 1997). The difference in this type of group, as opposed to the traditional support group, is that self-help group uses with peers that have been through similar situations to lead the group. ENRfu(Braithwaite, 1999). Professionals are often used as consultants or liaisons. Both groups offer basics of social support, avenues to seek information, and a shared experience of camaraderie, and advocacy ENRfu(King et al., 2000). It appears that the definitions of support groups and self-help are being used interchangeably with 60% of self-help groups actually run by professionals ENRfu(Braithwaite, 1999).

Over a three year period, Lindsay (1993) compared the effectiveness of a traditional group with a parent-to-parent (PTP) for families with infants in the NICU. In the NICU, the families received emotional, informational, and maternal role support for parenting by trained parent volunteers. The volunteers continue to follow the families after discharge and through the first year of life. The comparison group was offered traditional parent group meetings, with no trained volunteer. The families were assessed at the week of their infant's discharge, at one month after discharge, at four months after discharge, and 12 months after discharge. The dependent variables measured were maternal mood states, maternal-infant relationships, and home environment. The results indicated that the mothers in the PTP group had less anger, depression, and anxiety as compared to the traditional group. The report of the data analysis did not provide a clear

statement about how the dependent variables were measured or how the researchers arrived at their conclusions. Though this study is methodologically weak, there is a strong implication that peer support is beneficial for families with premature infants.

More recently, a Canadian qualitative research project studied nine different self-help groups for parents of children with special needs ENRfu(King et al., 2000). The project used a grounded theory approach to identify the structural process elements that caused self-help groups to flourish. Data were collected through semi-structured interviews from members of the self-help groups. Even though the groups had different focuses, the researchers found similarities among the groups. Each group had a group philosophy and activities; a growing sense of belonging and empowerment that emerged over time; and administrative details that were all managed in a similar manner. These groups seem to strengthen over time through interacting with each other and solving issues related to the group focus. Each group was observed to struggle with their own continued existence. The groups had to retain or encourage new members, adapt to the changing needs of the membership, maintain enthusiastic leadership, and obtain funds to support the group. The overall value of these groups seemed to be that the combined wisdom of the group, along with shared experiences, is more powerful than sole professional help.

People who join self-help groups are seeking support from others to normalize their experience ENRfu(Davison et al., 2000a). These groups give their members an opportunity to meet others that have gone through similar circumstances and to help them develop strategies for thinking and feeling about what they are experiencing. Social support groups that form around disability are intrinsic to today's healthcare setting especially where there is high anxiety regarding diagnosis, medical intervention, and unclear prognosis. In summary, the groups provide an emotional anchor to successfully function in their real-life experiences. In the next section, the experiences of the self-help

group will be applied to the online support group that has come into existence over the past 10 years.

### Online Support Groups

With a historical perspective, we quickly become aware that the Internet has had a significant impact on society in less than 20 years ENRfu(Cairncross, 2001). Created in 1991, The World Wide Web, used interchangeably with the term Internet, wasn't even created until 1991. An even more amazing fact is that we have only had the power to search the Web since 1994. The following quote will provide a measure of how rapidly important the web has become to people worldwide.

The Internet, after the invention of the World Wide Web, has attracted more users in more countries more quickly than any other communications technology. It took 13 years for television to reach a global audience of 50 million, thirty-eight years for radio, 74 years for the telephone- but only 4 years for the Web to achieve the same. Traffic on the Web now doubles at least every 100 days ENRfu(Cairncross, 2001) p. 37.

With the rise in the use of the Internet, families with chronically ill children have begun to network with other families through Internet support groups to cope with the demands of caring for their children ENRfu(Han & Belcher, 2001). People are assessing information in a variety of formats, such as Web sites, chat rooms, or listserves. Each of these formats has its own unique characteristics that provide individualized support or information that an individual is seeking. These groups are not counseling but are peer-mediated support groups that offer information, the sharing of personal experiences, 24-hour availability, selective participation, anonymity, and privacy. These Internet groups bridge the gap of isolation and do not have the typical barriers of face-to-face support groups, such as transportation, distance, and time restrictions.

The listserv or Internet mailing list is a popular format of computerized access for those seeking support for disabilities and for those who are limited in their ability to

attend face-to-face support groups (Ahmann, 2000). The format of communication is asynchronous, meaning that messages and replies are not instantaneous but posted through emails. Members must register or subscribe to become members of a listserv community. The registration component of the listserv allows the virtual community to establish their boundaries and restrict who has access to their postings ENRfu(Robinson, 2001). As in a typical discussion group, the listserv allows the give and take of responses, yet, allowing the individual member to post responses at their readiness. Some members of these online groups have reported that the people in the virtual communities have more in common with them than their next door neighbors ENRfu(Cairncross, 2001). Others members of online support groups have reported that they prefer seeking information from peers rather than professionals because they enjoy the collective experience of others who have gone through similar situations. Typically, these are users who have a difficult finding others who are going through a similar situation in their physical community. Some people find FTF support groups a punishing experience ENRfu(Braithwaite, 1999). These people are typically shy and do not like speaking in front of groups. The asynchronous on-line support group, void of visual and aural cues, decreases the discomfort of those who have difficulty expressing their feelings in physical group settings. Another advantage of online groups are that family members, professionals, and friends may join the groups to gain a better understanding of the disability and the effect on the individual or family.

These parent led Internet support groups mirror the philosophy of the typical face-to-face parent to parent support groups that have flourished since the 1970's ENRfu(Santelli et al., 2001). The positive attributes of these parent-led groups are that they facilitate a family member's acceptance of the stressful circumstance and provide information that will help improve the member's sense of well-being and ability to care for their child. Social isolation is an especially significant problem with families of chronically ill children because they are limited in their ability to attend meetings outside

the home. With the convenience of staying at home, the Internet support group seems to connect families at home with those who are in similar circumstances (Ahmann, 2000). Disadvantages of the online support groups are the perception that text communication may be misinterpreted due to the lack of visual and aural cues that accompany FTF communication; the groups may generate large volumes of postings that can be overwhelming; online groups may be addictive and prevent the development of real-world relationships; and that there is a bias towards those who have access to a computer and the Internet ENRfu(White & Dorman, 2001).

Research evidence is almost non-existent with regards to studying the characteristics of online support groups for parents of chronically ill children. One exploratory research project studied the characteristics of an Internet support group for parents of children with cancer ENRfu(Han & Belcher, 2001). The researchers electronically surveyed 73 parents who had participated in the Internet group. The families in the study were predominantly Caucasian, well educated, and of a relatively high socioeconomic class. The outcome of the study provided valuable information regarding the positive and negative aspects of an online parent support group. Positive aspects were as follows: the families were able to give and receive information without time or distance limitations; the families were able to express emotions and receive emotional support from those with shared experiences; and the families found the communication medium of written text appealing. Negative aspects of the online group were receiving messages that were off topic or inappropriate, the large volume of email received, and the lack of physical contact among group members. In conclusion, the outcome of the study provided introductory information that an online support group is an appealing alternative for some families who are not able to attend more traditional parent to parent support groups.

Online support groups serve as a cost-effective method of providing effective patient education ENRfu(Gustafson, Robinson, Ansley, Adler, & Brennan, 1999). The

fast growth of the Internet has the potential to change healthcare as we now see it. People are moving away from healthcare professionals for support and are being asked to assume more responsibility for their healthcare without the adequate resources to assume the care. In the past, health educators experienced the dilemma of trying to provide information in a broad approach but realized that they were often not meeting individual needs. Computer systems are now thought to be the most effective median for providing information and support with respect to individuality.

Braithwaite (1999) explored the communication of social support with an online support for people with disabilities. The purpose of this study was to discover what types of supportive messages were sent by computer-mediated communication (CMC); to discover to what extent social support is manifested; and to discover if the support messages were different from previous research findings. The researcher used the social support category system to code 1,472 support messages that occurred over a one month period. He recorded five categories of support, as follows: emotional support (40%); informational support (31.3%); esteem support (18.6%); tangible assistance (2.7%); and network support (7.1%). One unique form of social support was humor that was reported to be an unusually important source of support. The members were also noted to use poems and writing in their communication with each other. This group showed the greatest frequency of support messages to occur in the emotional category. Previous research from other studies have shown that information seeking was the most frequented category ENRfu(Cutrona & Suhr, 1992). This discrepancy in outcome indicates that groups may develop their support system interaction style in accordance with members needs. This outcome supports further research of the communication patterns of other groups.

The discussion of associated stresses to families with premature infants and the relationship of resources to adaptation highlight the complexity of the issue as related to the individual needs of each family. The review did substantiate the fact that the needs of

the family are complex and contextually related to the individual providing the care. Implications are that future research needs to take into consideration the individual needs of the family. The emergence of online support groups appear to be an effective method of providing support to a family to care for their child with special needs. The present study examined one participant's experience with an online support group for families with premature child to gain an understanding of the value of group in helping families care for their children.

### **Conclusion**

The review of literature has demonstrated that families of premature infants undergo on-going stress related to chronic medical disabilities. These families feel socially isolated and express a need for information and support to promote the well-being in their families and to assist in the caregiving of their children. However, there is a large gap in knowledge that we have regarding the recent surge of online support groups. Exploratory research of Internet support groups demonstrate promising outcomes that these online support groups may meet the needs of parents that are not able to attend traditional support groups or are limited in their ability to leave home to seek support. Theoretical frameworks were discussed that provided an understanding of the individual benefits and the group support dynamics of the online support group.

CHAPTER 3  
DESIGN AND METHODOLOGY

**Research Paradigm and Design**

The epistemological stance that influenced the selection of research design and methods in this study was constructivism. "Constructivism assumes the relativism of multiple social realities, recognizes the mutual creations of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects' meanings." ENRfu(Charmaz, 2000) (p. 510). The constructivist approach does not seek a single, universal, or lasting truth but seeks to understand human realities that are multidimensional. The constructivist approach, also, understands that reality is based on the perception of the beholder. Ultimately, knowledge is told through the constructs of the researcher's reflexive interpretation and the researcher's involvement in the system of the observed ENRfu(Doherty & Baptiste, 1993).

The overall methodological design of this study is qualitative. Creswell (1998) defines qualitative research as "... an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem" (p. 15). This type of interpretative, naturalistic design values the components of context and setting in data collection; respects the researcher as an instrument of data collection; and seeks to derive a deep understanding of the lived experiences of the participants ENRfu(Cresswell, 1998; Rossman & Rallis, 1998). Qualitative research does not seek to control or manipulate variables and is not concerned with implementation in a controlled environment. The qualitative research design understands the complexities of the real work and seeks to find answers within the naturalistic setting of their participants.

Qualitative research is an umbrella term that includes several distinct methodological approaches that are used to gain an understanding of a particular situation ENRfu(Merriam, 1998). The approach chosen for this study will be ethnographic. Wolcott (1999) states that

The underlying purpose of ethnographic research ... is to describe what the people in some particular place or status ordinarily do, and the meaning that they ascribe to what they do, under ordinary or particular circumstances, presenting that description that draws regularities that implicate cultural process. (p. 68)

This project provides a descriptive cultural study to understand the lived experiences of families with premature infants who network with other families through an on-line support group.

The essence of ethnography is to learn from people rather than studying people ENRfu(Hodgson, 2000). Data collection techniques are multiple and adaptable to the culture but typically rely on "... observations, informal interviews, and the researcher's own experience of events and processes." ENRfu(Rossmann & Rallis, 1998). The ethnographic tradition embraces the fact that the researcher brings their own subjectivities to the project that guide the inquiry ENRfu(Wolcott, 1999). The writings of the ethnographic project serve to paint a cultural portrait that includes the beliefs, the values, and the attitudes of the members of the culture being studied. ENRfu(Merriam, 1998).

While maintaining the principles of classic ethnography, contemporary ethnographic is not confined by the boundaries of the physical world ENRfu(Catterall & Maclaran, 2001; Hine, 2000; Miller & Slater, 2001; Nocera, 2002; Thomsen, Straubhaar, & Bolyard, 1998). Present-day qualitative researchers understand that human interactions and community occur outside the confined parameters of time and place ENRfu(Holge-Hazleton, 2002). Therefore, ethnography, as the research design, provided me with a

viable framework to gain a better understanding of the *way of life* of families with premature children who interact within the virtual community of the Premie-L.

### **Population Selection: *The Virtual Community***

The virtual community, studied in this ethnographic design, was the members who posted messages on the Premie-L mailing list (Premie-L). The home page of the online group states that Premie-L is “a non-profit foundation supporting families with children born six weeks or more before due date” ENRfu(Casey, 2001). This virtual community was chosen because it is the largest online support group for parents of premature infants, has public access, there is a rich mix of participant members, and there is evidence of multiple support resources (online and offline) associated with the online group (See Appendix A for listing of supports). Virtual communities are said to emerge as cohesive cultures when the group members communicate through textual conversations over long enough time to develop personal networks of relationships ENRfu(Nocera, 2002). Established in 1995, Premie-L is known to be a stable or cohesive virtual community as evidenced by the growth in membership, the persistence of meaningful conversation, and the outgrowth of resources aimed at meeting the needs of the members. The Internet organization, not only supports families, but also, actively solicits membership to others such as, medical professionals, NICU staff, authors, and adult ex-preemies. Premie-L has approximately 2000 members with members from 17 countries ENRfu(Ourbristane, 2002).

### **Entry into the Research Context**

As described by Creswell (1998), the primary component of an ethnographic study is for the researcher to become immersed in the lives of a culture that is being studied through prolonged observation. This type of study involves extensive fieldwork and participant observation as the researcher studies the behaviors, the language, and the artifacts that they produce. I am a partial insider to the culture of families with premature children because I have worked closely as a pediatric physical therapist with these

families for more than 20 years. Yet, I do not have the understanding that only comes from the lived experience of being a family member. None the less, the opportunity that I have had to provide physical therapy in the NICU and in the community after discharge has given me a broader view of the problems that these families face (See Appendix B for Subjectivity Statement). As a result of my association with families with premature children, I realize that there is a gap between the standard of support and the support that the families actually receive because medical and policy decisions are made on the perceived needs of the families. Consequently, gaining entry into the research context was an integral component of my ethnographic research.

My initial step was to join the listserv which I have now been a member since July 2001. I easily gained membership to the Premie-L support group because the group welcomes professionals associated with the care of premature infants. In preparation for this study, I continually monitored the listserv since becoming a member of Premie-L to create strategies for gaining access, to learn lingo and language specific to the group, to learn social conventions, and to begin to develop categories for later theme analysis. Wolcott (1998) calls this ethnographic reconnaissance. In addition, a key component of reconnaissance is to obtain permission from the gatekeeper "... who can provide entrance to a research site." ENRfu(Cresswell, 1998) (p.60). In keeping with this ethnographic tradition, I contacted Anne Casey, who established Premie-L.org and is listed as the list owner, and received her permission to implement the study using Premie-L.org (see Appendix C).

### **Data Gathering Procedures**

Guided by the traditions of symbolic interaction research within cultural studies, a multimethod approach was used to represent lived experience because it was not possible to study the direct experience of the lives of these families with premature children ENRfu(Denzin, 2003). The primary methods for data gathering were enumeration,

informant interview, fieldwork observations, participant observations, and researcher-generated documents.

- 1) **Enumeration** - This step, primarily performed as part of the pilot study, included cataloging of the Preemie-L web organization, copies of web site resources, and other related archival data. The archival data helped confirm and provided additional insight about the members of the Preemie-L. The related archival data were taken from the popular media to confirm that the issues encountered by the members of the list were current and attracting the attention of our society. (See Appendix D for Archival Data gathered during the pilot study).
- 2) **Informant** - Ethnographers have long relied on informant interviews to provide the "outsider" with an "insider" perspective ENRfu(Thomsen et al., 1998). During the pilot study ENRfu(Kennedy, 2002), I implemented an in-depth single case study to gain a more in-depth understanding of the perceived needs from one family's point of view. Furthermore, an informant interview served to provide a means of triangulation during the final data analysis. Prior to collecting data, I received permission from the Institutional Review Board of the University of Georgia to perform the case study and associated fieldwork, as described in the section (See Appendix E for Pilot Study Findings).
- 3) **Fieldwork** - Preparatory fieldwork was completed during the pilot study (See Appendix E for detailed findings). Field observations were performed as follows:
  - 1) Field observation in the home of one family who had twin infants with multiple medical complications and
  - 2) Field observation at the one year old birthday party of a medically fragile infant who was born prematurely (this infant was the daughter of the case study participant in the pilot study). The field observations allowed me to record information about families' activities, behaviors, and interactions while participating in everyday life experiences. Later, I used the data

from the field studies as a tool to confirm the experiences of the studied community of the Preemie-L.

- 4) **Participant Observation** - Participant observation was the primary data source and was defined as the prolonged observation and recording of text-based dialogue among the members of the Preemie-L mailing list. The mailing list is a specific component on the Preemie-L web site that serves as a forum for open discussion using a listserv format. Membership in the listserv provides the benefits of being able to actively participate in discussions and have messages automatically posted to the member's email account. In addition, the mailing list messages are publicly posted in an archive format on the Preemie-L home page and do not require membership or password to view. Messages are posted to member accounts and archives almost simultaneously. I chose to use the archives as the primary data source. As previously demonstrated in Internet ethnography studies ENRfu(Miller & Slater, 2001), data collection was passive and I did not identify myself, seek informed consent from individual mailing list members, or guide discussions under this research design (Refer to later discussion titled "Online Confidentiality, Privacy, and Ethics"). The mailing list was extremely active and generated a high volume of mail. Mundane comments that I would have made, as a researcher participant, did not seem to serve a worthwhile purpose for this study.

The archives from the mailing list were posted in a *date* and a *thread* format. Emails in the date format were posted sequentially according to the date and time of the message. Emails in the thread format were indexed as related to the topic listed in the subject heading of the email. I chose to analyze the messages in the thread format because this format of presentation was more conversational and assisted me in the understanding of the context of the message.

Data were collected and stored using NVivo software, computer-aided qualitative data analysis software (CAQDAS) on my password-protected computer ENRfu(Richards, 2000). Backup of the data files was kept in a locked location accessible only to me. An audit trail was maintained to provide a detailed description of how the data were collected, analyzed, and interpreted.

In conclusion, I observed and collected data until the analysis of the data seemed repetitive, major insights were supported, or until the research questions were answered ENRfu(Rossman & Rallis, 1998). This method using participant observation provided me with timely data to understand the world of the families with premature children.

- 5) **Researcher-generated Documents** - Researcher-generated documents (e.g. journals, etc.) were included in the study. Researcher-generated documents were initiated early in the study and were used in data analysis to add understanding to the information collected in the field and to track methodological processes ENRfu(Merriam, 1998).

### **Data Analysis**

The three levels of analyses that were used included descriptive analysis, categorization of themes and categories, and generation of theory or models.

- 1) **Descriptive Analysis** - A descriptive account of the Premie-L culture was developed to explain the character of this Internet community.
- 2) **Categories and Themes** - Construction of categories and themes were derived from the grounded theoretical framework using the constant comparative method of analysis ENRfu(Groves, 1988). Initiated in the pilot study, this type of data analysis involved developing categories and properties that assisted in the development of themes to provide an explanation for the data ENRfu(Merriam, 1998). NVivo software was used to analyze the data from this study. NVivo had

the capability to store data, to code data, and to assist in the management of data analysis ENRfu(Richards, 2000).

Strategies that facilitated the development of the themes involved systematic comparisons of different people, comparing data from the same person over time, within comparisons of events, the comparison of data with categories, and within comparisons of categories ENRfu(Charmaz, 2000). In addition, methods of ethnomethodology were employed to look at the social organization of the text communication ENRfu(Thomsen et al., 1998). This type of analysis provided additional information regarding the idiosyncratic language of the group that lead to a greater understanding of shared meaning embedded in the text by group members. In addition, themes and categories obtained from the pilot study were used in the development of the research questions for the final stage of data collection.

### ***Coding.***

A total of 1,226 messages from the Premie-L mailing list were analyzed from March 31, 2003 to August 31, 2003, the point when the data categorization was determined to be repetitive with no categories arising. Due to the high volume of email, the postings were organized for coding according to the month that the emails were posted in the archives (for example, April, May, June, July, and August). The emails were the units of analysis that represented the voices of the members of the Premie-L mailing list. Rich text Microsoft Word documents were created for each of the months and imported into NVivo for analysis. NVivo uses nodes to categorize data and to store ideas ENRfu(Richards, 2002). The software offers the advantage of creating "tree nodes" or hierarchical organization files that provide the feature of efficiently building categories that lend easily to making subcategories of the data. Tree codes are "...much like the hierarchical index system in a library" ENRfu(Richards, 2002)(p. 890).

Focusing the initial coding process, I assigned five "tree" codes to correspond to each of the broad research questions of the study, as follows (coding definition in parentheses): 1) impact of prematurity (topic or issues directly related to prematurity that has impacted the family); 2) perceived needs of the families (evidence indicating a family's need related to prematurity); 3) member perception regarding role of Preemie-L (evidence that indicates how the member feels about the listserv); 4) supports available to members (evidence that indicates concrete offerings of support that are available as a direct result of being a listserv member); 5) professional and family relationships (evidence that speaks to professional and family relationships as related to the prematurity). In addition, coding was preset to code for the attributes of roles, gender, geographic location, and ethnicity. Setting the tree nodes was not a rigid process of organizing data but provided a dynamic process in the understanding of the interrelationship of concepts and themes through out the data analysis.

I read each line of the messages and coded key passages in "chunks" or paragraphs of data as relevant to the appropriate codes. Another advantage of NVivo is that it allows you to code single passages with multiple coding categories to be able to visualize the multi-coding within one document. For each monthly document, I made coding reports for each of the primary tree nodes and then made summary reports documents that were coded. Additional subcategories were added under the primary tree nodes as appropriate. Beginning with April, each month was coded in entirety before proceeding to the next month. In keeping with the constant comparison method of data analysis, categories were added as they emerged from the data ENRfu(Groves, 1988).

As an illustration, the following email was coded for perceived needs (data from a member that indicates a need as related to prematurity for their family), professional/family relationships (data that speaks to professional and

family relationships as related to the prematurity), and roles (roles include mother, father, relative, career, etc.).

Hello Everyone;

Those of you with 28/29 weekers, if you wouldn't mind sharing when your child first started to sit on his/her own and started to crawl. My son Blake is turning eight months old tomorrow (five months adjusted age) and isn't sitting or crawling yet: he is "combat crawling" however. His OT and PT are telling me he is doing just fine. I was just wondering at what age other children born around the same time were meeting these milestones.

Thank you,

Tiffany (Mom to Blake, 28 weeker, mild spasticity in the arms/legs)

Subsequently, I ran separate reports of each code through out the document. For example, I was able to run a "perceived needs" report for the entire April document for comparison and further coding, leading to subcategory development. When I ran a coding report of "perceived needs", I re-coded the data that lead to the development 14 subcategories from the data report of April. The categories were: the need to share stories, school placement issues, help with feeding, help with obtaining further diagnostics, patience, medical information, need for other support groups, issues with the Internet, need to link off-list, need for general information, and issues regarding daily care. I then compared these subcategories with the node entitled "impact on the family". The coding for "Impact on the Family" from April discovered 11 distinct categories related to impact: feeding, medical issues, equipment, school, NICU experience, financial, death, psychological, social isolation, family conflicts, and, developmental issues. I was curious to know if what the family reported as an impact on the family coincided as a need as reported by family members. This strategy served as a triangulation strategy to indicate priority needs of the members. I also ran text searches in the data of "I need" and "you need" to further triangulate the data findings regarding needs and impact on families. Four preliminary categories were derived from the April data regarding "Member Perception" that included

values (member values the list), no values (only noted with requests to unsubscribe), expanded influence (indication of impact on real world) and triangulation (confirming of information). I dropped the coding of gender in the May analysis because gender was captured in the coding of role (such as mother is obviously a female). Subcategories, known as nodes in the NVivo software, were reorganized and collapsed to form the final categories. The node of advocacy was added in the May coding and the category of emotional support became more defined. The only new addition was the "R" rating in the subheading of one of the emails indicating the message may be disturbing for some readers. The message related to negative outcome was coding as appropriate to impact in the areas of health-related and emotional impact. Beginning in the July archive coding, no new categories were added.

As an additional coding procedure, I performed a character frequency count using a feature of NVivo that provided a numerical count of characters within each node. This count served as an additional tool in the final analysis that helped me rank the categories as seemed important to the families. The count was not totally accurate with respect to priority because some messages were lengthier (such as the stories of NICU experiences). Based on the frequency report, the ranking of impact was as follows: professional-family relationships (210,250 characters coded), NICU experience (66,716 characters coded), medical issues (36,760 characters coded), and death (11,505 characters coded). Ranking based on frequency coding for the top four categories related to need were: Need to share story (26,877 characters coded), health-related information (16,372 characters coded), school support (16,274 characters coded) and share medical information (8,663 characters coded).

- 3) Generation of Theories or Models - The third step included the process of developing inferences, making models, and generating theory to explain the

experiences of the families that are members of the Premie-L online support group. As previously discussed, I used a constructivist approach combined with a symbolic interactionist theoretical perspective to present as accurate an understanding of how families with premature children construct meaning of their own experience ENRfu(Charmaz, 2002). In the pilot study, I began with a conceptual orientation towards the Double ABC-X Model of Family Stress and Adaptation ENRfu(McCubbin et al., 1983). Starting the study with a conceptual orientation assisted in the development of guiding interview questions, coding, and analysis ENRfu(Miles & Huberman, 1994). The microtheory provided a framework to support explanation of how an individual family adapted to the strain of on-going stress related to the single crisis event of prematurity. The Double ABC-X Model was used again in this research phase to explain how individual family members use the Premie-L online support group to mediate the on-going strain related to the premature birth.

Once the data were analyzed, models or diagrams of the codes were developed using NVivo for making connections between the data that was necessary for theoretical development (Refer to Appendix F for Models of Coding). The visual process aided me in the interpretation of the data that ultimately lead me to an understanding of relationships in the data for theory development. Finally, I wrote a narrative description of the model that explained the findings of the study that was sent to Anne Casey, the owner of the listserv, as a member check.

### **Online Confidentiality, Privacy, and Ethics**

I performed a review of current literature and implemented personal searches/inquiries from well-known organizations in the field of research to obtain the most current knowledge regarding current rules and regulations related to informed consent in Internet research. Prior to the development of the Internet, governing research

agencies have had many precedents and formal guidelines to guide their decisions to ensure appropriate protection for human rights ENRfu(Mann & Stewart, 2000). At the present, Federal regulations continue to exempt researchers from obtaining informed consent if the collection of data occurred in a public place and that the identification of the subject was to be protected from disclosure ENRfu(Penslar & Porter, 2001). The issue has been raised to whether the Internet is a public or a private forum. The issue of *perceived* privacy and accessibility to the Internet complicates the issue of public or private domain ENRfu(Frankel, 1999). The most recent rules and regulations related to Internet privacy have been summarized in a recent posting from the Privacy Rights Clearinghouse (established at the University of San Diego Center for Public Interest Law).

There are virtually no online activities or services that guarantee absolute privacy... According to federal law, it is not illegal for anyone to view or disclose an electronic communication if the communication is 'readily accessible' for the public. (Electronic Communications Privacy Act, 18 USC § 2511(2)(g)(1)). For example, a message that an individual posts to a public newsgroup or forum is available for anyone to view, copy, and store. In addition, your name, electronic mail (email) address, and information about your service provider are usually available for inspection as part of the message itself. Most public postings made on the Internet are archived in searchable files... Thus, on the Internet, your public messages can be accessed by anyone at anytime-- even years after the message was originally written ENRfu(Network, 2002) (p.2).

The Listserves are considered to be "public activity" because messages are sent to a mailing list of multiple subscribers ENRfu(Network, 2002). On the other hand, messages that are sent personally from one Internet subscriber to another are considered "private activity".

The National Health Institute (NIH) and the American Psychological Association (APA) were contacted through email and/or web searches of their organizational sites to gain information regarding informed consent and Internet research. Both of these organizations are well respected in the arena of research and are known to uphold high standards regarding responsible and ethical research. Bronna Bodenstein, NIH LISTSERV Administrator, stated that the NIH does not have a specific policy with regards to Listserv research ENRfu(Bodenstein, 2002). She did emphasize that the NIH does value the privacy of their subscribers especially when discussing sensitive issues related to disabilities. The "Ethical Principles of Psychologists and Code of Conduct 2002" ENRfu(Association, 2002) was obtained from the APA web site. The APA document had no specific policies regarding Internet research but did state that psychologists may dispense with informed consent

Where research would not reasonably be assumed to create distress or harm and involves... naturalistic observations, or archival research for which disclosure of responses would not place participants at risk of criminal or civil liability or damage their financial standing, employability, or reputation, and confidentiality is protected... (p. 11)

Finally, the IRB at the University of Georgia was contacted for advisement. Confirmation was received that informed consent was not indicated for analysis of publicly available online archives.

As related to this study, Premie-L is an online support group for parents with premature children that utilizes a listserv format of communication among members. This type of online support group has been shown in the previous discussion to be considered a public forum and is excluded from the need to obtain informed consent from the members of Premie-L. Regardless, efforts will be made to maintain confidentiality and to remove all identifying information from the email postings in the findings. The forum name will be preserved at the request of the listserv owner. It is not anticipated that the

outcome of this study will cause any harm or emotional stress to the Preemie-L members.

### **Validity and Reliability**

The study utilized the strategy of triangulation to insure internal validity of the study. The three types of triangulation used were data triangulation, member check, and methodological triangulation. Triangulation involves substantiating the findings from multiple sources ENRfu(Herman-Kinney & Verschaeve, 2003; Mathison, 1988).

Drawing interpretations from multiple data sources (i.e. transcripts of the interview from the pilot study, field notes from the pilot study, surveillance of online interactions prior to and after analysis to monitor the historical and social structure of the group, and analysis of archival documents) provided triangulation of data to confirm patterns of behavior. Prior to the final interpretation, the analysis of the data was provided to Anne Casey, Preemie-L listserv owner (See Appendix C). Ms. Casey's comment was useful as a member check to solicit the participants' point of view on the findings and interpretation and to establish credibility of the study's findings. The member check also alerted me to errors or misinterpretations from the participants' points of view.

External validity was addressed through the use of multiple data sources and through the use of detailed descriptive writing. The reporting of the study used thick, rich descriptions of the methodology, data analysis, and interpretations to enable the reader to draw parallel to similar situations.

## CHAPTER 4

### RESULTS

There is no reason for any individual to have a computer in his home.

Ken Olsen (1926 - ), President, Digital Equipment, 1977

Herman-Kinney and Vershaeve (2003) comment that humans undergoing the stress of unforeseen circumstances will inevitably go to great lengths to gain understanding about their situation to regain control and predictability in their lives. The Premie-L Discussion Mailing List was observed to be a powerful resource for families who were striving to adapt to the impact of prematurity on their individual families. The results of this study will be organized around the framework of the five broad research questions that tell the story of the people in the Premie-L community: the impact of a premature birth on their lives; their perceived needs; available resources; and the value of the community towards the well-being of their families. Specific research questions with associated email passages are presented as follows (*personal comments are italicized within parentheses in this section*). Note that email messages are presented as posted on the listserv without corrections to grammar or spelling to preserve the character of the community.

#### ***The Community and Culture of the Premie-L Mailing List***

Hello everyone! I just wanted to jump in and introduce myself and my brand new daughter.... Looking forward to hearing from you all" wrote the new mother. This email represents a typical first-time post to the group. The question you may ask is " Who is this new mother and why is she so excited about being part of this Internet community?

The families of the Preemie-L bring the history of having a child born prematurely even though they come from diverse cultural backgrounds. The home page of Preemie-L.org states that Preemie-L is "a non-profit foundation supporting families with children born six weeks or more before due date" ENRfu(Casey, 2002). The opening statement under the heading provides us with an understanding that having a premature infant can be a scary and lonely process and that the main purpose of this organization is to support families going through this process. Enumeration of the resources on the home web site provide an understanding that the organization has a broad-based approach; with the listserv component representing only a small portion of the support network (See Appendix A).

Group membership was observed to be transient and varied in duration but there was a strong core of committed, veteran members who perpetuated the existence of this support group. These veteran members oriented new members and facilitated trust in the group by sharing their personal stories, providing updates, offering themselves to others, and upholding ground rules that served to manage the group. For example, Tameka (*new member*) introduces herself to the group, which subsequently solicits a response from Susan (*veteran member*) who welcomes her with an orientation message.

Hi. I thought I would introduce myself. My name is Tameka. I am the new mom to two beautiful baby girls who came into the world at 32 weeks on May 16<sup>th</sup>. The past week has been pretty overwhelming and seems like it has been much longer than a week. Anna was born weighing 4lbs 1 oz; right now she's still being fed by tube but is doing well. Betsy was born weighing 3lbs 0 oz; she's getting a bottle at every other feeding but is on the bililights for her jaundice. Both girls are breathing on their own now, which I am thrilled about.

I also have another child who is 3, and I'm finding it difficult to try to juggle being home and spending time with him and being in the NICU. Plus, I'm still recovering since I had a lot of complications after delivery and was in the hospital until Thurs.

Looking forward to getting to know you all.

Tameka

Replying on the same day, Susan answers:

Welcome Tameka and congrats on your twins...such a blessing. It is very hard to have your children in intensive care, and made worse (if possible) by having older children at home who you know are missing you and confused about what is happening to their family. Both my girls spent time in the NICU, my older daughter a 33 wkr and her lil sis a 35 weeker...I hope you enjoy the group as much as I have...they are the greatest parents in the world (my humble opinon)...warmly,  
Susan

As illustrated in the first email, Tameka sets the stage by announcing to the listserv that she has experienced the birth of premature twins. The intent of her message was to introduce herself and extend an invitation for help in dealing with this "overwhelming" event. Enthusiastically, Susan accepts the invitation by congratulating Tameka on the birth of her babies, affirming what she, as a new mom, is experiencing, acknowledging the impact on the family system, and closing with an endorsement of the value of the online group for support.

The primary voice heard on the list is from family members. Other life roles such as occupation play a secondary role in the conversations. There is a predominant feminine perspective since most of the members posting messages are female. Religious affiliation, race, or ethnic background is not extremely relevant to the discussions. The studied messages revealed that the members have many outside interests and obligations aside from the Internet. For example, their stories show that they participate in social activities relative to family and friends; they go to work, they attend doctor's and therapy appointments, they attend school meetings, and are seen as volunteers in the community. Members appear to value family unity and there is a prevailing assumption that families on the list want the best for their children and possess the life dream that their children will lead successful, meaningful lives. Metaphorically, the culture of the listserv may be described as a close-knit family. The members bounce ideas off each other, argue, discuss their fears, frustrations, anxieties, hopes, and, dreams. Not only does the organization provide a wide range of support and information though the Internet, but

also, sponsors an annual conference that offers the opportunity for face-to-face support of its members.

The following email exemplifies the values and beliefs of the listserv members. Responding angrily, Kaci chastises fellow member for breaching the norm of expected online behavior in response to an off-color joke.

If you want a little humor join a list that allows it. Trust me I thought the joke was a funny one...however ... Premie-L is not the forum for her to send for type of correspondence. Premie-L is for discussion and support of *preemie related issues* ONLY. The rules are spelled out very clearly and it was not appropriate for this list. Plain and simple. Follow the rules (*these are the ground rules for the list*)...

Hugs,

Kaci Mom to Kathy 14 - FT, Jonathon 10 - FT, Derek 6 - 34 weeker, Jim 3 - 31 weeker

Before you were conceived, I wanted you  
 Before you were born, I loved you  
 Before you were a minute old, I would have died for you.

The italicization of "*preemie related issues*" followed by "ONLY" in all capitals accentuates Kaci's perception of the purpose of the online group and the anger that she feels towards someone who apparently does not understand the seriousness of the issues surrounding the families. The poem that follows her byline serves to show the strong maternal emotions that she has for her child. Furthermore, this email exhibits the moral tension that exists between the need to support others like themselves and the need to chastise those that do not show respect to the seriousness of the needs of the families with premature children.

As observed in the previous examples, the language in the Premie-L list is informal, direct, and mimics conversational speech. Emoticons and abbreviations (Internet and medical) serve as symbols that further facilitate communication (refer to Appendix A for a list of abbreviations and emoticons that are used by the list). Although there is a routine to the format of messages (such as new member introduction, announcing of milestones, requests for help, etc.), the topics of conversation are dynamic

and emerge through member interaction. Messages typically contain medical jargon that would not be shared by those without some knowledge of prematurity. An important ritual is that members offer information that establishes group membership. For example, prior to giving advice a member typically will share their personal story to establish legitimacy to participate in discussions or will provide a summary of their family's story in the bylines of their messages.

This long email from a newcomer father is presented in its entirety because it exemplifies the people of Premie-L. The message accurately portrays that the crisis event often begins prior to the delivery.

Hi Folks

I have been a lurker for about 14 odd weeks, which just happens to be the age of my son Nathan. Our story starts about 11 weeks into this pregnancy with a hemorrhage, a big one. With our history of miscarriage (3) we went to the hospital expecting the worst, imagine our surprise when the little tyke was still kicking! My wife continued to have bleeding on and off right up till Christmas when it become heavier. She was placed on bed rest and then on Friday night 10th January, Sandra started getting contractions, this was 25 weeks into the pregnancy. We were panicked to say the least. Some drug, they couldn't use the big guns because of the risk of increasing the bleeding, managed to stop the contractions and the first steroid shot went in. The next night (why do these things always happen at night?) the same but with increased bleeding and then the same Sunday night. Monday morning they do an ultra sound and discover that the placenta is coming away and it is time for an emergency cesarean. We spent the entire time camped in the delivery suit as they expected the baby at any time. Thankfully we got the second steroid injection in and the pain and suffering that Sandra went through bought us the time for our sons lungs to mature. They rush Sandra off to the theater leaving poor old dad pacing the floor outside, want to see a very frustrated man? Watch a fire-fighter used to responding and fixing problems physically, get stuck outside an operating theater! Twenty minutes later out comes the humid crib with my son on board; they go off down the corridor. Thankfully the really nice nurse looks up and asks if I am the father, they then give me a ten second peek in and say to come up to the NICU in about an hour. Problems in the theater leave me outside for about another forty minutes, I start to give everyone that enters or leaves the theater, and there were a few, the 'eye'. In other words tell me what is going on, the old stare and wait is quite effective at times.

Thanks to blood loss leading up to and including the delivery the end up pushing eleven units of blood and 4 of something else into Sandra.

They eventually wheeled Sandra back to the delivery suit and I started moving

back and forth from the delivery suit to the NICU, it would be three days before Sandra was well enough to get into the NICU.

My first trip into the NICU was devastating, I walked up to the crib and was hit from a direction that I did not expect. A year ago we lost our daughter, she was still born at 27 weeks, and Nathan looked very much the same as Cynthia. This was a real shock, in fact Nathan was smaller.

Now for the good news, even though he came into the world at 25.5 weeks (840 grams, just under 2 pounds) Nathan has been incredible. He was only vented for eighteen hours, that's right hours not days. He went to CPAP but came off that relatively quickly as well and never needed more than twenty five percent oxygen at any stage! He went from strength to strength, no visible IVH, a small PDA that is still unresolved but with no symptoms, only stage 1 ROP but no progression and so on. He came home at 36 odd weeks corrected, 12 weeks after his birth. I know the future is still the great unknown but we have high hopes that all will be well, Goddess willing.

One of the first things I did in the early weeks was to read the entire archive from the premie list, this was at times harrowing, uplifting and supportive.

Recommended only for the strong of heart and stomach, but it did prepare me for what might happen. Without knowing everyone here and from the past helped us survive those terribly worrying early weeks.

To finish up Nathan is now 14.5 weeks old and can celebrate his zero'th birthday today!

Thanks

Thomas

Within this one email, Thomas provides an introductory update on the emotional roller coaster ride of his family's experiences; describes the shock of seeing his son for the first time, celebrates a milestone; shares his fears about the future, and consequently justifies his position to speak in the body of the message. He shares that he is a firefighter and we capture a glimpse of his frustrations at being the victim of circumstances. The story also provides the reader with an understanding of the stress of being torn between wanting to be with his wife and, at the same time, his son who are both medically unstable.

In summary, Premie-L is a stable or cohesive community of families with premature children as evidenced by the growth in membership since its inception in 1997. The persistence of meaningful conversation over the years and the outgrowth of

resources aimed at meeting the needs of the members. Specific archival data is presented in Appendix D to support the findings in this section.

### **Impact of the Premature Birth Experience**

The premature birth experience was observed to be a stress related event that placed extraordinary demands on the families. There were three major categories of impact on the family. The categories were health-related issues, professional-family relationships, and psychological/emotional issues. The categories were not mutually exclusive.

#### ***Health-related Needs.***

Health-related needs are described as issues related to pathology of prematurity. The issues include medical problems (chronic lung disease, feeding/digestive problems, sensory issues, etc.); financial issues (direct and indirect costs associated with providing care for the child); family management demands (juggling therapy/doctor appointments, daily caregiving issues, family relationships, etc.), equipment (not only durable medical equipment and medical supplies but the need for specialized equipment because children are often too small for age-appropriate items), and developmental issues related to disability.

In this email, Shelia's plea to the group illustrates the complexity of issues related to the impact of prematurity for families. She is aware that her daughter is at high risk for developing life-threatening complications from a common respiratory virus (RSV) because of the prematurity. This fear is confirmed in the literature ENRfu(Weisman, 2003). Her message underscores the issues associated that include management of chronic lung disease, financial implications, and family management demands with daycare.

*I hate to even mention Synagis (immunization for RSV)...it's SUMMER capitalization of the SUMMER signifies the absurdity of having to worry about the future cold season) after all (in the US anyway), but at Cindy's 9 month check up this week I had asked if she would qualify again this Fall (families must rely on the recommendation of physicians to be covered by insurance and follow standards of care established by professional associations)- she got RSV this past*

winter, I do daycare so she is exposed to other kids (albeit a very small group), and her siblings are in school. She won't be 12 months adjusted until the end of October, I \*thought\* she qualified based on that, but I guess not (*the italics surrounding thought seem to indicate a breach in expectations from the medical community*). Any thought on the possibility of appealing this decision with the insurance company? I feel as though the costs of possible hospitalization far outweigh the costs of the Synagis injections (though I know they are exorbitantly expensive!)

Thanks!

Shelia, Mom to Ron and Betsy, [10/92@24](#) weeks and Cindy, [09/02@34](#) weeks

Sheila is fearful of the future but is proactive about seeking resources to prevent her daughter from acquiring a serious respiratory illness that may result in a hospitalization. This mother is observed to have multiple responsibilities related to managing employment responsibilities; managing daycare issues with consideration to her daughter's health issues; and managing the financial issues of medical care. Although each family's experience as reported on the listserv is unique, the preceding email is representative of the impact that families with premature children experience.

### ***Professional-Family Relationships.***

Professionals are defined as people with specialized credentials whose services are required to manage issues related to prematurity. The collaborative relationship between the family members and a specific professional or agency is complex and variable. In some circumstances, relationships can be a source of comfort and in other relationships a source of strain.

In this illustration, Martha is explaining to the group about her concerns that her child is not gaining enough weight. She tells the story that she added a supplement to her child's diet and then checked with her pediatrician to make sure that there wasn't any problems with her self-guided intervention.

...Regarding the use of pediasure, we gave her one can ... at night before bed.... We started this on our own, and just double checked with the pediatrician to make sure that they didn't have any concerns about this. While the pediatricians didn't know if it was necessary, they support our decision, especially given the amount and timing that we were doing.

Martha

In this example, the relationship between Mary and her pediatrician showed collaborative intent with a family-centered approach from the pediatrician.

Presenting another point of view regarding relationships with professionals, Susan sarcastically expresses her opinion about what she "hates".

...So strange...one of my pet peeves (which of course is totally unreasonable) is when doctors disagree wildly over a topic. I realize it's totally normal and \*is\* the reason you ask for another opinion...but I gotta admit...I hate it when they disagree...I secretly feel that they're all just making it up as they go along...  
warmly  
Susan

Susan expresses an internal angst that involves a comprehension that doctors do not have all the answers that conflicts with her wistful desire to peacefully rely on the wisdom of the professionals. Her "hate" seems to be related to the situation and not directed specifically towards professionals. The ambiguity of the situation is observed to be unsettling for this mother.

Often times, the families were seen to insert the names of professionals in their conversations as if they were their neighbors or family.

Kendra and Ernie graduated from EI this morning. They both have done so well for 25.5 weeks.... I know that I should be ecstatic but I am also a little scared that I will no longer have someone coming to tell me how well my kids are doing and where they need improvement. Wendy and Alaina (our EI ladies) had become such a part of our lives that I know I will miss them.

With regards to family-professional relationships, this message to the group is an example of trust, reliance, friendships, and, perhaps, dependence on professionals.

The context of this next series of emails surrounds one mother's experience with early intervention (EI) professionals to receive speech therapy for her twin sons. In the first email, Laura is requesting assistance from the group regarding an upcoming IFSP (*Individual Family Service Plan*) meeting. Ironically, she expresses that she is relieved that her twin's language delays have been confirmed by recent early intervention speech assessment. Her response is contrary to the expected response from a parent of a typical

child who would be relieved to learn that their child did not show delays. As discussed in the previous section regarding health impact, developmental delays are not unexpected as related to prematurity that often lead to a subsequent need to collaborate with professionals for therapy and educational services. The particular situation is complicated by the fact that Laura is expecting an adversarial role with the EI professionals.

Well, we had our reassessment today by EI and the boys were evaluated at a 13 month level for receptive and expressive language. I'm relieved, because it finally means that they are going to start to get some more help than what I can give them. Anyway, our next step is an IFSP for them and I was just wanting to ask some seasoned parents what I should be expecting and what I need to bring with me. I've read so many fight about IEP's (*Individualized Educational Plans*) and I know that this is not going to be that difficult as the SLP and teacher were desperately trying to find a way to get them in. But, I would still like to be prepared.

Thanks in advance,

Laura

Bob and Dixon 18 months adjusted

In this email, Laura shows political savvy as she makes allies of the speech therapist and the EI teacher prior to the meeting. She does her "homework" by enlisting the help from veteran members of the list to prepare herself from the meeting.

Next, approximately two months later, the mother is observed to still be fighting a battle to receive speech services for her children. The communication difficulties of her children are perceived by the mother to be impacting her ability to care for her children and the well being of her family. The mother's state of mind is succinctly captured in the subject heading; "frustration".

Hi everyone,

Today I have been so frustrated and I just need to let it out somewhere.... I thought maybe here I could get some advice as well...I am so frustrated by their lack of speech. Today it was just compounded by the fact that they didn't want to eat anything that I served them, yet they couldn't tell me what they wanted ... Almost 2 months have passed since the IFSP meeting and we still haven't had our home therapy because the therapist was on vacation. Ugh....

Three days later, another update is posted from the same mother. Laura is shocked to find out about the lack of resources for speech therapy within the EI system.

Ok, more developments in our story... She said she wasn't sure if our home visits would start next week, but that the SLP should be giving us a call. When I asked her how many kids the SLP was seeing, she said it was a lot and that she was also doing the kindergarten kids. In addition, she is apparently only working half-time. Shouldn't they get another SLP to help out with the load?? Anyway.... I was just kind of shocked when I heard that ...

Laura

Bob and Dixon

In this final email, Laura finds out that after waiting for speech therapy for over the past two months, one of her sons, Dixon, does not qualify for services. The metaphor, "feel like being pulled around by a chain", provides an unsettling picture of about how this mother feels she has been treated by the professionals of the early intervention system.

...I had called last week to see when Dixon's IFSP meeting was going to be held and I was told by the teacher today that he hadn't qualified for services. I was thinking all summer that he would be getting speech therapy as well, and it was because they hadn't told me otherwise. I received no report in the mail (like we had after the first assessment in February) that said that for now he didn't qualify for services. ... I feel like I'm being pulled around on a chain and that this judgment on their part (as well as not informing me that he didn't qualify) is a flagrant violation. And now I have to go through a whole assessment on both the kids (to have Bob's IFSP re-evaluated as well) on Thursday.

I didn't think EI was supposed to be this difficult,  
but it is turning out to be a nightmare.

Thanks for reading my vent.

Lisa

The progression of emails painfully illustrates this mother's frustration with working with professionals when she had once eagerly anticipated their support. The result of the interaction is that the mother ultimately feels betrayed by the system, which confirms her initial feelings that she must be prepared for a battle.

The stories in this section were chosen because they capture the complexities of family-professional relationships. The context of professional-family relationships appeared more frequently than any other topic on the listserv. The stories show that families desire a mutual, collaborative relationship with professionals but experience seems to contradict this ideal. Also, the stories from these families provide evidence that the norm in family-professional relationships is most typically challenging adding additional stress to the well-being of the family. The impact of health-related issues and family-professional relations have a resulting psychological impact on the family. The next section will more specifically discuss this impact.

### ***Psychological Impact.***

What must be understood is that the psychological and emotional impact of prematurity is interwoven into every topic in this study. Nonetheless, the results of this category are presented separately because of the abundance of evidence relating to psychological and emotional impact on the family. The impact will be presented with reference to the following three areas: 1) events surrounding the birth in the NICU; 2) stress relating to the on-going nature of prematurity issues; and 3) death.

### ***NICU Experiences.***

First, the NICU experience and the emotions surrounding the birth are intense and persist over time. Marci welcomes a newcomer to the support of the group and confirms that the NICU experience is "tough".

I know the nicu experience is very tough, and I agonized many times over all my kids went though, but they are so worth all the worry and frustration! Hopefully I can answer some questions for others that are new to the "preemie" world.

In another example, a mother emphatically proclaims "... you will never be over it. It becomes part of who you are--a life altering experience."

Members share stories of NICU experiences with emotional passion as if the event had happened yesterday. Driven by the intensity of her own past memories, Linda breaks her silent position to share to the group.

Coming out of deep lurker mode to answer this one. When my son was in the NICU (28 weeker, 8 years ago now) the amount of time that I was allowed to hold him was limited to short spurts once or twice a day whilst he was in an isolette and then every now and then when he was in a open cot. We always had to ask if we were permitted to hold James and our cuddles were timed. I resented the limitations, especially when he was older and in an open cot and the urge to cuddle him all day every day was hard to resist...

Linda confirms that the intense NICU emotions endure over time as we learn from her that her son is now eight years old. The context of the negative stress that this mother is describing is related to the fragile condition of her infant that limits contact with her son, a lack of perceived control, conflicts with NICU staff, and ultimately a loss of the "normal" parent role. As previously illustrated, there is a common theme of conflict with professionals that in this instance began in the NICU.

Seemingly, the on-going anxiety of prematurity should lessen as the families move beyond the boundaries of the "NICU experience" but the chronic nature of prematurity related issues is noted to continually impact the families emotionally and psychologically. Furthermore, the complications of the premature birth separate these families from their families and friends who experienced a routine outcome of the birth of their children.

### ***On-going Stress.***

Maggie provides an update about her 19-month twins since their discharge from the NICU. With humor, she jokingly diagnoses herself with "Paranoid Premie Mom Syndrome".

We had our first play date on Friday with our Moms of Multiples group (never saw so many kids in one backyard) and they acted like normal 18 months old. Ernie didn't "freak out" at walking barefoot on grass which before has sent him into a crying fit. It still surprises me when I see them act "normal". I am still on the constant look out for anything that may seem abnormal. I also have to remind myself to let them be and not turn every event into a hidden physical therapy session. I told my sister that I don't suffer from PMS but PPMS "Paranoid Premie Mom Syndrome".

Her story provides an appreciation of her gnawing fear that her children may be "abnormal ". As evidenced, an ever-present anxiousness colors this mother's perception of life, which limits her ability to relax and enjoy her children "growing up".

***Death.***

The final topic of discussion in this category is the psychological impact of death. The definition of death involves not only the grief for the physical loss of a child but also the loss of a life dream of having a normal pregnancy or the loss of a life dream for a child who doesn't have to cope with disabilities. In a simple remark, Maggie illustrates "I did not lose a child but I still mourn the loss of my normal pregnancy and birth."

In another example, Catherine provides us with further insight into the emotional aspects of the death of a dream for a normal pregnancy that causes her to feel isolated from other mothers who experienced normal pregnancies.

I don't know about anybody else, but I still regret (*sorrowful emotions associated with looking back at what could have been*) that I couldn't even be all the way pregnant, or even get to the last trimester! Or what it would have been like to see Jordan after I had him, have him in the room with me, etc. when people complain about being very pregnant, I cringe (*emotional response associated with physical reaction*) and wish that I could have been 40 weeks pregnant instead of 25. I wanted people to ask me if it was a boy or a girl, not question if I was pregnant at all, as I was just starting to show. I realized that I don't entirely want another child, I just wish that it could have happened "the right way" ...I was strongly advised not even to try again...I just couldn't bear to put another baby through... I still have feelings of loss when I see a very pregnant person, even though Jordan is doing fine. I think NICU support groups need to maybe focus on the loss of the pregnancy a little more, not just saving the baby. Just a thought... I always get..." Just be happy you have what you have"... trust me, I am very happy...nonetheless...a dream was altered, especially if he going to my only.  
Catherine  
Mom to Joyce Anne, 25 weeker, now 21/2

There is an additional understanding received from this mother that she is receiving limited support because her experiences are not understood by others around her.

The presence of physical death is omnipresent within the culture of the group even if not spoken of in the daily messages. For example, seemingly without warning, a

message such as this will appear: "It is with great sadness that we send this email... Joel passed away this morning at 3:00 am.". Families are observed to use the word "angel" as a symbol to denote infants who have died, such as seen in the byline of one of the members "...angels Kim (4/4/98 - 4/4/98) and Dylan (4/4/98 - 5/6/98) and another little angel lost at 12 1/2 weeks 12/94".

Finally, as evidenced in the following email, there is a feeling by families that have experienced death of their children that there is a lack of understanding from professionals about their resiliency to cope with the circumstances.

When we first moved to Florida and Curt was a little over a year old, I called the NICU here and asked about volunteering. The coordinator told me that because of the death's of Kim and Dylan that they wanted me to wait longer before starting to volunteer. Like you, I wondered what they thought I would do. I even told her that I really wanted to be there for other parents who lost one or more multiples, but she wouldn't allow that either. Grrr.

These email passages provide evidence that for many of the families, the impact of the premature birth is an on-going adverse psychological impact for the entire family system. In response to the on-going strain, families are confronted with the need to find new resources to help them cope with challenges that affect the well-being of their families. As this last email demonstrated, what professionals feel family members need is not always what families feel that they need. The following section will present perceived needs from the members' point of view.

### **Perceived Needs**

The stories shared through the email messages provided evidence of what the families felt that they needed to improve the quality of their lives. Three categories of need were discovered as follows: information, social support, and advocacy.

#### ***Information.***

There was a need demonstrated for information about health-related issues, daily care (feeding, therapy, etc.) school issues, prognosis, and other general information. Different types of information were desired. There is deliberate intent in the messages to

receive information about personal experiences from peers that is different from the factual or more concrete information. Information was requested to improve the member's ability to take care of their children and to improve the well-being of their family. Overwhelmingly, health-related information was the most frequently requested area in this area.

The following email represents how one family utilized the listserv to acquire information about an eye disorder that is a common complication of prematurity ENRfu(Verma, Sridhar, & Spitzer, 2003). The background of the situation is that Pamela and her husband are caught off guard with the news that their baby urgently needs eye surgery. They must come to a decision quickly about whether or not to give the physician permission to proceed with the surgery. To help with their decision and to ease their mind about the predicament, Pamela turns to the listserv for help because she knows that she will quickly find others who have gone through a similar experience.

...What are your experiences with laser surgery?? The doc says that there are risks of vision loss, loss of peripheral vision, cataracts or glaucoma? Also, the anesthesia could set him back on getting off the vent? ... Any insight is appreciated.

In this example, Pamela seems to have already obtained medical specifics of the surgery from the physician but her priority at the moment is to gain information related to personal experience.

This worried mother turns to the listserv for advice about her toddler's development as shown in the preceding example. Specifically, she has a desire to know if her daughter's behavior is "normal" and if not is her behavior consistent with children who have autism.

... may I ask some advice, my daughter 35 weeker, who is not yet speaking, is now starting to starting to have tantrums.... does anyone know if this "normal " for her age, or is it to do with the sensory issues which I'm sure she has? ... We are worried cos the doc has mentioned "autistic characteristics" please help!!!

Her expression of fears and anxieties, along with her request for information, is seen as a need to explain her situation even if the information received confirms her worst suspicions.

At first glance, some information requested on the listserv seemed only to be about typical children issues but then the overtone of prematurity was quickly realized as I read more closely. The following request for information is an example.

My daughter was 10 weeks premature and is now 3 years old. She is only 21 pounds and is getting ready to begin potty training. Our problem is that ... we are having trouble finding underwear small enough to fit her. Does anyone have any suggestions where ... I could get an item? Any help would be greatly appreciated.  
Thanks

The overtone of prematurity in this message is that premature children are often smaller than their peers requiring a need for families to adapt situations for their children ENRfu(Verma et al., 2003).

Finally, there was an observed need to share information as well as a need to seek information by the members of the listserv. This need to share information may be more clearly understood as related to social support that will be discussed in the following section.

***Social support.***

There is plentiful evidence in the messages that show members actively seeking support for others going through the same situation. This social support also includes emotional support needed by the members. Social support from this online support group seems to be specifically desired because of anxiety related to long-term diagnosis, fear of the unknown, and confirmation of the experiences that they are experiencing. Indications of the need for social and emotional support have already been observed in many of the other stories discussed.

In response to a newcomer's message, the sentiment of Peggy's short message underscores the belief that there is a need that may only be filled by those who have lived the experience.

I hope that my words have helped you to know that you are not alone and that there are many of us who have walked in your shoes and understand your pain. Peggy, mom to Ann, 16, Molly, 14, 28 week twin, Nancy, 5.8, Lara, stillborn to due to TTTS and Bradley, 2.7

The online support group provides an intimacy of support that often eludes even the closest of family and friends.

My Dad is the same way. When we first brought Daly home, his comment was "He's not a preemie anymore...he's home." I think he got a better understanding after visiting and seeing video of Daly's struggles with living while in the NICU. He still makes comments about how he's fine now.. etc. I just smile and shrug. I know where to get support. :)  
Just thought you'd like to know you're not alone in the boat.

### *Advocacy.*

There was a need demonstrated to act collectively as a group for the acquisition of appropriate individual family support including medical care, education, and disability issues to improve the quality of lives of the children and families. Advocacy needs are illustrated through the frustrations of these two families in the following email excerpts. The context of the each email is related to school placement, testing, and support services.

Why do we have to go through these education headaches every year? Why can't they just give him what he needs where he needs it? It's so frustrating.

and

This will be Jim's 6<sup>th</sup> school in 6 years. .... We have worked hard this year and spent a lot of \$\$\$ with an advocate to lay out the ground work for a better program for Jim. We are currently at a school that is willing to work with us within this program. Jim is finally progressing like he never did in the 4 years before this. I am just sick about it all.

There is also a demonstrated need for members to advocate as a group. In the next email, this mother uses the listserv to widely inform other members of the need to contact congresspersons regarding an upcoming legislation.

On April 29, 2003, we are asking every parent, advocate, student, and teacher who cares about educating children with disabilities to call their Congressperson and voice opposition to H. R. 1350....

In a response to the posting, another mother confirms the need by expressing her appreciation for the reminder and adds "... this is really more important than many people realize until their child gets in the school systems in the US."

In summary, members demonstrated a need for a forum to develop strategies for thinking and feeling about what they are experiencing which will be presented more thoroughly in the next section regarding the availability of support for members of the Preemie-L listserv.

### **Support Availability**

The two major categories of support observed were information and social support.

#### ***Information sharing.***

The list provides dynamic informational support in accordance with the needs of the group about issues related to prognosis, resources, medical care, daily living management, disability, therapy, and finance. The information ranged from advice to referenced information.

In this email, specific information, along with the web site address, is presented as informational support. Note that there was no earlier request for this information but was offered by this member as a service to others to increase awareness of resources off the list.

Hi Everyone,  
There is a great article about the benefits of vision therapy in special kids today.  
You can reach it at  
<http://specialkidstoday.com/resources/articles/visiontherapy.htm>

This next email is more personal but serves as an informational resource for others going through the same circumstances.

The therapies you are receiving now should be covered though Early Intervention. Most private insurance will not cover therapy that's not rehabilitative (ie short term) in nature. They are really reluctant about PT unless it has a short term specific goal. This is one of the many challenges that parents aren't really informed about in the NICU, even if the neo's (*neonatologists*) discuss long term impacts like CP, etc. Partly it's not their fault, they just don't know that if these children need continual therapy that funding for that therapy will be hard to get, harder to keep, and often comes directly out of the parent's pockets (especially school age). A CP diagnosis probably won't garner you anything in the way of insurance funding for therapy, but might open up other sources of funding such as United Cerebral Palsy, Shriner's Hospitals, and Children's Miracle Network.

Shared from an insider's viewpoint, the veteran mother provides advice and information regarding therapies, the role of early intervention services, reimbursement complexities, and funding resources. The message is delivered in a mentoring tone as the more experienced member takes the novice parent "under her wing" to educate her about the "secrets" of obtaining therapeutic services. The underlying message is that the new mother must understand that the impact of prematurity is long term. Most importantly, the informational support advocates for the less experienced parent to actively assume responsibility for her child's outcome.

Members often search for explanations for what is going in their children's lives. An important role of the list is to provide plausible explanations for uncertain situations or phenomenon that just can't seem to be explained by current medical science. For this mother, an event that happened over three months earlier continues to be a source of concern. Worriedly, she solicits the group for their thoughts as she tells the story of her daughter falling off the couch.

Maron rolled off a very low couch onto a rug on May 14 (almost 3 months ago) – she landed on her back. When I picked her up she was breathing shallowly and seemed passed out. I freaked – called 9-1-1 she meanwhile started coming to, crying softly. At the hospital she went through a series of tests to check for concussion, etc. – all clear. Fast forward to July 9... Suddenly Megan went limp – and I recognized the same features from May 14... thought she knocked herself out the first time, but now I suspect some sort of seizure or even epilepsy...

Responding, a fellow member, who happens to be a nurse, answers with a plausible explanation.

It sounds like she definitely could have been into her "seizure" when she rolled off the couch or it could have triggered it.... I would most certainly have her seen by a pediatric neurologist as soon as possible. ...

In addition, she offers a plan for immediate action for the suspected condition. She uses the words "most certainly" and "as soon as possible" to emphasize the urgency that the mother should not delay in having her child evaluated by a physician. The information provided as support on the listserv may be understood as "taking care of each other" that is also part of the social support aspect of the group.

***Social support.***

The list provides an interactive social setting that offers opportunities for shared experience and a sense of belonging that confirms their experience, as seen through this welcoming message. .

I just wanted to say congratulations on your son's birth.... Hang in there and remember to take it a day at a time, it can be a roller coaster at times. You and your families are in my prayers

Finally, the need for social support extends beyond the virtual world as members seek extend friendships that have emerged online to the real world. In this instance, Shannon, who lives in a large, metropolitan, Midwestern city, offers her home for a pool and pizza party.

Hi guys,  
... I am inviting any interested Premie-Lers to my house on August 1st. We will swim and eat and chat from 10:00 am until however late anyone wants to stay....  
And all are welcome.  
Shannon

Confirming the need to get together, this mother replies, "I highly encourage anyone who can to seek out these opportunities to meet other "Premie-Lers". It is an amazing connection. Shannon's pool party is definitely on my calendar....". Other examples of

need to meet face-to-face are, as follows: "... I'm up for a Friday night cheesecake outing in July" and "I'm up for a zoo trip...". Most convincingly of the need to get together is the announcement from the listserv owner that Premie-L will be hosting a conference in August, 2004.

Hi everyone,

I have some great news! Premie-L will be hosting a conference jointly with Premie-child in August next year. YMCA of the Rockies in Estes Park for Wednesday August 18-22, 2004. We have an entire building reserved with 98 rooms that will hold 2-4 people each (I believe).... It will be fun to all be in the same lodge.... This will be our fourth ....

A testimonial from a previous conference attendee provides evidence of the need for such face-to-face conferences.

... I am so excited to be able to start planning for my trip out to the next conference. A thrilled to be going back to Estes Park It was such a great location! Also having us all in one building will be nice. Something I would love to see on the list of topics would be the effect on the family (especially siblings) of dealing with a child who has multiple mild or "invisible" disabilities. I'd be happy to help whoever you got to do it with my thoughts and the things that our family has faced. Can't wait until August 2004!!...

There are numerous examples of social support that will be more closely discussed in the following section regarding the value of the listserv.

### **Role of Premie-L: member perception**

The final section provides evidence to substantiate the members' perceptions regarding the role of the Premie-L to enhance the family's caregiving ability for their child and the well-being of the their child and family. The on-line testimonial messages and the stories that link off-list actions provide evidence that they value the social support, the informational support, and consider the Premie-L online support group to have meaningful relevance that goes beyond the Internet experience. The members feel that Premie-L increases their self-confidence, facilitates a sense of control over

challenging situations, and facilitates the active pursuit of goals that positively affect the future of their children and the well-being of their family.

The following passages are some comments that lend to the understanding that the members of Preemie-L value and enjoy the support of the community: "Is something wrong with the email system? I've not received any messages for 3 days? Miss you all!" (*value of social support*); "Just thought I'd come here for some frank answers" (*value of information*); and "I appreciate your reply. It is so comforting to know that other people are going through the same emotions, stress, and uncertainty that we are." (*value of social support*). Additionally, this mother expresses her appreciation for the support that she received that she perceived helped her to improve her ability to manage her daughter's behavior. "Thanks very much for all of your responses regarding my daughter Jenny's anxiety and SI (*sensory integration*) issues! You gave me some great ideas to help her deal with these problems. You are all such a great source of support." (*value of informational support, providing strategies to manage daughter's challenging behaviors*). In another example, this member provides evidence that "just lurking and listening" is advantageous. "... Thanks for all the support over the past year. Even just lurking and listening to conversation threads can be a great help..."

In one last example, poignantly, a member writes a message of support and the values of her own experiences with Preemie-L, in remembrance of the birthday of an infant girl who had died whose mother was a member of the list.

...Right now you are in the darkest moments that I hope you ever experience. None of our words will really change that. All we can do is let you know we are here and that we're willing to listen if you want to share some of your thoughts. ...The best advice I can give you is seek out those safe people and places so you can go running to them when you are ready to explode. I found the computer so good for that - I didn't have to wait for weekly support group meetings, I could go and pound out things on the keyboard at any time of the day or night.

This email provides a summation of the perceived value of the list with regards to support from an Internet-based support group that is "always there for you."

## CHAPTER 5

### DISCUSSION

There are many truths of which the full meaning cannot be realized until personal experience has brought it home. John Stuart Mill English Economist 1806-1873

With respect to studying experience, Denzin (2003) states that "the researcher strategically selects sites for interpretation that constitute the intersection of texts and interacting individuals" (p. 1012). The Preemie-L community was strategically selected because it offered a "virtual front porch" where a diverse population of families with premature infants had an opportunity to meet for meaningful conversation about issues that are important to them. The conversations that emerged from these virtual chats provided me with an opportunity to become involved as a sympathetic listener for the purpose of understanding their online culture and lived challenges of these families ENRfu(Herman-Kinney & Verschaeve, 2003). Though the in-depth text analysis portion of the study only comprised five months of listserv interactions, the conclusions greatly took into consideration the insight obtained from over two years of monitoring the list (pre and post text analysis), the archival findings that I analyzed, the discoveries obtained in the pilot study from "real world" families with similar experiences, and member check confirmation. This combination of research strategies served to establish the unique experiences of the group members of Preemie-L as relevant to a larger sociological and historical framework within today's society ENRfu(Denzin, 1989).

### **The Family: Implications of the Premature Birth**

As supported in the literature, the stories told by the members of the Premie-L confirmed that the increased survival rate of the premature infant is definitely not without cost ENRfu(Deihl et al., 1991; Jackson, Ternstedt, & Schollin, 2003, Verma, 2003; McCaleb & Luther, 1996; Miller et al., 1998; Palfrey et al., 1991; Sherman, 1995). The impact was observed to have long-term implications that effected the well-being of the families. Impact will be discussed according to the categories of health-related impact, impact of forced relationships, and intense psychological impact.

#### ***Health-related Impact.***

Members confirmed what is reported in the literature that health -related issues create enormous stress for the families ENRfu(Botting, Powls, Cooke, & Marlow, 1998; Cohen et al., 1996; Hogan & Park, 2000; Kaplan & Mayes, 1997; Lorenz, 2000). Health-related issues included chronic lung disease, nutritional and digestive issues, vision and hearing disabilities, neurological impairment, and developmental delays. Findings from longitudinal research examining the impact of prematurity show those premature infants with the lowest birthweights have the most complications after the birth ENRfu(Verma et al., 2003). The birthweights of the premature infants were not available universally from the members but indications from those that mentioned birthweight suggested that many were of extremely low birthweight. Furthermore, the longest longitudinal study provides evidence that these problems persist into young adulthood influencing educational success and ability to function independently ENRfu(Hack et al., 2002).

In a wider scope beyond the family, the impact is being recognized with regards to societal concerns. Recognizing the seriousness of the situation, the Social Security Administration (SSA) of the Department of Health and Human Service authorized the Agency for Healthcare Research and Quality (AHRQ) to prepare an evidenced-based report regarding the impact of prematurity for infants born with birthweight less than 1500g ENRfu(Quality, 2003). The intention of the report was to assist in the prediction

of disabilities of infants and young children for future funding implications. The methodological design of the report included a vast systematic literature review of original data regarding predictor and outcome variables related to disability. Evidence presented in the report confirmed that infants born with very low birthweight (VLBW) are at significant risk for abnormal cognitive development, neurologic disability, speech/language delays, hearing loss, behavioral disorders, learning disabilities, and visual disabilities. The health-related impact as described from the families' point of view combined with research evidence substantiate the gravity of the situation as related to the well-being of the family and the society as a whole. Related implications include financial concerns, caregiver employment, family management with daily routines, and concern for the future.

***Impact of Forced Relationships.***

Very low birth weight infants with multiple health-related needs require traditional well-baby follow-up and specialty follow-up from pulmonologists, gastroenterologists, nutritionists, neurologists, and developmental pediatricians ENRfu(Broyles et al., 2000). Minor illnesses in these very small infants may quickly escalate to life-threatening illnesses without quick, effective treatment. These issues cross the line of socioeconomic boundaries and effect the poor as well as the wealthy.

The normative experience for new parents is to obtain a pediatrician for their infant. Families with premature children not only have pediatricians but also have the requirement for numerous specialists that become an integral, necessary part of their lives. The on going health-related needs and disability-related issues necessitate families to closely collaborate with professionals from a wide range of medical and educational specialists. As observed in the lives of the listserv families and reported multiple times in the literature, the necessity of working with professionals is a source of strain ENRfu(Fialka, 2001; Fitton, 1994; Stephenson, 1999; Wang & Barnard, 2004). Families

of the Premie-L were observed to seek an active role in the arduous journey of cultivating relationships that were responsive to the needs of their families.

McGrath (2001) adopted the Model of Guarded Alliance to explain relationships between professionals and families in the NICU. The application of this model is extended to the families of the Premie-L to explain how these families perceive their role in collaboration with professionals. The three major stages of relationship as defined by the model are State I: Naïve Trust; Stage II: Disenchantment; and Stage III Guarded Alliance: Reconstructed Trust. During the initial stage of naïve trust, the crisis or the newness of a situation typically overwhelms family members causing them to feel that they do not have the competence to participate in decision-making. First time postings from newcomers from the listserv confirm the feelings of vulnerability in the NICU experience. Also, as was portrayed through the stories of Premie-L families, they begin to experience disenchantment at some point when they realize that professionals do not hold all the answers to the many questions of prematurity. Following the disenchantment stage, families begin to develop strategies, defined as the guarded alliance, to regain control of their child's future.

The adaptive strategies of the families are categorized into the subcategories of hero worship, resignation, consumerism, and team player. Each category involves different levels of perceived trust with the professional. Hero worship involves explicit trust in only one individual for all information and support needs. At the opposite extreme, resignation is characterized by a complete lack of trust or initiative to collaborate with professionals. The next two categories are more likely to provide an explanation for the behaviors of the Premie-L families. Consumerism is a term used to describe the behavior of families that go to great lengths to become expert consumers about their child's circumstances. This process, associated with increased energy expenditure of the individual, involves seeking outside information and resources in preparation for working with the professional. The last category, involving the highest

level of trust, involves the family actively participating as a team member in the decision-making process with the professional. The team player category is considered to be less energy intensive as compared to the consumer type because families in this category have a sense of confidence that involves obtaining trusted information from the professional that will result in family-centered intervention for the family.

There were several examples described by the Premie-L families that indicated that they felt like team players in their relationships with professionals. There seemed to be more trust relationships exhibited with pediatricians and early intervention service providers probably because these relationships involved a greater amount of time together as compared to other professionals or specialists. More often than not, members were observed to be functioning as "consumers" who felt that they had to "arm" themselves with knowledge for the purpose of collaborating with professionals. The ambiguity of the situations surrounding prematurity seems to serve as a catalyst for families to seek for other resources outside their professional network. The search for outside information is perceived as a quest by these Premie-L family members to gain control of the situation. The institution of the Internet as an everyday tool in the lives of these families makes it easier for families to act as consumers of information.

***Intense Psychological Impact.***

***NICU experience.*** Emotional impact related to the birth of a child for many families is well documented in the literature ENRfu(Goodman, 2004). Findings confirm what is already known that parents with premature children experience intense psychological distress during the neonatal period and immediately after discharge from the NICU ENRfu(Davis, Edwards, Mohay, & Wollin, 2003; Griffin, Wisba, & Kavanaugh, 1998; Meyer et al., 1995; Singer et al., 1999). In addition, the findings from the Premie-L group support previously reported research that the technological environment of the NICU is often frightening and overwhelming to the new parent who is concerned about the outcome of their infant's medical condition ENRfu(Seideman et

al., 1997). The knowledge gained from the families' stories substantiate previously published evidence that families do experience emotional distress in the NICU from a loss of the normal parental role, a perceived feeling of helplessness with loss of personal control, and stress from daily logistical problems related to visiting the NICU ENRfu(Affonso et al., 1992; Meck & Fowler, 1995). In a previous study, depressive symptoms reported by mothers of premature infants are reported to be nearly three times the symptoms experienced by mothers with children of typical births ENRfu(Meyer et al., 1995). Most studies have focused research intent on the mother's perception of stress with only recent studies beginning to study the experiences from the father's point of view ENRfu(Jackson et al., 2003).

Several members of the Premie-L listserv were observed to retain vivid memories of NICU experiences that persisted even when their child was of school age. Affleck et al. (1990) reported that mother's retain specific memories related to the NICU at six months post-discharge from the NICU. Most commonly the intensity of memories were related to the medical acuity of the infant's condition, competency of the mother's coping behaviors, and difficulties with professional relationships in the NICU The implication of studying a family's long-term memories of the NICU experience is to discover predictive variables that may be associated with negative psychological outcome of the parent and to assist in the improvement of family-centered programs in the NICU.

**Death.** The findings show that death plays an unwelcome role in the lives of these families. Capitulo (2002) who studied an online support group for perinatal loss states that "parental grief is among the most difficult and painful bereavement experiences (p 1)". The aspects of death that are woven into the lives of many of the family members are associated with miscarriage, stillbirth, and neonatal death. These dreams encompassed the loss of a normal pregnancy, the loss of future pregnancies, and ability of their child to assume a satisfying outcome within the context of their family and society. These findings bring to the forefront that these families do experience on-going

sadness, mourning, and regret related to the death of *expected* outcomes. Including the category of "loss of dreams" under this topic area may not seem appropriate but feelings shared by list members provided enough evidence that there was a similar bereavement response related to "things that could have been" to include their experiences in the same category as physical death. More research is indicated in this area to support families during this process.

Additionally, family members from the Premie-L who experienced death of an infant were similar to the mothers of the previously mentioned perinatal loss online support group ENRfu(Capitulo, 2002). There was an expressed attachment to their children after death and a concern in both groups that their children would be remembered. Both groups spoke by name of their children and added their birthdays and remembrances to their bylines. Perhaps, the families in each of these groups found safety in their ability to express these feelings in these online support groups where they would not normally feel comfortable sharing openly with others who had not experienced the situation.

The importance of understanding the aspect of deaths in these families is becoming more significant in our society. In vitro fertilization (IVF) has become a much more routine choice for families with infertility problems ENRfu(Arias, MacDorman, Strobino, & Guyer, 2003). Associated with IVF, there has been a subsequent increased report of multiple births, prematurity with extremely low birthweight, and infant loss from complications. Also, there are an increased number of families who are confronting the loss of one infant while at the same time facing the situation of having another infant from the same pregnancy in the NICU. Related to quality-of-life issues, some of the mothers of the Premie-L who had experienced loss felt that professionals demonstrated a lack of understanding of the bereavement process of parents. These findings are confirmed by the results of one recent focus group study that reported that professionals do not appreciate the intense emotional aspects of infant loss for families ENRfu(Ellison

& Hall, 2003). These conclusions should challenge professionals to become aware of the grief associated with pregnancy-related losses. Often, the focus is on the living without acknowledgment of loss, which may in the long run stifle the healthy bereavement process.

***Burden of parenting.*** The findings validate evidence from recent research that families with infants of extreme prematurity are experiencing greater parental burden as compared to infants that were born full-term or with normal birthweight even when the children reach school age ENRfu(Taylor, Klein, Minich, & Hack, 2001). In a prospective cohort, multi-site study, Taylor et al. (2001) followed three groups of children (families of 60 children with birthweights less than 750g, 55 children with birthweights between 750g and 1499g, and 49 children normal birthweight full-term controls) to examine the long-term sequelae for families with infants of premature birth. As compared to the full-term infants, parents of infants in the lowest birthweight category experienced "... lower perceptions of parenting competence, more difficulties related to child attachment, a more negative impact of the child's health on the family, and higher rates of both child-related stress and adverse family outcomes (p. 159-160). Results from parent interviews suggested that school performance issues related to learning and behavioral difficulties were significant stressors. Other sources of stress included worries about their children's future, impact on the integrity of the family, their child's ability to be accepted by peers, and caregiver burden related to alternations in daily routine. The results of the described study reflect the psychological mindset of many listserv families and provide additional substantiating evidence that the negative psychological impacts of prematurity are on-going and do not end during the neonatal period. This fact may explain why the families continue to participate as active members on the listserv even when their children are school age.

As discussed earlier in the review of literature ENRfu(Palfrey et al., 1991), the families in the studied online support group felt that coping with the multiple, health-

related issues created enormous stress on their family's lives. The health status of the infant seems to be an influencing factor regarding the level of stress perceived by the family ENRfu(Jackson et al., 2003).

### **The Family: Perceived Needs**

Based on the Double ABC-X Model of Family Adaptation, evidence presented in the review of literature explained that families develop strategies and seek resources in response to challenging events that negatively affect the well-being of their family ENRfu(Beresford, 1993; Deardorff, 1992; Ellison & Hall, 2003; Lavee et al., 1985). Specific resources desired are unique within each family but always include a combination of existing resources and the acquisition of new resources to meet the challenging demands. The findings show Premie-L online support group served as a vehicle for new resources as families sought strategies to mediate the on-going stress associated with the impact of prematurity. The Premie-L listserv provides both emotion-based resources and problem-focused resources that have been described by Deardorff (1992) to be the two major categories of *needs* sought by individuals who are striving to develop strategies to decrease stress and restore well-being.

**Informational.** The Premie-L online support group provides a venue for obtaining information and the opportunity to systematically process information with others in the same situation. This need for information has been associated with a desire to decrease an individual's perceived stress by mediating inconsistencies in previously held knowledge; to mediate fear of unknown situations; or to substantiate information previously held ENRfu(Cheng, 2003; Wood, 2000). Families obtain knowledge from a variety of sources (such as family, the media, professionals, etc.) but seem to need to acquire information from others going through the same circumstances.

**Social.** Intimate social support, typically gained from the immediate family or close friend, has been cited as a helpful resource for managing stress ENRfu(Beresford, 1993). Reports from members of the on-line support group provides awareness that

support from their immediate families and previously close friends have not been helpful in mediating the stress of prematurity because they do not understand the situation. These families did not indicate that they were socially isolated from others but were socially isolated from others who had lived the experience. The online support group provides social support from others who have lived the experience.

*Advocacy.* This category of need is a combination of informational and social needs. The findings indicate that many of the families from the listserv demonstrated a need to strongly associate themselves with a group that aligns with their own perceptions of a situation. This need is founded on a desire to increase their sense of self-efficacy over their own circumstances that includes acting collectively as a group to facilitate change. Based on social cognitive theory, a sense of human agency over one's life is associated with the ability to make positive adaptations to stressful experiences that has forced changes in one's life ENRfu(Bandura, 2002).

### **The Family: Gaining Control**

The process of gaining access to the Premie-L online support group was observed to be a powerful resource that facilitated a family member's acceptance of the stressful situation and provided information that improved a family member's sense of well-being and their ability to care for their child. As noted in other online support groups (Ahmann, 2000), the Premie-L offered the convenience of staying at home while connecting with others with similar circumstances from around the world. Specific mechanisms with respect to the community and the underlying mechanisms of the support processes will be discussed as related to gaining control over the associated stresses of prematurity.

*The Premie-L: The Virtual Community.* The Premie-L group is a "single function online support group" ENRfu(Fingeld, 2000, p. 244) whose sole purpose is to support families with children born prematurely. One of my undertakings was to compare how the characteristics of the Premie-L online support group compared to previously

reported characteristics of face-to-face support groups. Consistent with the findings based on face-to-face support groups by King et al. (2000), the virtual community of the Premie-L exhibited a shared purpose; a growing sense of belonging, and self-efficacy that increased over time. So, the question still remains "What makes the Premie-L online support group more appealing to its group members than a face-to-face group?" As noted in the literature, the critical difference between the "real world" and virtual support groups have been linked to the technological features of the Internet ENRfu(McKenna & Green, 2002). As discussed, research is extremely limited in the area of online support groups for families. In a search of the literature, only one exploratory research study of an Internet support group was found that specifically studied an on-line support group for families ENRfu(Han & Belcher, 2001). The findings of the Han & Belcher (2001) study were similar to the reported findings in my study of the Premie-L. Members of both groups expressed that they were drawn to online support groups because of the 24-hour availability, the ability to connect with those with shared experience and selective participation. As evidenced in the Premie-L support listserv, the group was always in session and that there was always someone to talk with who had undergone the "preemie experience". Finally, members appear to value family unity and there is a prevailing assumption that families desire the best for their children as observed with their concern for their children.

***Informational Support.*** In review, the combination of information and ability to process the information with others provides a strategy for coping. The power of education to improve a person's sense of self-efficacy is a classic premise by the well-known social psychologist, John Dewey ENRfu(Musolf, 2001). Dewey was a strong believer in the theoretical framework that embraces the concept that individuals through acquired cognition have the adaptive capability to change their circumstances to meet the everyday challenges of their lives. He also believed in the power of interaction among individuals to produce adaptive change. Through the process of information exchange,

Preemie-L provides a venue for change in a member's ability to care for their children. In summary, Internet group provides informational exchange that fosters a new perspective of thinking for informed decision-making regarding care of their children. Most importantly, the new knowledge increases self-confidence that these family members are not victims of their circumstances.

***Relational Support.*** Bowman and Bowman (1998) explain that critics of virtual communities (that is, scholars, counselors, business administrators, and so forth) have raised the debate that the lack of "...access to visual cues, inflections of voice, body language, physical conditions...(p. 438) threaten the development of genuine, meaningful social relationships. Conversely, as supported in the literature ENRfu(Montero & Stokols, 2003), the members of Preemie-L were observed to use the cognitive processes of "...attention, memory, and learning, in combination with more complex processes, like emotional reactions..." (p. 64) to adeptly negotiate technological issues for the development of meaningful relationships. The information obtained from this study serves to provide evidence that on-line members are very capable of managing the issues of social intricacies without the availability of aural and visual cues.

The Preemie-L online support group provides support to its members by providing a feeling of connection through the observance of rituals, the provision of emotional ties, the fostering of rights and obligations, and the opportunity to experience a level of familiarity that no one else outside the group could offer. The rituals and strategies described by the listserv members were very similar to findings reported from approximately 200 parents who described their life management strategies for parenting a child with disabilities ENRfu(Scorgie & Wilgosh, 2002). The Preemie-L group and the parents in the research study used social support to celebrate birthdays and milestones, reinforced positive attitudes, fostered trusting instincts, and encouraged keeping a sense of humor. These rituals, traditions, and support provide a sense of comfort to the families in both groups.

Finally, the findings from Preemie-L study support the notion put forth by other researchers that the phrase "on-line support group" is a misnomer because it implies that all interaction takes place solely within the virtual world of the Internet ENRfu(Bellini & Vargas, 2003). The use of on-list, off-list, and other activities (such as phone calls; snail mail) serves to provide evidence that these virtual communities are real people who interact meaningfully with each other using an interconnected web of virtual and "real world" resources. Early studies provide evidence that the primary role of computer-mediated communities is to provide a meeting place for discussion and the true "community" of the on-line support group occurs within the social context of the members, both on- and off-line ENRfu(Parks, 1996). As Parks (1996) insightfully stated "the fact that relationships that begin on line rarely stay there raises even more profound questions about our understanding of cyberspace" (p. 93). The acceptance of this concept is important because it helps us understand the social support of the Preemie-L.

### **The Family: Well-being and Preemie-L**

A theme that has been reiterated several times and is worth repeating again is that meaningful interaction on the list provides opportunities for problem solving from a collective experience and influences the development of self-efficacy.

*Identity.* Based on symbolic interactionism, Vryan et al. (2003) provides the following insight regarding situational identity.

...as we come into the presence of others, we mutually construct a definition of the situation with an essential feature being the identities of the participants . Defining our own and others' situational identities allow us to know how (and how not to act); it informs our expectations and interpretations of our own and others' behavior. (p. 368) ENRfu(Vryan, Adler, & Adler, 2003)

In the context of the online group, the family is able to let their guard down, ask questions, find out how others acted in similar situations, and then begin to develop strategies in response to certain situations. The confidence gained from the re-defining of identity ultimately facilitates a sense of well-being. Seemingly, families that do not have

access to this type of support group, either on- or off-line, would have fewer opportunities for adaptation outside their initial roles.

*Human Agency.* One of the critical outcomes of this study is that it provides evidence that the Premie-L online support is a vehicle for human agency with the outcome of promoting self-efficacy in these families. The power of agency is implemented on three different levels of action ENRfu(Bandura, 2002). By definition, personal agency is implemented as an individual; proxy agency relies on someone else to bring about a desired outcome; and collective agency relies on group action to accomplish goals. All three levels of agency were observed within the interactions of the group.

Individual members of Premie-L were observed to exercise personal agency as they sought the resources of Premie-L to improve the circumstances of their individual situations. The expansive ability of the Internet to span the world has been shown to facilitate the acquisition of resources that these families would have had difficulty finding in their own immediate community. The acquisition of these resources was observed to empower a member to exercise personal agency. The belief that one has power to negotiate challenging circumstances in life is the essence of self-efficacy ENRfu(Bandura, 2002).

Self-efficacy beliefs regulate human functioning through cognitive, motivational, affective, and decisional processes. They affect whether individuals think in self-enhancing or self-debilitating ways; how well they motivate themselves and persevere in the face of difficulties; the quality of their emotional life, and the choices they make at important decisional points which set the course of life paths. " (p. 270-271)

Proxy agency plays a smaller role on the listserv. This type of agency is observed through the testimonials from list members that have experience as lurkers. These silent members intentionally do not actively interact but receive the benefits of others' communications.

With respect to collective agency, the group was observed to pool resources to advocate change for the purpose of improving the well-being of the lives of the families of Premie-L. There is a perceived collective agency that the group does serve the needs of the members as evidenced by the messages of the members. Perceived collective agency has been shown to enhance group functioning and may provide a possible explanation of the longevity of the online group.

In summary, the success of the group would not be possible if there was not a combination of human agency and collective agency. For an individual family member to feel successful in his or her ability to improve the well-being of their family, there must be a an associated feeling of ability to exercise control over one's life. This group seems to value the individualism of the families as well as the collective power of the group to improve the well-being of the individual families.

CHAPTER 6  
IMPLICATIONS FOR THEORY, PRACTICE, RESEARCH,  
EDUCATION AND POLICY

***Introduction***

Prior to the study, as influenced by the writings of Dallas Willard (1998), I reflected on the quintessential ingredients of qualitative research and realized that I was drawn to discover those aspects of a person's experience that are not visible to the eye such as personality, will, character, desires, needs, and resiliency. This understanding of my internal motives led me to pursue a qualitative research design that resulted in a descriptive cultural portrait of the lived experiences of families with premature children who participate in the Premie-L online support group. Based on my professional working relationship with families with premature children, I entered this study with preconceived assumptions that guided my inquiry into the challenges that these families face. Documenting my assumptions at the onset served as a measuring stick to gauge from whence I came. I assumed that there was a gap between the standard of medical care and what the families perceived that they needed and finally I assumed that the online support group was a positive resource to help families cope with challenges associated with prematurity. As I progressed through the study, I became increasingly aware that my assumptions were only superficially on track. As guided by assumptions, implications for theory and practice, research, education, and policy will be discussed.

### *Implications for Theory and Practice*

The findings of the Premie-L online support group served to construct a collective story of multiple realities that lead me to a deeper understanding of the impact of prematurity on their lives. Forte (2003) explains that:

Symbolic interactionism (SI) offers a distinctive sociological imagination: a disciplined capacity to identify the personal troubles, joys, and self-indications of group members and locate these lived experiences in collectively constructed symbol systems and in associated social arrangements, social processes, and public issues ENRfu(Forte, 2003) (p. 916)

I discovered that the email messages from family members were typically shared as stories that provided me with the unique opportunity to broaden my understanding of the complexities of the issues within the context of many different families. Through the stories of their real life experiences, I was able to comprehend the threads of similarities and shared beliefs that brought them together as families with premature children. Online support groups, who do not use this narrative, conversational form of interaction, may not provide this same opportunity for gained knowledge of lived experience.

Through my role as physical therapist and early interventionist, I began this study with an assumption that families with premature children are under significant stress as related to impact of prematurity. What I didn't appreciate prior to this study was the complexity of the impact of prematurity that is on going and cumulative. The findings confirm that the families must continually find new resources to adapt to the challenges that are presented, as the child grows older. Implications are that the challenges are just as intense at school age as at birth. The significance is that, not only, the present health of the family is at risk, but, the future health of the family is at great risk. The need for support programs that assist families should be an integral component from birth onward with a life-span approach.

The Premie-L support group was found to be a positive support that improved the functioning of families with premature children. Since family functioning influences the developmental outcome of children, providing access to computers (such as in the

NICU) for families with limited access to computers is implicated. Promoting membership by professionals would also increase knowledge of the families' perspectives.

### ***Implications for Research***

#### ***Methodological Design: The Virtual Ethnography.***

One of the implications is that the research design may be used as a model for future ethnographic studies whose purpose is to understand real world experiences of participants as facilitated through cyberspace meeting places. Previous understanding of virtual communities was that these communities exist in a parallel universe to real-world experiences ENRfu(Parks, 1996). In opposition, the findings of the Preemie-L study implicate that are in existence virtual communities that are not detached from real life. The members of the Preemie-L were observed to form personal relationships that migrated to off-line and continually interchanged aspects of physical daily life with on-gings of online activities in their online communications. The research design based on the Preemie-L listserv interactions suggests that the study of online communities are a viable option to study culture without the expense of losing offline *real world* activities.

In keeping with recent developments in ethnographic research, this study served to redefine definitions of classic ethnography (such as physical locality, long-term, intensive fieldwork, and participant participation) to encompass the cultural processes that exist in a textual community of real people ENRfu(Eichhorn, 2001). In virtual ethnography, the researcher no longer travels to a physical location for study but is able to access "the place" from his or her home ENRfu(Eichhorn, 2001). The *place* that is of critical importance in traditional ethnography was considered to be more of a symbolic value within my virtual ethnography.

Traditionally, participant observation is an integral component of ethnography. Redefining participant participation, I observed the online conversations of the online members without participating in the conversations. In traditional ethnography,

participating in face-to-face situations with participants involves physical presence. Following the research design of the ethnographic study of Trinidad ENRfu (Miller & Slater, 2001), my role as participant observer was to monitor the interaction's on the Preemie-L. The implications of the findings were that I was able to gain extensive cultural knowledge of an online support group through long-term observation without interrupting the environment. On the other hand, my initial research during the pilot study, I did engage in traditional ethnographic methods. I performed interviews and fieldwork studies that provided me with a greater understanding of the impact of prematurity and was instrumental in developing the research questions for the study. Implications are that when the purpose of the study is to gain knowledge about a real world group of people; the outcome is enhanced when traditional ethnographic methods are used in combination with the newly constructed methods of virtual ethnography.

***Future Research Implications.*** Each category discussed in the impact and perceived sections have implications for future research. There is a significant need to follow these children born prematurely in longitudinal studies as there is only one study published that has followed premature into young adulthood ENRfu (Hack et al., 2002). The subjects in that study were primarily of low SES and from an urban city. Further longitudinal research is indicated as more premature children are surviving of lower birth weights as compared to 20 years ago. The outcome and impact on the family in the next 20 years is unknown secondary to the on-going advancements in medical knowledge and technology. Additional knowledge will help guide the process of decision making in medical and educational programs that ultimately affects the future of these families.

Recent studies report changes in the epidemiology of multiple births in the U. S. ENRfu (Russell, Petrini, Damus, Mattison, & Schwarz, 2003). There is a need to specifically study impact on families with multiple births (such as twins, triplets, quadruplets, etc.). As a result of multiplied stress factors, particular research questions would be to discover if they have different or additional needs as compared to families

with single premature births. Also, there is an indication to compare the outcome of multiple premature births with single premature births.

There is a need to study relations between families and professionals over time as this variable was shown to be a considerable source of stress with families. A seemingly inherent adversarial role was observed to begin in the NICU that continued through school age. Research designed to uncover antecedent variables or preexisting prejudices would be helpful in the process of improving the collaborative relationships. Associated with family-professional difficulties, there is an implicated need to study the persistence of NICU memories and effects of loss of a child as related to coping and well-being.

In addition, there is an implication to study gender, racial, and ethnic differences as participatory members of online support groups. The majority of the participants of the Premie-L who posted on the listserv were women with almost no reference to age, racial, or, ethnic background in the discussions. This increased use by women as opposed to men on the listserv contradicted findings from the literature that provides evidence of a gender gap in Internet use with men using with greater frequency than women (Morahan-Martin, 1998). In addition, very few studies have examined the use of Internet support groups as a function of race and ethnicity. Recently, Fogel et al. (2003) investigated the potential psychological benefits of an online breast cancer support group as related to race and ethnicity. The study included 189 white, African American, and Hispanic American women. Differences reported among categories of group members showed no differences in interpersonal social support except for the categories of belonging and self-esteem where the minorities perceived a lower level of support as compared to the Caucasians. The decreased perception of belonging is an important finding because the findings from the Premie-L group indicated that a sense of belonging played an important role in helping family members cope with the stressful situation of prematurity. Future research into the demographics of group participation may have societal and clinical relevance to coping and online membership.

### *Implications for Education*

First, there is a need to educate professionals about the family's point of view regarding their concerns and priorities of need. The implication is that professionals who have a greater understanding of the family perspective will experience improved working relationships. As discussed, the quality of the family-professional relationship has been shown to play a critical role in the outcome of the child and the well-being of the family ENRfu(Van Riper, 2001).

Furthermore, professionals are traditionally educated in the specifics of their fields with limited guidance on how to meet the needs of families undergoing cumulative or acute stress ENRfu(Latourneau & Elliot, 1996). In practice, professionals are beginning to tune into the needs of the family but lack critical understanding of the relationship between stressors, coping, and psychological well-being of the family. As each family presents with their own complex scenario, the professional must be able to adapt to each family for effective intervention. Therefore, professionals would benefit from education regarding foundations of family systems theory to increase their competence to assist families. This process includes recognition of stressors, the understanding of resources to adapt to new situations, and coping mechanisms that facilitate well-being of the family. Specifically, there needs to be education regarding the bereavement process that families undergo as a healthy process of adapting to the loss of a child.

On-going psychological stress had been shown to have a negative impact on parenting and child outcome in families with premature children ENRfu(Melnyk, Feinstein, & Fairbands, 2002). Educational programs designed to increase professional competence in early signs of psychological stress of parents are implicated. The importance of early intervention has been stressed in this area because the problems seem to escalate over time with increase parental anxieties, negative parent-child interactions and problems related to developmental outcome.

From my association with professionals, there seems to be a lack of understanding about the benefits of these online groups and a fear that families will receive misinformation. Educational programs aimed at increasing the professional's awareness of the benefits and demystifying the role of the online support group would be helpful. Encouraging professionals to join list or read the public archives would be another strategy to increase awareness of family concerns and decrease fear about the online groups.

***Implications for Policy.***

The family is very essential to the success of society but is strongly dependent on the quality of relationships within and outside the family. Individuals from well-functioning families are thought to be emotionally balanced and contribute to the well-being of greater society. Societal influences that affect a family are social norms and prejudices, governmental regulations and policy, and societal institutions that affect opportunity for personal growth. Outcomes of this study provide evidence to assist in the development of public and healthcare policy and funding authorization to support these families. Specific attention is indicated for funding that increases the eligibility of premature children in early intervention programs for follow-up, funding to support families with financial needs related to the complex health-related needs, funding for counseling to promote psychological health of the family members, funding for programs that facilitate advocacy, and funding for longitudinal studies that increase the knowledge of the impact of prematurity on educational outcome. Financial support for family planning and transitional programs to the community from school are warranted as recent research indicates that many children born prematurely have difficulty functioning independently in society.

**Limitations**

The outcome of this study is limited to the expressions of the messages that are posted on the Internet forum at the time of the study and from archival data posted on the

home web site of the Internet forum. The results of this study may not represent the views of families with premature children who did not post messages, whose messages were censored, or families without computer access. This online discussion forum is a moderated site, meaning that all messages are read by members of a committee prior to posting of the message. Messages that are considered to be abusive, objectionable, or questionable in authenticity are not posted on the forum. Only one online support group for families with premature infants is studied and results may not be generalized to other online support groups.

### **Conclusions**

The growth of the Internet has contributed to the development of a new kind of support group that goes beyond the confines of a face-to-face support group. One of the most significant outcomes of these online support groups is that they create a global environment that produces intercultural commonalities that encompass issues surrounding prematurity. ENRfu(Bandura, 2002). Beliefs, values, and information can be transmitted within unprecedented amounts of time as never before. Whereas, in the past, these families would have felt socially isolated. They, now, have the opportunity to quickly develop meaningful relationships with others who have experienced similar situations; leading to improved well-being of their families.

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APPENDIX A  
ENUMERATION OF PREEMIE-L WEB COMPONENTS WITH SELECTED  
EXAMPLES

## APPENDIX A

Enumeration of Preemi-L web components, with selected examples

1. Home page - presents the mission statement and an overview of purpose, resources, and links to the web site (see p. 133)
2. Discussion forum - a bulletin board not requiring membership
3. Preemie-L Mailing list - a listserv support group requiring membership
4. List archives - public archives of listserv support group, not requiring membership
5. FAQ's and advice - frequently asked questions and advice sheets for new parents (see (p. 134)
6. Selected resources - resources for parents that include listing of conferences, links to information sheets, recommended books and web sites (with links), photo galleries, personal stories, Spanish resources are included
7. Prematurity related list/forums - Comprehensive list of related online groups associated with the issues of prematurity, such as international preemie groups specific to a country, Preemie-child for older children, feeding problems group, post-preemie pregnancy group, and other special needs listserves
8. Preemie-L Mentors Program - online mentor program that exists to provide individual support for new parents
9. Medical and Internet Abbreviations - Comprehensive list of common medical and Internet abbreviations used on the Preemie-L (see p. 137 for list of abbreviations)
10. Recommended book list - With links to Amazon.com, the list is categorized with respect to early days, emotions and psychology, development of premature babies, breastfeeding, stories by parents, premature baby and child care, general parenting, sleeping, communications and speech development, long-term medical problems, and children's books

11. Recommended products - List of commercial products, with links, associated with prematurity, such as birth announcements, preemie baby clothes, baby carriers, breastfeeding equipment, and keepsake preemie dolls

# Parents of Premature Babies Inc.

## (Premie-L)

A non-profit foundation supporting families with children  
born six weeks or more before due date

*Having a premature baby can be a scary and lonely business. We hope that through this web site we can offer each other support and the benefits of a wide range of experiences.*

*If you would like to join the group, or find out more, follow the links below.*

- About Premie-L
- Premie-L Discussion Forum
- Premie-L Mailing List
- List archives
- FAQs and advice
- Selected Resources
- Prematurity related lists/forums
- Premie-L Mentors Program
- Medical and internet abbreviations
- Recommended booklist
- Recommended products
- 

The Premie-L web site is maintained by [Anne Casey](#)

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This page has been visited times since 27<sup>th</sup> April 1999

Premie-L gratefully recognizes the support and sponsorship of [VICNET: Victoria's Network](#), [Hewlett Packard Australia](#) and [Children's Medical Ventures](#)

## Frequently Asked Questions for Preemie-L listserve

### 1. How do I subscribe to Preemie-L?

You can receive Preemie-L mail as individual messages (the list) or as a digest (messages in batches). To subscribe to the list, address an email to [majordomo@vicnet.net.au](mailto:majordomo@vicnet.net.au)

Leave the subject line blank. In the body of the message type  
subscribe Preemie-L

Same thing for the digest except the request message will be  
subscribe Preemie-L-digest

When you subscribe to either the list or digest, you don't need to include your email address unless the address is different to the one you are sending from.

Before subscribing, please read through the [Preemie-L ground rules](#)

### 2. How do I unsubscribe from the list?

To unsubscribe from the list, address an email to [majordomo@vicnet.net.au](mailto:majordomo@vicnet.net.au)

Leave the subject line blank. In the body of the message type  
unsubscribe Preemie-L *youremailaddress*

That's it - but remember to use the actual address you are subscribed under instead of *youremailaddress*

### 3. How do I unsubscribe from the digest?

To unsubscribe from the digest, address an email to [majordomo@vicnet.net.au](mailto:majordomo@vicnet.net.au)

Leave the subject line blank. In the body of the message type  
unsubscribe Preemie-L-digest *youremailaddress*

Please note, you can't unsub from the digest unless you specify Preemie-L-digest  
Preemie-L (without -digest) won't work.

### 4. How do I change from the list to the digest, or from the digest to the list?

To change from the list to the digest, address an email to

[majordomo@vicnet.net.au](mailto:majordomo@vicnet.net.au)

Leave the subject line blank. In the body of the message type  
unsubscribe Preemie-L *youremailaddress*

and on the next line

subscribe Preemie-L-digest *youremailaddress*

To go from the digest to the list, just reverse the majordomo commands given above.

Please note, your unsubscribe request will go through automatically but the subscribe request will need to be approved and may be delayed by up to 24 hours.

**5. How do I post a message to the group?**

To send a message to the group, address your mail to [Premie-L@vicnet.net.au](mailto:Premie-L@vicnet.net.au). This works for both the list and digest. When you reply to a message from a listmember and you want the message to go to everyone, remember to cc to [Premie-L@vicnet.net.au](mailto:Premie-L@vicnet.net.au).

**Important** - Please ensure your messages to Premie-L are sent in plain text not HTML. The listowner can help if you're not sure how to set your mail to plain text.

**6. How do I contact the listowner?**

Write to [annec@vicnet.net.au](mailto:annec@vicnet.net.au)

**7. How do I use the Premie-L archives?**

The Premie-L archives, from January 1997 onwards, are at

<http://lists.vicnet.net.au/cgi-bin/lwgate/PREEMIE-L/archives/>

The archives are organized by month, most recent month at the top of the page. Within each month, the most recent messages are at the bottom of the page.

**8. Why has my mail stopped coming, and what should I do to start it again?**

If your mail stops coming it is likely that you have been unsubscribed for technical reasons. Most servers have occasional problems that cause mail to be returned to the sender (most common reason to be unsubbed). Another common reason to be unsubbed is full mailbox. ISPs including AOL and most free email accounts have a limit on the size of your mailbox and when messages exceed the limit they bounce to the listowner. If you are unable to read your Premie-L mail at least several times a week, the digest version will be a better option.

If your mail stops coming, you need to subscribe again.

**9. Why do messages bounce?**

Messages bounce when the email address you are sending from is not exactly the same as the address you are subscribed under. Messages also bounce to the listowner if they include "admin" words such as help, subscribe and unsubscribe (as well as shortened versions of these two words). The word "unstable" also causes Premie-L messages to bounce.

**10. What are "R" rated postings?**

"R" rated postings contains research, statistics, information or other content related to developmental outcome for premature children. The rating is provided as a courtesy for those listmembers who do not wish to read posts relating to this topic.

Return to the [Parents of Premature Babies \(Premie-L\)](#) home page for more information about our organization, Frequently Asked Question advice sheets, and links to other Premie-L and recommended online resources.

# Ground Rules for the Preemie-L mailing list

We hope these ground rules will help our community avoid some of the potential problems of this environment.

Your opinions are welcome! You can email any comments directly to [Anne and Gary](#).

1. Mail to the group should be of broad interest to the group as a whole, that is, those caring for premature and ex-preemie babies, and other interested people. Messages dealing with preemie-related experiences, feelings and issues, family health issues and updates on babies and siblings are welcomed by the group.
2. Please don't send attachments with your mail to Preemie-L, and don't cc Preemie-L mail to other listserves or to a large number of other addresses as this will cause messages to bounce. This is due to the software used to manage the listserve.
3. No flaming - any messages which are critical of another Preemie-L listmember should be sent directly to that person or to the listowner.
4. Controversial discussions relating to prematurity are welcome as long as there is no flaming. When ethical issues arise, the [Guidelines for Ethics Debate on Preemie-L](#) are helpful.
5. Postings that could be construed as defamatory, libellous or offensive to individuals, organisations or institutions are not to be posted to Preemie-L - we could be sued for this!
6. It may sometimes be necessary to check that stories are genuine. If you are unwilling to provide information for this purpose, should it be requested, please do not subscribe to the list. This ground rule has become necessary to protect the list from hoaxes.
7. All postings to Preemie-L are copyright to the author of that posting and permission of the author must be obtained before republishing.

Please respect the legal protocols of copyright - that means not quoting more than 10% of any article. Providing a link to material published on the internet, such as online news articles, is fine.

Please don't offer to photocopy and distribute journal articles to other listmembers as this is a breach of copyright - remember our archives are public and we could be sued.

8. Mail which has been sent to you privately should never be forwarded to the list. If you are concerned about mail received privately from another Preemie-L subscriber, please contact the listowner.
9. The writings and opinions posted to the Preemie-L mailing list are strictly the opinions of the writer, and do not contain any endorsements, or guarantees of any kind. Further, these opinions and writings are in no way meant to be considered as medical advice, nor are they meant to replace any medical advice. Always discuss concerns and questions with your physician.
10. Preemie-L membership constitutes an undertaking to abide by the list ground rules, and to be considerate of other members when posting mail to the list. Members who are unwilling to abide by the ground rules will be unsubscribed.

## **Medical and internet abbreviations commonly used on Preemie-L**

### **Medical abbreviations related to prematurity**

ACC - Agenesis of Corpus Callosum  
 ASD - Atrial Septal Defect - a hole in the wall between the two upper chambers of the heart  
 ASD - Autism/Autistic Spectrum Disorder  
 BF - Breastfed or Breastfeed/ing  
 B/M - Breast Milk  
 BM - Bowel Movement  
 BP - Blood pressure  
 BPD - Bronchopulmonary Dysplasia, damage to lungs that often occurs after long term (>28 days) ventilation  
 CP - Cerebral Palsy, disorder of the nervous system characterised by abnormal muscle tone and movement  
 CPAP - Continuous Positive Airways Pressure, low pressure maintained in lungs to help baby with breathing difficulties  
 CVI- Cortical Vision Impairment  
 CVL - Central Venous Line  
 DNR - Do Not Resuscitate, a medical order not to resuscitate a terminally ill baby.  
 ECMO - ExtraCorporeal Membrane Oxygenation - supports both heart and lung functions when other treatments are inadequate  
 ECG - Electrocardiogram - records activity of the heart (also known as EKG)  
 EEG - ElectroEncephalogram - measures brainwaves for seizure activity  
 ELBW - Extremely Low Birth Weight - under 800 gr  
 FT - Full Term (37+ weeks gestational age)  
 GA - Gestational Age  
 G-tube - Gastrointestinal Tube - tube goes through the abdominal wall and directly into the intestines  
 GERD - GastroEsophageal Reflux Disease  
 GMH - Germinal Matrix Haemorrhage, the same as Grade I IVH  
 HELLP - Haemolysis, Elevated Liver enzymes, Low platelets  
 HMD - Hyaline Membrane Disease, also known as RDS  
 HMF - Human Milk Fortifier  
 IUGR - Intrauterine Growth Retardation - result is SGA  
 IVH - Intraventricular haemorrhage (brain bleed)  
 LBW - Low Birth Weight - under 2500 gr (5lb 8 oz) at birth regardless of g.a.  
 NEC - Necrotising Enterocolitis - inflammatory bowel disease  
 NG-tube - NasalGastric Tube - tube goes through the nose and down to the stomach  
 NICU - Neonatal Intensive Care Unit  
 OT - Occupational Therapy/ist  
 OG-tube - OroGastric Tube - feeding tube that goes through mouth and down to the stomach

PDA - Patent Ductus Arteriosus - when the ductus artery fails to close after birth.  
 PDD - Pervasive Developmental Disorder, also known as Autism/Autistic Spectrum Disorder  
 PIE - Pulmonary Interstitial Emphysema  
 PT - Physical Therapy/ist  
 PTL - PreTerm Labor  
 PROM - Premature Rupture of membranes or Prelabour Rupture of Membranes, when the membranes rupture prior to the onset of labour  
 PVL - Periventricular leukomalacia, a condition where areas of the brain are affected by lack of oxygen and/or blood supply which causes damage to brain tissue  
 RAD - Reactive Airway Disease  
 RDS - Respiratory Distress Syndrome, respiratory difficulty due to immaturity of lung tissues and deficiency of surfactant in the air spaces  
 ROP - Retinopathy of Prematurity, an eye disease found primarily in premature infants  
 RSV - Respiratory Syncytial Virus - a virus causing infections of the upper and lower respiratory tract in preemies.  
 SCU - Special Care Unit  
 SGA - Small for Gestational Age  
 SID - Sensory Integration Disorder  
 SIDS - Sudden Infant Death Syndrome  
 ST - Speech Therapy/ist  
 TPN - Total Parenteral Nutrition - nourishment provided intravenously  
 TTTS - Twin To Twin Transfusion Syndrome, occurs in identical twins, can result in the death of one twin  
 UAC - Umbilical Arterial Catheter, tube inserted through artery in baby's navel, used to draw blood samples, provide nutrition, infuse blood and medications and monitor blood pressure (also known as UAL)  
 UAL - Umbilical Arterial Line, tube inserted through artery in baby's navel, used to draw blood samples, provide nutrition, infuse blood and medications and monitor blood pressure (also known as UAC)  
 UVC - Umbilical Venous Catheter, tube inserted through vein in baby's navel to give fluid and nutrients and to monitor blood pressure  
 VLBW - Very Low Birth Weight - under 1500 gr  
 VSD - Ventricular Septal Defect - a hole in the wall between the two lower chambers of the heart

Links to more detailed explanations of some of the abbreviations can be found on [The new language: common abbreviations](#) by Jane E. Brazy, Ph.D. This page is part of an excellent web site [For parents of preemies: answers to commonly asked questions](#)

### **Internet abbreviations common on Premie-L and other boards**

BRB - Be right back (chat room comment)  
 BTW - By The Way  
 DH - Dear husband (also DS Dear son and DD dear daughter)

DHAC - Don't (or Doesn't) Have a Clue  
FIL - Father in law  
IMHO In My Humble Opinion  
IMNSHO In My Not So Humble Opinion  
LOL - Laughing out loud  
MIL - Mother in law  
OTOH - On The Other Hand  
ROFL - Rolling on the floor laughing  
TTFN - Ta Ta For Now  
TTYL - Talk To You Later

<:)> Happy face

<:(> Sad face

:-| Straight Face

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Return to the [Premie-L Home Page](#)

APPENDIX B  
SUBJECTIVITY STATEMENT

## APPENDIX B

## Subjectivity Statement

I am female, Caucasian, and was born in 1955; in the small university town of Starkville, Mississippi. My childhood can be described as growing up in a traditional middle-class Southern Baptist two-parent family, with one younger brother. Both of my parents were college educated with degrees. I had a comfortable lifestyle as supported by adequate financial resources and social support from family, friends, and church. My father was a local businessman and my mother was a stay-at-home mother. My early childhood experiences provided me with a sense of family values, the appreciation of support from family and friends, and a strong work ethic.

I have been married for 27 years to the same man and have two daughters, ages 20 and 16. I do not have the personal appreciation of having a premature infant but I am a parent who understands the angst and sacrifices that is associated with parenting children.

Two significant life events occurred during my freshmen year in college at Mississippi State University. The events were that my mother died and that I met and married my husband. My mother's death was related to a heart condition resulting from complications of Rheumatic Fever when she was a child. Memories of my childhood include my mother's limited ability for physical activity and surgeries that required us to travel to another state to receive services. During my mother's surgeries, my brother and I would either stay with family or in a hotel across from the hospital. I observed how my father adapted to the needs of my mother; assuming responsibilities around the home and hiring a maid who assumed the daily household responsibilities. I do not remember my mother's physical limitations being a burden on the family because of family resources and family support. Even though physically limited, my mother assumed the role of coordinating the family activities and was very involved in the lives of her children. My mother's death created a crisis event that affected adversely the relationships and the well

being of my family. We were forced to find additional resources to regain emotional and structural equilibrium within the family. During that time, each of us perceived and coped with the crisis in different ways and sought support outside the family. This experience taught me that individual members of a family may cope differently in response to the same crisis situation. Within 6 months of my mother's death, I married and moved away. Experiencing my family's adaptation to my mother's disability and her death, provided me with the wisdom to relate to others who must also adapt to a crisis event and the associated cumulative stress over time.

During the early years of my marriage, my husband and I moved to Atlanta. I continued my education and received a Bachelor of Science (BS) in Physical Therapy from Georgia State University in 1978 and an Advanced Masters (MMSc) in Physical Therapy with an emphasis on Maternal and Child Health from Emory University in 1991. I am currently a doctoral student in Early Childhood Special Education at the University of Georgia with emphasis on early intervention and family development. My desire to seek higher education at the PhD level has been fueled by my passion to support families. I have become increasingly aware that I can not effectively implement early intervention services for any child in isolation of the family.

For over 20 years, I have clinically practiced in pediatric physical therapy in a variety of settings but my primary interest has been working with premature infants and their families. I have had the opportunity to work with these families both in the neonatal intensive care unit (NICU) and in the family's home after discharge from the hospital. My role, as physical therapist, is to support families and help them learn to interact and developmentally support their infants. The families that I have worked with have come from diverse backgrounds and have differed in family structure, ethics, values, and religion. These relationships have given me insight into rituals, symbolism, and general ways of behaving that are unique to other families; beyond the traditional two-parent family that I experienced growing up. I have learned that there are no stereotypical

families yet I have observed a common theme that runs through these families. This theme is that all families undergo stress during the hospitalization of their infant and all families must adapt to the birth of the premature infant. The families are observed to widely vary in their perception of the event and their response to the stress. The emotions portrayed by members of family range from quiet reticence to belligerent anger. An emotional roller coaster is the best word picture that can be used to describe the range of emotions displayed by the families over time. Often, I feel at loss to provide the emotional support that these families appear to be seeking.

Survival of the infant is the main priority of healthcare providers in the NICU with a growing trend towards recognizing the importance of the family in the life of the child. Support programs have emerged that attempt to address the emotional needs of the parents. In the NICU where I work, a parent support group is offered at night and is led by the hospital. This group seems to appeal to those families who are new to the NICU experience but seems to leave out those families who have transportation needs, must travel long distances, or have childcare issues with other siblings. Parents with infants who have been hospitalized past their infant's initial due date, comment that they don't want to depress the parents of new premature infants. Therefore, they are observed to drop off in attending the meetings. Once the infant is finally discharged home, the resources for parent support for families with premature infants are even more limited. The family is unable to access typical outlets of societal support because the discharging physician will frequently instruct the family not to take their medically fragile infants out in public because of the risk of infection. The families that I work with in the home have many times turned to me for emotional support and guidance. I remember feeling overwhelmed and inadequate to provide the support that they often needed, as well as, recognizing that there were limited resources that I could refer the families. These experiences have driven me to search for the appropriate support for these families.

Over the past several years, I have increasingly become involved with families who suffer the emotional toil of coping with prolonged care of a medically complex infant. I have experienced first-hand the costs to the well-being of these families. Many of these infants require long-hospitalizations and re-hospitalizations after discharge. I have observed that the highly technological environment of the NICU intimidates parents and have had parents confide in me that they lack autonomy in making informed decisions about their infant. Friction has been observed in the relationships between the professionals and the families. Occasionally, I overhear staff sincerely stating that they are acting in the best interest of the family but feel that the family does not have adequate knowledge to make informed decisions. As a member of the professional group, I understand the predicament that professionals are experiencing as they strive to provide the best care available in a changing medical world but also appreciate the family viewpoint.

I worked with one family whose infant was hospitalized for two years before being discharged from the nursery. I saw the strain on their marriage and the struggle to manage their lives with a child in the hospital. The family became increasingly detached regarding the care of their child as the hospitalization lingered on. At discharge, I observed the difficulties as the parents prepared to take the child home. I, along with others, felt guilt that we should have been more persistent at trying to engage this family with their child. The child was discharged home with a tracheostomy, oxygen support, and the necessity for skilled nursing care at home. I watched as the family struggled with the insurance company for medical coverage for nursing, medical equipment, and the therapy needed in the home. The parents were reluctant to give up their careers as teachers and wanted to continue their lifestyle that they had prior to the birth of their child. In reality, their lifestyle did change as they sacrificed leisure and time together to provide care for their child. I became aware that one of the parents had to take sick or vacation leave when the home care nurse did not come, or for follow-up appointments

with multiple medical specialists, or when the child required additional hospitalizations or surgeries. Neither of the parents had family that lived within a distance to provide support. This family's story leads me to ask several questions? Are there a growing number of families with similar issues? How do these other families cope? What are their resources that would improve the well-being for families with similar problems? Would research on this topic provide specific information that would improve legislative and health care policy to help support these families?

The opportunity that I have had to provide physical therapy in the NICU and in the home has given me a broader view of the problems that these families face. As a result of my association with families, I realize that there is a gap between the standard of care and the care the families actually receive because medical decisions are made on the perceived needs of the families. I see that the professionals in the NICU feel that they are adequately preparing the families for a smooth transition from the hospital to home. On the other hand, I see the plight of the family as they struggle to cope with the pile-up of stress factors associated with caring for their medically fragile child. From my standpoint as a physical therapist, I have become acutely aware that I cannot effectively provide physical therapy unless the emotional well-being of the family is addressed. A family that is coping poorly with the care of the child is not able to appropriately interact with their child to foster developmental needs.

I have become acquainted with several families that have experienced similar difficulties as described in the previous family's story. Interestingly, some families with similar stress factors do not seem to have the difficulties with coping and show less emotional distress. This discrepancy between the family outcomes makes me curious to learn how the resilient families differ from the families that do not cope as well. The Double ABCX model of family stress and adaptation will serve as my theoretical framework for my qualitative study because it provides an explanation of how individual families adapt to the strain of on-going stress related to a single crisis event.

In an attempt to gain a better understand of the family's point of view, I recently subscribed to the Premie-L Discussion Forum which is an Internet parent support group for families with premature children. The interactions and the dynamics of the group have fascinated me. The power of parents helping parents is evident. This groups seems to transcend the difficulties of distance, time, and the need for childcare. Messages from group members underscore an important function of the list that is to bring isolated families together with others to discuss similar concerns. I have observed the providing of information, the outlet for emotional expression, encouragement during difficult times, and the arena to tell their stories to those who they feel really care. There seems to be a genuine caring atmosphere for each other on the list. Lurking (Internet term for a person that reads the messages on the list but does not post messages) on the Premie-L has peaked my interest to learn more about this Internet culture. I sense that a wealth of specific information about the perceived needs of the list members could be obtained through a content analysis of the listserve messages.

My ultimate concern is to promote genuine collaboration between professionals and families to improve support and effective intervention for these families. The first steps toward genuine collaboration include finding out from families what they really need; not just we, as professionals, perceive they need. My concern and my experience with the computer discussion group has lead me to implement a qualitative study that seeks to capture the characteristics, the beliefs, the values, and the needs of the members of the Premie-L discussion forum.

My personal characteristics will lend to the success of this type of qualitative study. I am an effective listener that encourages others to tell their story. I am intuitive and am able to hear what people say and what they don't say. I will need to be cautious to verify my interpretations with the participant during the interviews. Also, I am comfortable with email communication and sustain several long-term friendships through

email. These prior experiences with email lead me to believe that meaningful relationships and support can be established on-line.

In conclusion, my assumptions are (a) that families with premature infants are under stress that affect their ability to care for their child and their quality of life; (b) there is a gap in the standard of medical care and what the families perceive they need; (c) there is a lack of specific knowledge regarding what families need; and (d) the Premie-L discussion provides the vehicle to empower families that results in improved coping skills and quality of life for their child and family.

Sept, 2001

APPENDIX C  
INTERNET COMMUNICATION WITH ANNE CASEY, INCLUDING  
LISTSERV PERMISSION AND MEMBER CHECK INTERACTIONS

## APPENDIX C

Internet Communication with Anne Casey, including Listserv Permission and Member  
Check Interactions

Subj: **Re: listserv research**

Date: 5/29/2002 5:27:09 AM Central Daylight Time

From: *annec@vicnet.net.au (Anne Casey)*

To: [Starkville@aol.com](mailto:Starkville@aol.com)

Dear Elisa.

You are very welcome to join Premie-L. I am interested in your research and would like to read your paper when it is finished. All postings to Premie-L, both the listserv and the Forum, are copyright to the author and need the written permission of the author to be reproduced. We also ask that Premie-L is acknowledged and the home page <http://www.Premie-L.org> quoted. You are welcome to use the name of Premie-L in your presentation.

I apologise for taking so long to get back to you. Good luck with your research. The internet is very suited to the needs of families of premature babies. Prem parents have a great deal to talk about but little often little opportunity to find others who are knowledgeable and interested, and available at times that are convenient.

Best wishes

Anne Casey

At 05:49 PM 5/14/02 EDT, you wrote:

>Hello Anne,

> Turns out she was one of the morns that I was working with in our NICU. I

>recognized her on the list and she was willing to talk to me further. My

>goal is not to destroy the community by playing an active role on the list.  
 >I envision cataloging the responses into categories to understand how  
 >parents support each other and what is important to them. I noticed that  
 >you wrote in one of your writings on the web site that each person owned  
 >copyright to their postings. I assume that I would need to get individual  
 >permission to use a quote when I write up the study. This is my last  
 >question for now. Do you mind if I use the name of your group when I write  
 >or do presentations. Your group is so well-known that it is hard to  
 >disguise. My ultimate goal is to demystify the power of the Internet  
 >support groups for health professionals. Sorry for rambling on but I really  
 >need your feedback before I finalize my research.

> Thanks so much for your help,  
 > Elisa Kennedy PT  
 > Doctoral Student  
 > Early Childhood Special Education  
 > University of Georgia  
 • Athens, GA, USA

Member Check Interacton

Dear Elisa,

I apologise for taking so long to reply to you. My son had surgery in  
 November and I've been way behind in my correspondence.

I liked your research categories and think you are very much on the right  
 track. I would be very interested to follow the progress of your dissertation.

best wishes

Anne Casey

At 09:48 5/01/04 -0500, you wrote:

>Hello Anne,

>I am writing to inquire if you received the email that I sent you on Nov  
>24th regarding my dissertation research about Premie-L. I wanted your  
>feedback on my results. There was an attachment that including my findings.  
>Thanks so much and Happy New Year,  
>  
>Elisa Kennedy  
>  
>Here is a copy of the first message:  
>Greetings Anne,  
> It has been awhile since I touched base with you about my  
> dissertation regarding Premie-L. To give you a summary, I am a pediatric  
> physical therapist with more than 20 years of experience with families  
> and their children in the NICU and after discharge in the community. As a  
> result of my relationship with these families, I have become aware of the  
> lack of understanding about the impact on families with regard to  
> prematurity. I was especially intrigued by the support that families  
> gained from Premie-L. I have attached the categorized findings for each  
> of my specific research questions. Prior to final interpretation of the  
> data, I would really like your feedback to know if I am on the right  
> track. The primary source of data collection for these research questions  
> was the archives of the Premie-L mailing list.  
>I want you to know that I appreciate your time and look forward to hearing  
>your feedback.  
>  
>Thank You,  
>  
>Elizabeth "Elisa" Kennedy  
>Ph.D. Candidate

>Early Childhood Special Education

>University of Georgia, USA

Ms. Casey explains that her son had surgery that delayed her response to my study. This scenario provides further confirmation that the impact of health-related needs is on-going and affects the daily lives of these families. Following is the document that was attached to the email as presented for feedback from Ms. Casey.

The purpose of my dissertation is to describe and understand the lived experiences of families who participate in the Premie-L community. The intended audience for my study is professionals who work with families with premature infants. Specifically, my hopes are that the findings of the study will promote genuine collaboration between families and professionals to improve support for families with premature infants. To increase my knowledge, I have spent the past two years monitoring the list as a member of Premie-L, have interviewed and spent time in the home of a member of Premie-L whose child was in the NICU where I work, and have spent time in the home of one family who had twins with multiple medical complications.

Specific research questions and the findings for my study are as follows:

**What is the community and culture of the Premie-L that provides an environment to support families with premature infants?**

All families on the Premie-L bring the history of having a child born prematurely even though they come from diverse cultural backgrounds. Premie-L is a stable or cohesive community of families with premature children as evidenced by the growth in membership, the persistence of meaningful conversation, and the outgrowth of resources aimed at meeting the needs of the members. Group membership is transient and varies in duration but there is a strong core of committed, veteran members who perpetuate the

existence of this support group. These veteran members orient new members and facilitate trust in the group by sharing their personal stories, providing updates, offering themselves to others, and upholding ground rules that protect the group.

The primary voice heard on the list is from family members. Other life roles such as occupation play a secondary role in the conversations. There is a predominant feminine perspective since most of the members posting messages are female. Religious affiliation, race, or ethnic background is not extremely relevant to the discussions. The culture of the listserv may be described as a family. The members bounce ideas off each other, argue, discuss their fears, frustrations, anxieties, hopes, and, dreams. The contents of the messages reveal that the Internet is not the sole focus of these members. They have family obligations, they work, they go to doctor's or therapy appointments, are seen as volunteer, and advocate for their children. Members value family unity and there is a prevailing assumption that families on the list want the best for their children and possess the life dream that their children will lead successful, meaningful lives.

As mediated through the Internet, the language in the Premie-L list is informal, direct, and mimics conversational speech. Emoticons and abbreviations (Internet and medical) serve as symbols that further facilitate communication. Off -topic talk, jokes, and spam email are not well tolerated. Though there is a routine to the message format (i.e. new member introduction, announcing of milestones, requests for help, etc.), the topics of conversation are dynamic and emerge through member interaction. Messages typically contain medical jargon that would not be shared by those without some knowledge of prematurity. An important ritual is that members offer information that establishes group membership (i.e. prior to giving advice a member typically will share their personal story to establish legitimacy to participate in discussions, families provide a summary of their family's story in the bylines of their messages, etc.).

**What impact has the premature birth experience had on the families from the Premie-L members' point of view?**

The premature birth experience is seen as a stress related event that places extraordinary demands on their families. There were three major categories of impact on the family. The categories were health-related issues, professional-family relationships, and psychological/emotional issues. The categories are not mutually exclusive.

### **Health-related Needs**

Health-related needs are described as issues related to pathology of prematurity. The issues include medical problems (chronic lung disease, feeding/digestive problems, sensory issues, etc.); financial issues (direct and indirect costs associated with providing care for the child); family management demands (juggling therapy/doctor appointments, daily caregiving issues, family relationships, etc.), equipment (not only equipment and medical supplies but the need for specialized equipment because children are often too small for age-appropriate items), and developmental issues related to disability.

### **Professional-Family Relationships**

The normative experience for new parents is to obtain a pediatrician for their baby. Families with premature children not only have pediatricians but also have a numerous specialists that become an integral, necessary part of their lives. Professionals are defined as people with specialized credentials including educational specialties whose services are required to manage issues related to prematurity. During the early years of the child's life, families have relatively brief periods of time when they don't require the services of these professionals due to the chronic nature of issues related to prematurity. At some point, disenchantment is observed as family began to realize that professionals do not hold all the answers to correct their child's problems. Families are observed to seek an active role in the arduous journey of cultivating relationships with professionals that are responsive to the needs of their families. The collaborative relationship between the family members and a specific professional or agency is complex and variable. In some circumstances, relationships can be a source of comfort and in other relationships a source of strain.

### **Psychological/Emotional Impact**

Psychological/emotional impact can be categorized into the following three areas: events surrounding the birth in the NICU; stress relating to the on-going nature of prematurity issues; and death. The NICU experience and the emotions surrounding the birth are intense and persist over time. The complications of the premature birth separate these families from their families and friends who experienced a routine birth. The final category, death, involves not only the grief for the physical loss of a child but also the loss of a life dream of having a normal pregnancy or the loss of a life dream for a child who doesn't have to cope with disabilities. In response to the on-going strain, families are confronted with the need to find new resources to help them cope with challenges that affect the well-being of their families.

### **What are the perceived needs from the point of view of the members?**

The four specific categories of need that were discovered were information, advocacy, help with feeding, and social-emotional support.

#### **Information**

There is a need for information about medical-related issues, daily care (feeding, therapy, etc.) school issues, prognosis, and other general information. There is deliberate intent noted in the messages to receive information about subjective experiences and specific information that will improve their ability to take care of their child and improve the well-being of their family.

#### **Advocacy**

There is a need for members to act collectively as a group for the acquisition of appropriate individual family support including medical care, education, and disability issues to improve the quality of lives of the children and families.

#### **Social-emotional Support**

There is a need to develop close social relationships with others going through the same situation to normalize their experience. Social support from this online group seems to be specifically desired because of anxiety related to diagnosis, to medical intervention, and with unclear prognosis related to prematurity outcome. Members seem to need a forum to develop strategies for thinking and feeling about what they are experiencing.

**What types of support are available from the point of view of the members on the list?**

Two major categories of support observed were social/ emotional support and information sharing.

**Social support**

The Premie-L mailing list provides an intimacy of support that is not available from close family and friends that have not lived the experience of having a child born prematurely. The list provides an interactive social setting that provides opportunities for shared experience and a sense of belonging that confirms their experience. The virtual meeting place offers 24-hour availability and selective participation. There is anonymity and privacy in that a member may gain significant support from listening to the conversations without actively participating (lurking). One of the disadvantages of face-to-face support groups has been stated that some people are too shy to speak or attend such groups. The on-line support group bridges the gap of isolation and does not have other barriers of face-to-face support groups, such as transportation, distance, and time restrictions. Meaningful interaction on the list provides opportunities for problem solving from a collective experience and influences the development of self-efficacy that ultimately facilitates a sense of control in the midst of a stressful situation.

**Information sharing**

The list provides dynamic informational support in accordance with the needs of the group about issues related to prognosis, resources, medical care, daily living management, disability, therapy, and finance. The information ranges from advice to

referenced information. Members often search for explanations for what is going in their children's lives. An important role of the list is to provide plausible explanations for uncertain situations or phenomenon that just can't seem to be explained by current medical science. Finally, the list serves as a source of confirmation for information received from a variety of sources (media, professionals, family, etc.).

**What are the members' perceptions regarding the role of the Premie-L to enhance the family's caregiving ability for their child and the well-being of the their child and family?**

The testimonial messages and the stories that describe off-list actions provide evidence that they value the social support, the informational support, and consider the Premie-L online support group to have meaningful relevance that goes beyond the Internet experience. The members feel that Premie-L increases their self-confidence, facilitates a sense of control over challenging situations, and facilitates the active pursuit of goals that positively affect the future of their children and the well-being of their family.

APPENDIX D

DOCUMENT/ARCHIVAL COLLECTION AND REFLECTION (PILOT PROJECT)

## Appendix D

### Document/Archival Collection and Reflection (Pilot Study)

#### Document/Archival Collection and Reflection

For my research project entitled “*Isolated by Not Alone: An Internet-based Self-help Forum for Families of Premature Infants – A Pilot Study*”, I am collecting information about the families who belong to the forum, the perceived benefits of the forum, and the social community of the forum. My ultimate purpose is to determine if the Premie-L listserv is able to support families in ways that would enhance their caregiving ability and the well-being of the child and family. The primary source of data collection in this pilot study phase has been derived from an in-depth face-to-face interview with a member of the Premie-L discussion forum. The archival data will help confirm and provide additional insight into the members of the Premie-L discussion forum. The bulk of the archival data was taken from Premie-L.org, the home web site for the Premie-L mailing list. In addition, documentation is presented, as taken, from a popular, well-known magazine to demonstrate that the issues encountered by the members of the list are current and attracting the attention of our society.

The home web page is presented to introduce information about the parent organization that sponsors the Premie-L discussion listserv. The home page states that the Premie-L is “a non-profit foundation supporting families with children born six weeks or more before due date” ENRfu(Casey, 2001). The opening statement under the heading in bold provides us with an understanding that having a premature infant can be a scary and lonely process and that the main purpose of this organization is to support families going through this process. The Mission Statement of the Premature Babies (Premie-L) is presented because it provides the core purpose of the organization and the strategies that the organization proposes to use to support families. Information offered on the home page and from the mission statement, provides us with an understanding that the organization has a wide-spread approach; with the listserv representing only a

portion of the support network. Not only does the organization provide a wide range of support and information through the Internet, but also, sponsors an annual conference that offers the opportunity for face-to-face support of its members. The popularity and extensive support system offered by this organization lends credence that there is an authentic need world-wide to provide support of parents with premature children.

Anne Casey, who resides in Australia, is noted to maintain the Premie-L web site and is the organizer of the Premie-L organization. The paper, *Online Communities for Information Exchange and Peer Support: A Case Study ENRfu*(Casey & Hardy, 1998) is provided because it gives details regarding the formation of the list, demonstrates the wide-spread international influence of the organization, and contributes to our understanding of what led Anne Casey's to establish the Premie-L organization. It becomes clear that the list, not only, provides information but also has a clear social focus. The people who responded to the list were not only hungry for information but also wanted to learn from those who had survived the process. Most importantly, they wanted to talk about their shared experiences. This information validates the information that I obtained from the face-to-face interview with Anna Diaz, a current member of the Premie-L listserv. Finally, this on-line paper provides important information regarding the ground rules and provides evidence that the list has demonstrated the ability to monitor itself for accuracy of information.

With respect to gaining insight into individual members, the most valuable information came from a series of postings that occurred in response to an initial request from one member Sept, 2001. She pointed out that it would be fun to place an emphasis on themselves rather than their children for a change. It was almost like an ice-breaker activity as she shared her purpose that she hoped that it would facilitate communication on the list. The beauty of this thread was that it gave me an opportunity to gather information about the people on the list and to compare it to the information I had gained

in the face-to-face interview with Anna. Thirty-two postings were available for analysis. Following is a summary of the 32 “About Me” postings:

Of the 32 postings that responded, all were women. I do not know if this reflects that the list members are primarily women or simply this is who responded. The known ages of the women ranged from the 20’s to the 50’s. Almost half of the people were in their 30’s with 13% of the members in their 20’s and 16% of the women in their 40’s. There was one woman in her 50’s and she was a foster parent of a premature child. Twenty-two percent of the women did not list their ages. Judging from the return, I speculate that most members are women and are in their 30’s. The listserv member that I interviewed is a woman in her 30’s; providing further evidence that my assumption may be correct and that she might be quite representative of the gender and age of others on the list.

The descriptions that the members provided demonstrated the diversity in their backgrounds, but also, uncovered the similarities that crossed the diverse backgrounds. Some of the people were only children and some were from large families. Their present families ranged from 1 to 4 children in the home. The geographic location of these members spanned the United States and internationally to Australia and New Zealand. Five of the members have lived their whole lives in one place but others moved and traveled extensively.

An examination of the marital status of these members revealed that all were currently married except for 3 members. These 3 members reported that they were divorced. Most of the married women that responded had not been married before (79%). These percentages may not accurately reflect the list membership. I wonder if single mothers are less likely to write on the list because they have greater trouble in managing daily responsibilities. It seems logical that they would have less time to sit down at the computer and write stories of their background. I am curious why so many of the members in this group had not been previously married.

The educational background of the members ranged from high school completion to the attainment of a PhD. Fourteen (44%) of the members had college degrees. Seven (22%) had previously attended school but did not obtain a degree. Three members are currently in school. The stories provide information that some members did not finish their education because of marriage and some because of the birth of their child. Yet, some were able to complete post-graduate degrees after the birth of their children. One woman completed her MBA degree after the birth of triplets. Judging from these postings, education is valued by this group. Perhaps, people with higher education are more likely to pursue information-seeking and support on the Internet.

Though employment of the group varied, the employment status of all the women changed after the birth of their children. I wonder how this fact compares to the general population of mothers who deliver term infants without problems. About half the women were employed in some capacity but the other half stated that they were Stay At Home Moms (SAHM'S). Few women worked full-time or described their job as fulfilling. Only one woman described her job as a dream job though there were others who said they had their dream job prior to the birth. Some expressed that they hated their job and only worked because of financial reasons. Some expressed joy at being laid off after the birth. Several talked about having to take a less full-filling job because of they prioritizing the needs of their child over their need to develop a career. The range in emotions regarding employment probably parallels the general population of women after childbirth. But, the real question is: Do these women have less choice because of the complexity of medical needs of their children? (Refer to the selected comments and quotes from members on the attached About Me – Summary). This discussion reminds me of the struggles that Anna is currently experiencing. She shared with me in the follow-up interview that she has come to terms with the fact that she is no longer going to be a career woman. She talked about how she loved her job and is afraid that she is going to be fired because of her responsibilities at home that conflict with work.

In the midst of their current situation, almost 30 percent of the women reported active involvement in volunteer work. One woman started a support group for similar parents entitled *Parents Empowering Parents*. One woman was a La Leche leader and another woman was a volunteer for March of Dimes and spoke to medical students about the preemie journey. Many of the others were actively involved in church work. I was especially affected by one woman's story (BTH). She described growing up in a dysfunctional background and has experienced great hardship in her adult life. Yet, in the midst of her circumstances, she reaches out and provides support and peer advice for others who have gone through similar circumstances. I imagine that others who are going through tough times will be inspired not to give up after reading her story. This discussion of volunteerism, reminds me of my initial interview with Anna. I asked her what she would do if she could be boss of the universe for the day. I was surprised at her answer. She told me that she would start a support group for parents of premature infants that only spoke Spanish. Apparently, she is not much different from many of the other members in the About Me group. Perhaps, volunteering provides a sense of well-being from helping others.

A wide-breath of personalities was exposed as the members told about their hobbies and interests. The most common interest among the members was reading (25%). If all the outdoor type of activities were lumped together, we would see that this group likes to be active outdoors. There were many who liked to sew, cook and bake, do arts and crafts, and perform in community theater. Each activity had at least two members listed except writing. There were others that stated that they were writers but this one person gave me the impression that they wrote for leisure. There were several members who stated that their interests were actually former interests because they did not have time anymore after the birth of their children (refer to the quotes in the attached summary). Others reported accomplishments or shared dreams that they had for future ventures. It appears that the members that had writing skills were more successful at

using their skills in a satisfying manner as compared to the others. One member started a newsletter and one woman turned her journal into a theatrical production in a local theater. It is probably not a coincidence that so many of the women in this group have writing talents because writing is the basis of communication on the list. This discussion of hobbies and interests makes me aware that I do not know what Anna's hobbies or interests are outside of her child and family.

Only 6 people discussed religion. All 6 were Christian except one member who reported to be an agnostic humanist that recently joined the Unitarian Universalist Church. I am surprised that there was not more discussion about spirituality because I have casually observed evidence on the list that spirituality/faith is important to many of the members during times of extreme stress. It doesn't mean that spirituality is not important to these women but that it may not have been the venue for discussion. Anna shared in the follow-up interview that she is Catholic but has been angry with God since the birth of her daughter. She explained that she feels that their family and Camilla did not deserve this tragedy. I have seen this topic discussed previously on the list.

The telling of their stories provided the opportunity for many to share intimate details of their lives. Ten members (32%) expressed that their families were under significant stress. All talked about how their life had been changed with the birth of a premature child. Four people expressed that the birth had strained their marriage. On the other hand, 2 people expressed that the circumstance had strengthened and matured their marriage. Two others said that the experience had strengthened them personally. Six of the members (19%) talked about depression associated with the birth of their premature child. Two women talked about the guilt associated with the event. One over the fact that she had another premature infant and one over the fact that her infant had fared better as compared to some of the other infants on the list. During the interview, Anna talked about the double standard and explained that she was often annoyed by parents whose children had not suffered as much as her child. Perhaps, this woman in the About Me

group did have legitimate emotions of guilt regarding her daughter that seemingly escaped disability. Anna also had similar experiences with depression and strain on her marriage.

Strength of character is observed as I read the obstacles and tragedies that several of the members had overcome earlier in their lives. One member was a cancer survivor; having been diagnosed with cancer and insulin dependent diabetes as a child. One member has survived a dysfunctional background, drug abuse, and having an autistic child and a premature infant. Others have survived the loss of close family members. Alcoholism, substance abuse, and spousal abuse have touched the lives of 4 of the members. Each of these 4 members demonstrating strength in how they handled the bad situations.

The last archival document is an article that was published in May, 2000 *Life* magazine ENRfu(Funderburg, 2000). The article centers around the birth of Jason Michael Walden, Jr, born at 25 weeks gestation to Laurie, 23, and Jason, 22, in a hospital near Atlantic City, NJ. Immediately after birth, Jason was helicoptered to Children's Hospital of Philadelphia. The story of the birth unfolds and the reader catches a glimpse of the fear that the family goes through during the series of events associated with the birth. Laurie had gotten pregnant only 3 months after they had married. They had been living with Laurie's family because they could not afford to live on their own. Jason was enrolled in a computer course and Laurie had planned to do the same. The family's dream was that Jason would be able to get a job after training so that they could afford an apartment. The unexpected birth of their son is shown to change the direction of their lives.

Jason's neonatal course in the hospital is intricately described, including the ethical dilemmas that face the families and healthcare professionals. A point is made that more infants are being saved at younger ages but many are experiencing prolonged hospitalizations and the possibility of long-term disability. Laurie is diagnosed with

depression one month after the birth. She describes the guilt that she is not a good mother and is not doing everything she should be doing. This situation and the feeling of depression is similar to the stories expressed in the About Me group.

At the end of the article, a doctor talks about his struggles with working with this population of infants. He has developed convictions that he should not be overly optimistic with the parents of these infants. He feels that he is protecting them by not giving them false hope. This discussion definitely reminded me of my discussion with Anna during our 2 interviews. Anna reiterated to me in 2 different interviews that she thought “it was cruel” to be given poor prognostic information even though she was not angry with a doctor for doing it. Obviously, this controversy is not unique to Anna’s situation as observed by this article.

In conclusion, the information from the Premie-L organization, the information from the About Me group, the *Life* article, and the results of the interview with Anna all provide evidence that substantiate that fact that managing the care of a premature infant is a stressful event for the families around the world. The documentation demonstrates that the families, even from diverse background, need and seek support to improve the well-being of their families. From the evidence collected from the Premie-L web site and from the personal interview, the listserv does seem to be a viable resource to help families care for their infants and to improve the well-being of their families.

APPENDIX E  
SINGLE CASE STUDY (PILOT PROJECT)

## APPENDIX E

### Single Case Study (Pilot Study)

#### Presentation of Findings and Discussion

##### Participant

Anna Diaz (AD), the interview participant, is a mother to Camilla, a nine-month-old infant that had been hospitalized in the NICU since birth. She and her husband have a four-year-old son. She is highly educated with a MBA and is employed as a national sales/promotion manager for a well-known wireless company. The mother was originally from Puerto Rico and English, though spoken proficiently, is her second language. The family had recently moved to Atlanta from Florida because of Anna's job. Anna had found the Premie-L listserv while surfing the Internet for information regarding prematurity. Anna's infant daughter has multiple problems related to prematurity including respiratory problems requiring a tracheostomy and oxygen support, developing cerebral palsy, cortical blindness, and feeding problems. Due to complications related to prematurity, Camilla will need not be able to attend a regular childcare center, will require skilled medical care, intensive developmental therapy, and will require multiple follow-up appointments with medical specialists.

Anna was found to be very similar to other members of the Premie-L listserv with respect to the demographics of gender, age, and educational background. Archival analysis revealed that most of the members are women, in their 30's, and valued education. 44% of those posting a response to the archival thread, had college degrees and all had completed high school. Anna was in a first-time marriage as typical of most of the respondents (79%). She was characteristic of the wide diversity of backgrounds displayed by the list members. The geographic location of these members spanned from the United States to Australia and New Zealand. Though employment of the group varied, the employment status of all the women changed after the birth of their children.

A wide range of emotions was displayed in response to discussions of employment. Anna also expressed struggles with change in work status after the birth of her child

AD: Well, I think the fact that.... and this is a personal struggle that I have right now.... I was very career-minded and starting last week I don't think I'm gonna be able to be a career mom anymore or a career woman anymore. .... I will have to be dedicated, really, twenty-four hours to my daughter.

In midst of their current situation, almost 30% of the women reported active involvement in volunteer work. Anna, also, discussed the desire to volunteer to help Hispanic families who were going through similar situations.

AD: I will tell you that my heart goes out to those parents, specifically Hispanics, that don't speak English. At this point, I have thought about, you know in my free time, I would love to do something, in the hospital, for those parents that don't speak English, specifically if they speak Spanish.

The telling of their stories provided the opportunity for many to share intimate details of their lives. Ten members (32%) expressed that their families were under significant stress. All that responded talked about how their life had been changed with the birth of a premature child. Four people expressed that the birth had strained their marriage. On the other hand, 2 people expressed that the circumstance had strengthened and matured their marriage. Two others said that the experience had strengthened them personally. Six of the members (19%) talked about depression associated with the birth of their premature child. Two women talked about the guilt associated with the event. During the interview, Anna expressed similar issues as she questioned the reason why Camilla had been born with so many problems

AD: Um, and I think it was after Camilla was diagnosed with everything. Um, yeah I had a hard time because I don't know if I told you this but we're good people. We never used drugs. We have a drink occasionally. We are not abusive parents. We actually consider ourselves very good parents.

## Data Interpretation

Themes emerged from the analysis of the data as follows (*researcher comments are in italics*):

### Theme 1- Existing Resources: Capability to adapt to a single crisis event

This theme focuses on the pre-existing resources that a family has available to help them adapt to the initial crisis event of the birth of a premature infant. Seven sub-categories were defined to assist in the explanation of the theme. These sub-categories were family values, religious faith, financial resources, family/friend support, personality, formal education, and Internet access (Refer Existing Personal Resources Diagram).

A discussion of the existing resources category is as follows:

Anna's (AD) personal resources (financial resources, educational level, beliefs and ideologies, personality traits, and satisfaction with marriage, family life, and employment) could be considered a strength, which provided a strong foundation to facilitate positive adaptation to the initial crisis birth event. She was observed to be the type of person that was able to adapt to a crisis event in a manner that facilitated stability during the moment of the event. The following evidence is presented to support the preliminary findings: I am aware from personal interactions with the mother in the Neonatal Intensive Care Unit (NICU) that this family is a dual-income family and has private insurance to assist with medical costs. As observed on email communications from the mother, her job title is Marketing/Promotions manager at an international wireless corporation.

AD ... I considered ourselves well-educated and we know that the only way to learn to do things is through reading and getting ourselves educated regarding anything that she is suffering with or could suffer within the future.

She demonstrated the optimistic personality traits that appeared to facilitate a positive adaptation, yet, she expresses uncertainty in the face of an unanticipated event. She was resourceful, a protagonist versus a victim, independent, and resourceful. Three weeks

prior to the delivery of Camilla, Anna had moved to Atlanta because of a job promotion. The rest of the family and furnishings had not yet arrived. Her perception of the birth seemed to be strongly linked to her strong personality traits and outlook on life. The onset of the birth of her child did not seem to cause Anna to question her central belief system that things would turn out for the best but she was observed to question her previous religious beliefs.

AD ... at the beginning uh I was going to church and I was going to pray. But I have noticed that my faith has changed a lot. Like you know, not in a good way.... I never, ever, gone through my mind of hurting someone, nor my husband. And we are not the type of people that will go to church all the time but we had our faith.... I love my daughter and I need to learn how to deal with, but I don't think it's fair. And I love her to death. And I'm gonna do anything that it takes to her better.... But, I don't really understand why we have to go through it when we had other things in mind, and we were planning on better things for everybody in the family.

She appeared to have maintained an internal locus of control as indicated by the fact that she always seemed to believe that she had the control to be able to ultimately affect the outcome of her situation. The first situation was illustrated by the onset of labor contractions and was an indication of her independence.

AD: Well, uh, I had moved here, I was living by myself, I was in my apartment and ... I started to feeling contractions, I was 24 weeks gestation, and...I went into the hospital, drove myself..." "And I was by myself, no furniture, all I had was my bed and the TV..."

Another illustration was when she seemed to have bargained with God to gain back control of her situation.

AD ... Yeah, I'm mad and I will deal with it. I'm don't pray for oh please God get Camilla better. I just say ..... you know I feel a little bit overwhelmed and your're

gonna help me get through this because you can't help Camilla but you can help me... So, I guess we are at peace now (meaning relationship with God)

She looked for the positive in the situation immediately after the birth and was quick to assess the situation, to resolve the outcome in her mind, and to use the comforts of previous religious rituals (i.e. chaplain, attending church) to adapt to the event.

Following are illustrations that demonstrate her attempts to maintain a positive outlook of the initial birth event and her "take charge " attitude that is seen through the interviews and field observation.

AD: When she was born, she, we heard a little bit of cry and that was very positive

AD: ... I didn't even know what to think, to be honest, all I thought, well let's bring in a chaplain and christen this baby and see what happens...

She never gave up full control of her situation to others and was observed to maintain the ability to problem solve in a difficult situation

AD: ... they brought me in again, and that's when they told me you are either going to have this baby here, either now, today, or you are going to spend a very long time in the hospital. I was like: OK, well I need to know... because I need to call my husband if this baby is going to be born today and I have to bring them from Florida and I have been in conversations with my husband...

At the initial birth crisis, there was no other indication of any outside friend, neighbor, or family support.

AD: ...I was by myself....

This could be construed, as a negative aspect regarding positive adaptation but the strength of the other personal resources seemed to outweigh this one negative aspect.

Theme 2 – New Resources: Capability to adapt to an on-going crisis event

A pile-up of stressors is observed as the family is faced with the on-going stress created by the medical problems that occur in their premature daughter. A need for

additional resources and support systems is described by Anna as the family attempts to adapt to the on-going crisis. The new resources required or obtained as related to the on-going stress can be categorized in the following sub-categories: family/friend support, financial resources, child care, religious faith, knowledge, emotional support, interactions, and medical resources.

The first resource that the family sought was information regarding prematurity. The family realized that they had a knowledge deficit that interfered with their decision making and their ability to interact with professionals in the NICU.

AD: . . . . Three days after Camilla was born we (Anna and her husband) went to Barnes and Noble and we bought a premie guide . . . . and every time she has something, or she was diagnosed with something, I could go in and reference what it was and instead like getting the bad news, talking to a doctor, and get so overwhelmed with medical terms.

As a researcher, I saw the progression of Anna's utilization of books to the Internet to search for information. As additional diagnoses and medical conditions were added to their daughter's health condition, Anna was observed to seek additional resources.

AD: . . . I mainly go into the Internet. And I look for the I know Camilla was diagnosed with blindness I went to the uh to the um nurse's site CP or for visually impaired

Anna was observed to develop a social/emotional support system that she was lacking at Camilla's birth. After the birth, immediate social and emotional support appeared to come from the hospital staff and from Anna's work. The preexisting resource of family was not an apparent asset with managing on-going stress. Both of the grandparents and immediate family lived too far away for immediate support and there was evidence that the family was having difficulty with accepting Camilla's medical condition.

AD: ...I 'm like Mom, she has a condition that is not going away. They don't get it. None of them (meaning the family), gosh, probably I'm too harsh. But they need to get it. You know when they come to visit they need to understand that probably she'll be on a walker the rest of her life... You know these are the things that I'm that I've prepared and that I envisioned 'cause I need to get ready for the worst...

Anna was observed to seek support beyond the NICU support group as Camilla's hospitalization continued to lengthen and her emotional status began to decline. Her resourcefulness is evident as she seeks for emotional support and help for others in similar situations.

AD: ...I stopped going every Thursday ... and at one point it got so depressing...

AD: ... I have been looking for a Spanish-speaking therapist and I have not found anyone. I looked for some help and they recommend her and she actually she works here (at the hospital) but I think, honestly, they should give those resources for the parents as service from the hospital.

The chronic medical condition of their daughter is creating the need for the family to seek other resources to manage medical care and to begin to consider alternate plans for the future regarding financial issue and career goals. At this point, the family is not aware of the full financial ramifications of chronic illness in an infant. At the initial crisis, employment was a financial resource but now seems to be a questionable resource.

AD: Well, they are setting everything up, through the case manager at the hospital. They are getting the agency that is going to work with Camilla for nursing and equipment

AD: I need to work, for, of course, financial reasons and the second reason is that they (*her company*) moved me here. So, I have to pay back the company two years all together. So, I've thought several things like –working part-time,

telecommuting... But I need to work, so unfortunately, we will figure a way out...

In this last quote, Camilla is explaining that she agreed to work for her company for two years if she accepted the job and they moved her to Atlanta. She is experiencing the dilemma of financial demands and providing care for her daughter who cannot attend a typical childcare center.

The family's perception of the birth event is seen to change as they adapt to the on-going issue. They continue to demonstrate a realistic attitude that helps cope with immediate situations at hand.

AD: We're really positive that things will get much better and what I have seen with therapy; anything can be done.

The strength of her marriage continued to be an asset as the couple was observed to develop additional communication strategies to cope with the loss of the dream for a normal infant. .

AD: I have a good husband and he supports everything and we have the same attitude. If it's good for her, yeah, let's do it. ... We cope in a different way. It was difficult. He did it on his own and I did it on my own. (*They were talking about working things out by themselves*) At one point, we started talking and you know this is our reality and this is what we are going to do. And we are here, Camilla is going to be her for awhile... then we started talking to friends and family... I think the family was talking about that Camilla didn't die and that she was going to live.

The Premie-L listserve was perceived by Anna as an acquired positive resource. This resource will be discussed within the interpretation of the third theme.

### Theme 3 – Value of the Premie-L listserve: on-line support

Anna perceived the Premie-L listserve as a positive resource to obtain advice, to seek medical information, and outcome information regarding Camilla. This information empowered the family to make informed decisions regarding care of their daughter. Also,

the Premie-L was noted to provide emotional and social support by normalizing the experience and decreasing the fear of the unknown. Ultimately, the Premie-L was observed to be a positive resource because Anna valued learning and receiving support from those that had gone through similar situations. The Premie-L was noted to provide an avenue for giving support to others that in turn promoted a sense of well-being in the list member.

AD: “The advantages are that you can find anything there. If you have a question, you will get an answer, and in 100 different perspectives. So, you see whatever fits best for your situation.”

“There are so many courageous parents out there that you can learn from...”

Disadvantages noted were the large number of postings received on a daily basis and the inability to control unwanted or inappropriate information.

AD: the over the excess of information is not good sometimes.

The analysis of information from the Premie-L.org web site validates the information that I obtained from the interview process. The home web page introduced information about the parent organization that sponsors the Premie-L discussion listserve. The home page states that the Premie-L is “a non-profit foundation supporting families with children born six weeks or more before due date” ENRfu(Casey, 2001). The opening statement under the heading in bold provides an understanding that having a premature infant can be a scary and lonely process and that the main purpose of this organization is to support families going through this process. The Mission Statement of the Premature Babies (Premie-L) provides an understanding that the organization has a wide-spread approach; with the listserve representing only a portion of the support network. Not only does the organization provide a wide range of support and informational through the Internet, but also, sponsors an annual conference that offers the opportunity for face-to-face support of its members. The popularity and extensive support

system offered by this organization lends credence that there is a authentic need for world-wide to provide support of parents with premature children.

### Discussion

This single case-study pilot project provided an intimate opportunity to understand the impact of premature birth and the transitions that a family experiences as they respond to chronic strain associated with the birth event. Management of these complicated medical issues create enormous stress on family structure ENRfu(Deihl et al., 1991). Research has shown that resources are a determinant of how well a family will cope in response to a stressful situation and which strategies that family will use in adaptation ENRfu(Beresford, 1993). These resources refer not only to existing resources but also to new resources that the family acquires to on-going stress. Resources may be categorized into internal personal resources and family system resources or social support ENRfu(Beresford, 1993; Deardorff, 1992; Lavee et al., 1985). Coping is defined as the process that one goes through to mediate the effects of stress. Overall, coping includes a complex interaction between an individual and the environment that ultimately affect the sense of well-being of the individual and the entire family. The findings from this study provided an understanding of associated stressors and the need to obtain new resources to successfully adapt to the situation.

Personal Resources. Personal resources include both physical and psychological variables ENRfu(Beresford, 1993). Examples of personal resources are physical health of the caregiver, educational level, beliefs and ideologies, personality traits, previous coping experiences, competency in caregiving, marital satisfaction, satisfaction with life, and parenting skills. Personality variables, such as optimism, are regarded as important defense mechanisms in positively adapting to a stressful situation. This category of resources includes a person's overall approach of life. In this case study, Anna was observed to seek positive aspects in her infant that would help facilitate an easier adjustment to her infant's disability.

During the time surrounding a crisis birth event, family may be especially vulnerable to guilt and self-blame regarding the child's condition ENRfu(Beresford, 1993). This vulnerability is not considered pathological but may hinder the process of coping with the stressful event. Resources do not always have the same mediating effect. For instance, families have been shown to use the support of prayer and their religious belief system to interpret and define the birth experience of their child. In contrast, other families have been observed to question their belief system that would allow the birth of an infant with a disability. The wide range in available personal resources explains the adjustment variability as observed in families as they attempt to mediate stress in their lives. This discussion highlights the importance of examining personal resources in the context of the individual family as demonstrated in this case study. Anna was observed to experience emotional distress with the birth of her premature infant. She was observed to challenge her previous religious faith that had previously provided comfort. Through out the interview process, Anna portrayed an optimistic outlook that helped her adapt to the difficult situation.

Social support. The second category of coping resources is located within the social context of the family. Social support includes marriage partners, extended family and friends, economic resources, and community support services ENRfu(Beresford, 1993). The availability of social support has been shown to be a coping resource in families with children with disabilities ENRfu(Beresford, 1993; Miles & Holditch-Davis, 1997). Types of social support are categorized into levels of support that help define the intimacy of support from within the family to the environment outside the family. The first level is considered to be close family members and friends with the second level including neighbors and more distant friends. The third level of support includes formal and institutional support that is considered infrequent support.

Positive social support is observed in families that have higher perceived life satisfaction levels within the family, have a cohesive family structure, are adaptable to a

variety of situations, and have the ability to express emotions within their families ENRfu(Beresford, 1993; Hawley, 2000; Stephenson, 1999). A strong marriage relationship assists a family in coping with stress but the on-going stress of caregiving for the child causes marriages to be vulnerable. The build up of demands within a family has been shown to increased relational strain within a family ENRfu(Stephenson, 1999). Families that are able to develop strong intimate social supports are more likely to withstand pressure within the family. Anna was observed to seek social support from the professionals in the NICU, her husband, and from the on-line support group as she compensates from the lack of close immediate friends.

The information we have regarding caregivers and children is primarily based on research from families with children with developmental disabilities not requiring skilled medical care, illness requiring lengthy hospitalizations, or acquired trauma not related to birth ENRfu(Beresford, 1993; Day & Alston, 1988; Hilbert et al., 2000; Horn et al., 1995; Melnyk, 2000; Sherman, 1995). We cannot assume that families with premature infants have the same resource needs. Future research is indicated to study the needs of families with premature infants with complex medical needs.

The perception of stress and the ability to successfully cope are closely intertwined because a family member's perception of stress directly affects the well-being of the family. The gap that occurs between an individual's perception of stress and society's perception of stress supports the need for qualitative research that seeks to understand the viewpoint of the families. This gap in understanding also lends understanding why people would seek from support from those going through similar circumstances, such as peer-mediated on-line support groups. The emergence of on-line support groups appear to be an effective method of providing support to a family to care for their child with special needs.

## Expanded Field Notes of Home Observation and Birthday Party

### Home Observation of Family with Premature Twin Infants

Tuesday, October 9, 2001, 10:25 a.m. to 1:10 p.m.

*The purpose of this observation was to observe the routine activities of a family with premature infants. Expanded field notes are as follows (observer comments are in Italics):*

The project was fully explained to the family and the mother signed the consent form for the field observation. The infants and family members were provided with pseudonyms to protect confidentiality. The mother and grandmother chose the pseudonyms for the infants.

I had previously known this family while the infants were hospitalized at in the NICU at Northside Hospital in Atlanta, GA. The infants were born at 28 weeks gestation. The infants were born 5 months ago, but their corrected gestation age was 7 weeks. During the hospital course, the infants experienced multiple medical problems related to prematurity. Both infants, had respiratory distress syndrome and bronchopulmonary dysplasia, that required prolonged time on a ventilator and interfered with the development of bottle feedings. Malfaldo was discharged home 3 weeks earlier than Penelope. After discharge from the NICU, Malfaldo quit taking her bottles for her family. The family struggled and sought help from us (*the therapists and nurses*) for recommendations. (*I think she was discharged too soon, she had just started taking all her bottles and father had always had difficulties feeding Malfaldo, this is a reason I wanted to do the study, to show the issues that occur with early discharge*). Eventually, the family was able to get her take all her bottles but the feedings would often last an hour. At the time of observation, this was the 3<sup>rd</sup> week that both infants had been home with the family. Malfaldo had a longer hospitalization because of problems related to severe gastroesophageal reflux (GER). While in the NICU, she was known to scream inconsolably after a bottle feeding. The problem was so significant that she developed an

oral aversion to the nipple and oral feedings had to be suspended for one day. Other medical problems related to poor feeding were intolerance of formula and an intestinal infection (Cdiff). The infection was related to an overgrowth of bacteria caused by antibiotics used to treat other infections. At the time of discharge, she was still battling problems with Cdiff and GER but had demonstrated a fair ability to take all her bottles. *(the dilemma was – would she do better at home in a quieter environment and would this reduce the stress on the mother, having one infant at home and one infant in the NICU)*

The family's home was located on a cul-de-sac in a well-established neighborhood in a northern, fairly affluent suburb of Atlanta, GA. The homes in the neighborhood were approximately 30 years old with large trees lining the street. The family's home sat in the middle of a cul-de-sac; with a large front porch stretching three-quarters across the front of the home. The short asphalt driveway curved uphill toward the front of the home where the living room window faced the driveway. The mother came to door and greeted me while I was getting out of the car.

I walked up the brick steps to the porch and the mother held the door open for me. The mother directed me through the foyer to the living room on the left. I handed her two sacks of lunch food that I had picked from a deli on the way to the observation *(I hated to show up empty-handed, I had mixed feelings about doing the observation as research and coming to visit with family as a friend from the NICU, even though I was staff, I always take food when I visit a new parent)*. The living room was approximately 15 ft. by 10 ft. and had a large window that looked out on to the front yard. *The room seemed to be organized as "infant command central"*. A display of leaf patterns filtered through the window from the brilliant fall sun outside. The couch, that faced the window, was the prominent piece of furniture in the room. On the floor at one end of the couch, sat a basket filled with baby items and other medical-looking items, such as tubes. At the other end of the couch, a stack of diapers, blankets, infant bibs and a changing pad was observed. Looking around the periphery of the room, I saw one infant swing, two infant "bouncy" seats, a basket of rattles and infant toys and two Boppy pillows (commercial

brand horseshoe-shaped pillows). An entertainment center, containing a TV, was positioned along the short end of the room. The room was clean and orderly.

I walked into the room and Grandmother (the mother's mother) was seated on the couch with Malfaldo on her lap. She was holding a pacifier in the infant's mouth. She smiled and welcomed me. A smaller infant was sitting in an infant seat on the floor facing the couch. *I had previously met the grandmother in the NICU.* Starting out, I was confused with which infant was Malfaldo and which infant was Penelope. The mother straightened me out. The little infant was Penelope and the larger infant was Malfaldo. The family offered me a chair, but I sat on the floor. (*I thought if I sat on the floor, the visit would be perceived as less informal, I really wanted to blend into their routine as much as possible, the mother was sitting on the floor, so I sat on the other side of Penelope*). As the mother and I settled on the floor, the mother picked up Penelope. Both of the infants were clean and dressed in thick sweaters and socks. Penelope's outfit was coordinated in green and Malfaldo in pink. We spent about 30 minutes talking after I arrived.

Each of the infants had pacifiers that were held in their mouths by their caregivers. Penelope was sucking furiously on her pacifier in her mother's arms. The infant's body seemed stiff with her shoulders back and hands fisted at her shoulders. We began to talk and catch-up with what had been going on since they had left the hospital. I said, "I notice Penelope still had the same pacifier from the hospital". The mother replied that she had a lot of those green pacifiers (*Preemie Soothers from Children's Medical Venture, not sold except through a catalog*). She told me that every time, one of the pacifiers fell on the floor in the NICU, she would pick it up, take it home, and wash it (*the policy in the NICU is to throw away anything that hits the floor, somewhat wasteful but infection control is a priority*). "I even have some pacifiers in the plastic that I was given when we were leaving the hospital". I asked the family if they always had to hold the pacifiers in the infants' mouths. The mother didn't answer the question but said that she was trying a new pacifier with Malfaldo that hopefully she could learn to hold in her

mouth by herself. The pacifier was larger than the green pacifier and had a bulb on the end. *(I got the impression that she didn't think that Penelope would be able to hold her pacifier in her mouth without assistance)*. The mother told me that Penelope had Cdiff, again. *(the bacterial infection that causes pain, frequent diarrhea, and subsequent irritability)*. She said that she had found out from the pediatrician the previous day. Vancomycin had been prescribed. The mother was hoping that the infection had been caught early. I asked if the infants were sleeping through the night. Mother and grandmother answered simultaneously, “no”.

The mother brought up the experience of Penelope being admitted to Scottish Rite, less than 48 hours, after she had been discharged from the NICU. She related how hard the experience had been and how different it had been from the NICU at Northside. *(I was aware of the re-hospitalization, she was admitted because of dehydration, once home, the family was not able to get her take her bottles,)*. She talked about being alone with Penelope in a room. *(The NICU is arranged in pods and there is always someone around)* She felt that she could not leave Penelope because the nurses did not appear to be prepared for her infant. She told the following story:

The nurse assigned to Penelope did not understand how to tube feed an infant that had rice cereal added to the formula. The mother kept telling her what size tubing to use. The mother tried to tell the nurse that the rice cereal would clog a small tube. The nurse replied that they did not have that size tubing at Scottish Rite but she would look around for a larger tube. She left and returned later, stating that she couldn't find any larger tubing. The mother couldn't believe that the hospital did not have any larger tubing. The nurse proceeding to put the formula with rice cereal into the small tubing and it clogged. She did it a second time and it clogged. Eventually, a neonatologist from Northside (who has privileges at Scottish Rite, also) brought tubing from the NICU at Northside Hospital (the NICU and the children's hospital are located directly across the street from each other). While in the children's hospital, the Cdiff infection worsened. The diarrhea got so bad that she had blisters on her bottom when she was discharged from the hospital.

I told the mother that I knew that the therapist at the children's hospital (who works in the NICU and at Scottish Rite) recommended that the mother learn to tube feed Penelope so she would have an “out” at home when Penelope refused to eat. (this would

involve the mother learning to put a tube down the infant's nose for the feeding, this is a standard way of feeding premature infants but typically infants are not discharged on tube feedings). The mother related that she couldn't stand the thought of putting a tube down Penelope's nose because she saw how Penelope fought the nurses when the tube was going down her throat. I asked Mom if she thought that sometimes Penelope was just not physically able to take a bottle and would benefit from that "rest period" that a tube would give her. The mother hesitated then told me about the past weekend. I would never have considering using a tube but if she had continued screaming and refusing to take a bottle like the past weekend, I think that I might have considered learning to use the tube (this was the weekend before the medicine was started for Cdiff). The mother stated "I'm use to the battle but it was getting tiring" (this let me know that the feeding difficulties are taking a toil on the family)

The grandmother told me that she primarily takes care of Malfaldo so that the mother can take of Penelope, "... because she has been so sick". I was told that this pattern of dividing up the responsibilities began when Penelope was hospitalized. While the mother stayed at the hospital with Penelope; the grandmother took care of Malfaldo at home. The grandmother explained that she had moved Malfaldo's crib into her room to keep from disturbing the sleep of the father who had to go to work everyday. The grandmother expressed that she was initially afraid to take a shower when she first assumed responsibility for Malfaldo but then "I finally tried it, and she did OK".

I ask the family if Babies Can't Wait had gotten involved with the infants. The mother reported that both infants were enrolled in Babies Can't Wait. Penelope had started receiving physical therapy (PT). The mother reported that the PT said that Penelope was stiff (this was a problem in the NICU, she was so stiff because of GER pain). She continued that to tell me that Penelope does not like to lie on her stomach and that the PT was getting a wedge to help her. The mother said that BCW was, also, going to get a feeding therapist to help both infants. Malfaldo's problem was that she was still

munching and biting on the nipple. There was a mix-up with BCW at the initial referral. BCW assumed that the family could not speak English, since they family had a Hispanic background. A service coordinator (SC) was sent that typically works with families who only speak Spanish. Once the SC figured out the family spoke English, a new S.C. was assigned. The mother reported that both of the S. C.'s were nice but the miscommunication delayed the infants getting services. (shows how cultural assumptions can get you in trouble, also highlights problems with bureaucracy, I know the first SC and he is a wonderful asset to the families who only speak Spanish, I know it would have been a waste of his assets to continue to work with this family, the mistake started at the referral source).

The phone rang and I offered to hold Penelope. (I wanted to see how stiff she was and to see if I could get her tolerate her stomach while on my lap). I placed Penelope on my lap on her right side. I bounced my legs and gently rolled her back and forth, towards her stomach. Every time, I rolled her towards her stomach, she arched, and cried. (this is technique that usually works in getting infants to tolerate prone, indicator of later developmental problems). I sat Penelope up to an upright, supported sitting position facing me, then moved her to my arm. The mother returned from the phone call and told us that "it was Carolyn", the respiratory therapist from the NICU. The mother said that she wished Carolyn would come to visit (shows support of staff from the NICU but is it enough now that the family is home, the mother appreciates the phone calls but wants the visits). I held Penelope until she began to fuss. Then, I passed her back to her mother.

At that point, the grandmother laid Malfaldo down on the couch, announced that she would warm the formula, and left the room. The mother explained the schedule of bottle feedings (I will have to admit that I got lost in the explanation). Grandmother called from the kitchen and wanted to know the amount of formula for Penelope. The mother was sitting Indian-style on the floor. Cradled within the nest of her mother's legs, Penelope fell asleep. Looking down at the sleeping infant, the mother began to pick fuzz

from between her fingers. She stated that one of Malfaldo's fingernails was long and might scratch her. The mother scooted backwards across the floor with Penelope still sleeping on her lap. She retrieved the infant nail clippers from the end table by the couch and clipped the infant's fingernails. (this seems to be a typical mother-infant activity). The infant began to stir and wake up. Penelope's arms began to wave up and down in a reciprocal pattern.

Grandmother returned to the living room with the formula and Penelope's medicine. She handed the mother a large, short glass bottle of infant formula and an empty taller, slim bottle (These are the kinds of bottle, you would find in the NICU for feeding infants) and a brown syringe filled with medicine. The mother told me that the pharmacist had flavored the medicine with cherry so that it wouldn't be so hard to give it to Penelope. I asked the mother if the pharmacist had provided the medicine in syringes. She said "no" that she had saved them from the NICU so she could draw up the correct dosages. Mother told me that Penelope's formula had been changed to Neocate and that she seemed to be less irritable. The mother and grandmother smiled at each other when she said "less irritable". The mother continued to say that Penelope cried "24-7" when she first came home. (I think the smiles meant that the irritability is relatively not as bad). The mother added a portion of the medicine to the empty bottle and filled up the rest of the bottle with formula. From the floor, she reached up and placed the larger bottle on couch end table.

Holding Penelope in her left arm, she placed the nipple in the infant's mouth and the infant began to fret. The mother began to repeat, in a sing-song voice, the following phrases: "I know it", "Remember to breathe and swallow", "Don't choke, remember to breathe and swallow". The mother looked up at me and said, "that's a problem sometimes". (referring to the fact that Penelope has problem coordinating sucking, swallowing, and breathing, this is something that we worked on in the NICU, I am seeing how it carried over into the home, this is a typical pattern of soothing infants but the

words are not typical). She said, “not that great”. (I am sure if she is talking about the taste of the medicine or how she is taking the bottle). During the feeding, the mother rocks in a rhythmical pattern forwards and backwards to calm the infant. The infant is fretful through out. After about 5 minutes, the mother takes the nipple out of the infant’s mouth (as if to give the infant a rest). After a minute, she places the nipple back in the infant’s mouth and Penelope is observed to suck. Mother looks at me and says, “This is better than usual”. The mother explained that she often gags and chokes when taking her bottle. Grandmother added, “Maybe you should come all the time”. Then Mother placed the infant on her shoulder to burp. Penelope bobbed her head at her mother’s shoulder as the mother patted her back.

The mother began to talk about her experiences with doctors. There was one G-I (gastrointerologist) doctor that she intensely disliked. The one who saw her in the NICU. The mother said that he told her that Penelope’s problems were psychosocial and that the family should just be prepared for a hard 6 months and that she would outgrow the reflux problems. (I wish he could have been there with me to observe the impact GER was having on this family and infant’s life, this is one of the reasons I want to do this study). I asked the mother how many other doctors the girls had to see. The mother told me that both of the girls had the same pediatrician but had different eye doctors. ( Penelope’s had severe retinopathy of prematurity (ROP) and required laser surgery in the NICU).. A retinal specialist followed Penelope. Malfaldo had milder ROP and received follow-up from a general pediatric ophthalmologist. A pulmonology specialist saw both of the girls. Malfaldo did not see the G-I specialist. Penelope has an appointment with an ENT in December because she failed a hearing screening in one ear. The mother told me that she was concerned about the hearing and wished that the appointment could be moved up.

The mother removed Penelope from her shoulder and returned to bottle feeding. After the infant had finished that bottle the mother said, “took complete medicine”. She put the infant back on her shoulder to get out another burp.

While the feeding process is going on with Penelope, Grandmother returns to the room with Malfaldo's bottle. The bottle was angled and different from Penelope's straight, cylindrical bottle. Sitting on the couch, grandmother positioned her almost totally reclined and supported on her left arm. She said that they liked the angled bottle because the infants got less air while sucking. I observed Malfaldo's pattern of sucking. The infant's lips formed a seal around the nipple but the infant's jaw was moving up and down (this is not a typical pattern of infant sucking, she was probably munching or biting on the nipple, I understand why she will be receiving therapy for her feeding). During the feeding, Malfaldo pulled her legs up towards her stomach (I don't know whether she was being playful or trying to avoid taking the bottle). "Much better" said the grandmother to the infant. ( I am not sure why she said this, I think that it may have been that she had been having a hard time getting her to start sucking, my attention had been focused on Penelope). Grandmother took the bottle out of Malfaldo's mouth and put her up on her shoulder. She pats her back in attempt to get out a burp. I looked over at the mother and she still has Penelope on her shoulder. Mother takes Penelope down from her shoulder and puts the nipple back in her mouth. Penelope screams. Mother takes the nipple out of the her mouth and puts her back on her shoulder. She continues to pat her back and in the sing-song voice says, "Come out little bubbles" (meaning the burp). Continuing in the sing-song voice she says "we get tired, because we work so hard". At that point, Penelope drops her head down on mother's shoulder. (I am not clear if the mother was completely talking to Penelope or letting me know that feeding is such a difficult issue, whatever the reason, I got the message, feeding is difficult for mother and Penelope). The mother took Penelope down from her shoulder and ,once again, offered the bottle. Penelope took the rest of the formula in the bottle.

The mother performed a multitask activity of holding Penelope and re-filling the bottle with formula and medicine. She held Penelope in her left arm, the bottle cap in her mouth, and poured a mixture of formula and medicine from the larger bottle into the

smaller bottle. After the bottle was filled and the nipple screwed back on the bottle, the nipple was placed into the infant's mouth. "Going into a trance" said mother. (I think that Penelope must have been tired and was staring while sucking on the bottle). Mother repeated the previously described pattern of sing-song talking and rhythmical rocking. She repeated "we forget to swallow, we hate it when we choke .... Now gulping". Mother continues to rock back and forth.

Looking back over at the grandmother on the couch, I saw that Malfaldo had become quiet and still but I could hear her making smacking sounds on the nipple (she appeared to be drifting off to sleep). The grandmother tugged on the bottle in Malfaldo's mouth (she was trying to get Malfaldo to suck).

I asked the family when they had time to do housework, like washing the clothes. The mother said. "Mother is the laundry queen". (referring to the grandmother). The grandmother told me that she gets up early each morning and starts the wash.

Returning my attention to mother and Penelope, I observed Penelope stop sucking, loosen her lip seal on the nipple, and make direct eye contact with the mother. A moment later she tightened her mouth and returned to sucking. (even though feeding is difficult, such a neat moment of quality mother-infant interaction observed). The routine, as previously described continued, with the mother putting Penelope back on her shoulder to get out a burp.

Grandmother was heard to say, "my arm is getting tired". The grandmother had been sitting on the couch, the entire feeding, holding Malfaldo in her left arm without support. Immediately following that statement, the mother said to Penelope, "Going to have to change your view (she was facing the window and now must be positioned facing away from the window). She switched Penelope to her right arm. I said, "what about the Boppy pillows?". (I have previously mentioned seeing the Boppy pillows in the corner, these are used to position infants while feeding, either breast or bottle, I thought they used them in the NICU to prevent strain on back, necks, and arms, makes me wonder).

The grandmother said, “Oh!, I forgot about that”. She left the room and returned with a Boppy Pillow. (I wondered why she didn’t use the two pillows in the corner of the room). She sat down on the couch, positioned the horseshoe pillow around her left side on the couch and rested her arm with Malfaldo on the pillow. The mother continued feeding Penelope while resting while positioned with her left arm. Grandmother showed me a bump on her left wrist. She felt that the bump was caused from the strain of holding Malfaldo.

The telephone rang, the mother says “Ooh, the telephone. Let’s see which doctor is calling us now. We have left messages with two. “We saw a little blood in her diaper this morning.” While holding Malfaldo in her arm, she stands up from the floor and goes into the next room to answer the phone. Returning from the phone call, she said “It was Aunt Penelope”. She told me that Penelope was named after her aunt who was a pediatrician in New York.

After the phone call, mother returned to her previous position on the floor while Grandmother continued to feed Malfaldo as positioned on the Boppy pillow. After several minutes, Penelope began to fret and stiffen her back. The irritability began to build until she began to cry, arch backwards, and push her legs out in front of her. Mother continued to offer the bottle to Penelope and was heard to say “you have to take it, remember to swallow”. Once again, continuing in the sing-song voice. (Though I knew that the mother was becoming frustrated, she never showed her frustration, never raised her voice, but continued speaking in the soothing, motherese language).

Now, Malfaldo, began to fret and grandmother bounced her up and down with her arm. The bottle feeding was not completed, yet. The grandmother said (to Malfaldo) “you too sleepy.... See what happens (meaning she should have taken a nap)... I’ll give it to you later (meaning she is going to let her sleep).” Malfaldo is now asleep on the arm of the grandmother. Malfaldo is laid down on her stomach on a pallet of baby blankets on the couch. The grandmother covered her with a blanket as she slept quietly with her hand

to her mouth. The grandmother left the room and dishes were heard rattling in the kitchen.

The mother says Penelope has taken the minimum of at least 50 cc's. At that point, a pink trickle of formula began to dribble from Penelope's mouth onto to her bib. (the cherry flavored medicine caused the formula to turn pink, I don't know if she had spit because of reflux or if she was tiring and was losing formula from her mouth, instead of swallowing, she must take the minimum to keep her from losing weight.) Mother takes the nipple out of Penelope's mouth and places it on the end table. The infant's eyes widen and she catches her mother's attention. Penelope then raises her eyebrows and the mother responds by widening her eyes and raising her eyebrows. Reciprocal interaction between the mother and infant was observed as they repeated the pattern over the next several minutes. The infant's posture was relaxed with legs flexed in a neutral position and arms resting at her side. (such quality interaction, the mother was in-tune to the infant and picked up quickly on non-verbal signs of interaction). The mother places Penelope on her knees as she leans back on one arm behind her. From this position, the mother and infant are observed to have face to face contact. The mother talks to the infant and engages Penelope into following with her eyes as she moves her face from side to side. The mother states that she feels that Penelope's vision is improving but is not sure how well she hears (I remember that she failed her hearing screen in one of her ears). The mother requested that I get a toy from the basket in the corner of the room. I selected a bright toy that squeaked. I knelt behind mother so I could observe the infant's face. I saw her visually track the toy in a horizontal and vertical pattern. Out of Penelope's line of vision, I squeaked the toy and was not able to elicit head turning to the sound. She was noted to quiet her movement to the sound stimulus but did not turn her head. Grandmother came into the room and began to participate in the play. She held up a toy and tried to get Penelope to look at the toy. After a few minutes, Penelope began to push and redden in the face. The mother said that she thought Penelope was working on a dirty

diaper. The mother continued to encourage Penelope to follow with her eyes; using infant rattles and toys. Penelope began to look away and the mother said that Penelope definitely had a dirty diaper.

As the mother stood up from the floor, the grandmother placed a changing pad on the couch. She placed a black, white, and red crib mirror with plastic links hung from the mirror on the inside of the couch. (brightly colored links, typical infant toy, light and easy to manipulate, can hook on rattles to encourage and entertain the infant, age-appropriate toy, apparently this was to distract ). The family jointly worked together to complete the task. The mother began to change Penelope's diaper and Penelope began to cry. The infant alternately flexed and straightened her legs and flapped her arms up and down. The grandmother said, "we do not like diaper changes". The mother crooned the following phrases: "you are OK, Mommy's hands are cold". "Ooh, I don't remember her diapers smelling this bad in the nursery!" said the mother. I observed a large dark green stool in the diaper (typical of an intestinal infection). The mother wiped the infant's buttocks clean and showed me the scars from the previous Cdiff infection. I observed the healed but scarred skin on Penelope's buttocks. The mother said, "Oh, it was sooo bad, there were blisters". The skin was slightly red from the bowel movement but the skin was not broken from irritation. After completely cleaning the infant, the mother applied a heavy dose of Desitin. "We use lots of Desitin, we don't want it to happen again". Snapping up the infant's outfit, the mother stated that she wished infant clothes had zippers on the inside of the pants to make dressing easier.

Once dressed, both the mother and grandmother sat on the couch. Penelope was held in the crook of the mother's left arm and Malfaldo was asleep on the blankets on the other side of grandmother. Both infants were quiet. The mother said "See, this is what we do everyday." The mother and grandmother chuckled. I was sitting on the floor facing the couch. I noticed that Penelope's eyes began to widen, she swallowed, and she began to stiffen her back. (This is a typical GER pattern, the stomach contents push up from the

stomach, into the esophagus, into the throat, the infant swallows to make it go down, eventually the acid irritates the esophagus and causes pain). Penelope began to cry, again. The mother bounced her up and down and eventually placed her in the infant seat on the floor in front of the couch. The infant immediately quieted and closed her eyes. “She’s asleep” said the mother. “Sometimes, she just can’t handle being held”. Shortly after that statement, Penelope began to stir, whimper, and escalate to a cry. The mother picks her up as Penelope arches. The mother rests Penelope on her lap and cradles her in her arm. Penelope continues to stiffen her back and legs. Her feet were held tightly flexed, her elbows flexed, and her hands were tightly fisted. Occasionally, she would relax this position then return to pushing. This pattern continued for approximately 10 minutes. She eventually fell asleep in the mother’s arms.

We continued to visit as the infants slept. After the grandmother had offered me something to eat or drink three times, I took her up on the offer of coffee. (I felt that I needed to accept the offer because I sensed that I was causing the grandmother distress that she wasn’t being a good hostess). The mother told me that the infant’s most fussy periods were from 5 p.m. to 11 p.m. when Michael came home from work (their father). “The atmosphere really changes” said the mother. He bangs the pots and pans when he cooks and turns on the TV in everywhere room, well, at least in two rooms. The TV volume has to be turned up so he can hear over the banging of the pots and pans. (By the look on her face, I could tell the mother was mildly amused at Michael) The mother said “I think they get over stimulated in the evening.” We are so quiet during the day with just Mother and I here. We occasionally turn on the TV and music, but that’s about it.

Grandmother brought me a cup of coffee and slices of fruit bread on a pottery plate. She set up a TV tray to play the items on. The mother said that the people who work with her husband had sent them a lot of food and the bread was part of the food. (another indication of support, resources). The grandmother sat down on the couch and had a cup of coffee with me. The family apologized that they had not had time to get out

the sandwiches I had brought them. I assured them that it was OK and that the food was really for them. (I don't know when they have time to eat). I asked them if they were able to get a catnap during the afternoon. They both smiled and nodded. Mother said, "we fall asleep with them in the afternoon".

We continued to talk as the infants slept. We talked about the terrorist attack on the World Trade Center. They talked about watching it on the TV while caring for the infants. (I knew that the grandmother lived in NY but I wasn't sure if the grandfather was still in NY). I asked the grandmother if the attack had affected them directly in NY. Grandmother told me, "not directly", because we live in Queens. She did mention that the grandfather was still in New York (I wanted to ask what her husband thought about her being here in Atlanta for so long, or how long she was prepared to stay, but probes did not bring forth information, since this was an observation, I didn't think it was appropriate to pursue it, I was trying to get an understanding of family support, including sacrifice). We continued to "chit chat" about the best place to buy fish in Atlanta, the buying out of Harry's Farmer's Market, and neighborhood markets in NY that will cook the fish you buy and let you eat it there. (The conversation gave me a better understanding of the family network). During our conversation, the phone rang again and it was the nurse from the pediatrician's office. I did not hear the conversation. The mother returned and said the nurse would discuss the problem with the doctor and call back (more uncertainty and waiting for phone calls from doctors).

I asked the mother if she had ever had a chance to look at the Premie-L Discussion List that I had told her about in the NICU. She said that she had gone there once but was overwhelmed at the number of messages. (I don't think she got past the home page) She said that she didn't subscribe to be a member. (I know that she was active on the Internet before the infants were discharged, this shows a limitation for the preemie list, will be interesting to see if she follows-up with the list after things quiet

down on the list) I talked some about the study and the family picked the pseudonyms for the infants. They laughed.

I saw Mother yawn and I decided that it was time to go. I told them that I had to go but that I would come back and bring others now that I knew the way. They encouraged me to bring other people from the hospital. I told them not to get up and thanked them for letting me come. I let myself out of the house and the visit ended. (After leaving the observation, I turned off the radio, stopped at the first available parking lot and expanded my notes, it was difficult to take notes, especially during conversations, I wished I could have had a tape recorder and got permission for an interview).

### **Reaction to Field Observation**

I had mixed feelings about doing the observation with this family because of the multiple roles I was assuming as friend, therapist, and researcher. I had somewhat resolved my emotions because I had told the mother about my project when both of the infants were in the NICU. She had suggested that I come and “hang out” in their home. The first time I called, the mother had just left to take Penelope to a G-I appointment. The grandmother told me over the phone that they had been having a difficult time with Penelope crying all the time. I had already heard through the hospital grapevine about the difficulties the family was having with the infants. After hanging up, I did not want to call back and ask the mother if I could come observe. I hesitated to intrude in their personal lives even though I knew they wanted visitors. I don’t think I would have felt the hesitation if I was only going to visit. On the other hand, my close relationship with the family from the NICU allowed me to enter their home and observe the “real world” of the family. When the observation ended, I no longer had any misgivings about the observation and I was glad I went.

This field observation was more intimate than most field experiences. There was no way for me to blend into the woodwork. There were only three of us in the room with two infants. I felt that the best approach was for me to blend into their routine. This is

why I sat on the floor with them and carried on conversations with them as I would have done in the NICU. This meant I could still ask my “therapy” questions. The action was very slow and the experience seemed more like an interview. I do regret not having a tape recorder to record our conversations. It was very difficult to take notes when the family was talking directly to me. Turning off the radio and stopping to write notes before I got home, helped me retain details of the observation.

In the NICU, I observed that this family had the pre-existing resources that provided them with the support to adapt to the initial crisis of the premature births. They had a supportive family, a stable marriage, financial resources, and emotional stability. This observation provided me with specific information about how this family adapts to on-going stress related to the medical problems of prematurity. I observed the pile-up of stressors that included, the feeding difficulties, the irritability of one of the infants as related to medical problems, the re-hospitalization of one of the infants, the following up with the multiple medical specialists, dealing with the institutional bureaucracy, the physical stress on their bodies, and the management of household demands. I observed how they obtained new resources to balance the stress. The grandmother was a valuable asset as she assisted with the daily burden of caregiving for the infants. Also, I observed how the family had support from co-workers and continued support from the staff of the NICU. The mother had managed to get both infants enrolled in Babies’ Can’t Wait much quicker than most of my parents.

Though the burden of caregiving was observed to rest on the mother and grandmother, I observed that the father assumed the responsibility of cooking and shopping for the family, as well as, continuing to work a full-time job. This balance of responsibilities provided me with more insight into how the family adapted to the situation.

The mother never showed frustration or impatience though I could tell she was tired and the pile-up of stress was beginning to wear on her. Her steady, quiet personality

is complementary to her difficult infant. I did not mention in the field notes but the mother has Lupus and almost died giving birth to the infants. I am concerned that the mother is not able to obtain needed rest to prevent a flare of Lupus.

Overall, this experience ignited my passion to learn more from these families. I was confirmed that my purpose for research is worthy.

### **Birthday Party Field Observations**

#### **Expanded Field Notes**

Date: 1/27/02

Location: Suburb Atlanta

Time: 2:00 - 4:30 pm, on a Sunday afternoon

Length of Observation: 4:00-5:30 pm

Note: the names of the participants have been changed to protect the identity of all.

The event was the first birthday party of Camilla Diaz, held at the Diaz home. The home was located in a suburban neighbor in the northern aspects of a large metropolitan city.

There were many homes compacted close together, appearing to be less than one-half acre lots. The homes were generally clear and orderly with at least 2 cars in front of each home. These homes reminded me of what I call "starter homes". As based on the other neighbors that I saw in the yards, the neighborhood was multicultural in population.

Their home was a 2 story, brick front home with a garage in the front of the house.

I was one of the earlier people to arrive at the party. When I arrived, I rang the door and the father answered the door. I entered the high foyer, a stair case climbing to the left and I was a picture of Anna in her wedding dress hung from the wall as taken in their native country of Puerto Rico. I looked to the stairs and saw the 4 y.o. brother

coming down the stairs. He made eye contact with me, rubbed his eyes, and returned back up the stairs.

I walked out to the foyer into the den or family room area. I saw an Afro-American couple on the couch (man and woman) on the couch. They were watching a NFL football playoff. Two young women, appearing to be in their 20's, came in after me. They were fellow employee's of the mother. I had remembered that one of them had come to the NICU to Camilla with the mother over lunch one day. I entered the den, the father offered me something to drink. I declined. I noticed that there were 2 sitting areas in the room. One that looked on to the TV. The other area faced the patio with an inside window looking over it from the kitchen.

Dad told me to go upstairs ( I was curious that he told me to go upstairs, seemed like I was being embraced as an insider and didn't have to wait to see Camilla). I went upstairs. There were 3 bedrooms at the top of the stairs and a full bath. Two of the bedrooms were small and were the children's rooms. The master bedroom was larger. I entered Camilla's room. I saw Camilla in the crib. The mother was completing getting her dressed for the party. The home-health RN was sitting in a soft, easy chair in front of the crib. She had a notebook in her lap (looked like this was for medical reporting). It was a very small room. Furniture in the room consisted of the crib, the easy chair, a chest of drawers, suctioning equipment, a large green oxygen tank, and a portable oxygen tank. There was a mobile over Camilla's crib. The mother was putting perfume on Camilla. She showed me the bottle. It was "infant cologne". The mother said that is was 5 yrs old and that she had it since A. It was perfume from outside the US. Camilla was dressed in a velvet/sateen dark blue dress with a sash and bow in the back. She was wearing a pearl bracelet. I noted that there were not pearl earrings in the infant's ears. ( From previous conversations, I knew that earrings in infant's ears were part of their culture, the reason that she didn't have earrings was because of her medical disability, the mother has earrings but can't get anyone to pierce her ears). Dark curls framed the infant's face and

she had glassed on. The mother said that she had gotten the glasses only one week before. Camilla was also wearing white infant shoes with tiny yellow pearls and lace frilly socks. Alexa made no eye contact with anyone in the room. I returned downstairs after saying hello to the mother.

Shortly after I arrived, another mother entered the home. She was JD, a ‘preemie mom’. She was introduced as a “preemie mom”. Her child was in the NICU the same time as Camilla. JD showed me picture of her daughter that I had know in the NICU. She would be one year old on 4/11/02. I said to her “you were in the hospital last week?”. She said, “yes, we lost a baby”. (I had heard that she had been hospitalized for premature labor and had lost the infant). She went on to say that “it’s OK but tough. We tried to keep it to ourselves until I had to go to the hospital. I know people were thinking how stupid! They were probably thinking, ‘2 months after you have G. (her infant) home from the NICU’, It was a surprise (not planned pregnancy). I would have been on bedrest longer than with G. It would have been bad. It’s the best thing but hard to go through.” She was telling me this story as she held the pictures of G. We continued to look at the pictures. I was G. with a long narrow head, no hair. She told me that Babies Can’t Wait (BCW) was following her but that she had no needs at this time. She had gotten a letter from BCW stating that G. did not have needs and that she was not eligible for babysitting, which turned out to be respite care. She had thought that she would be losing all her follow-up care. She continued to say that she didn’t care about respite care because her husband, the father, wouldn’t let her use the service.

Sometime during our conversation, a group of people entered the party. They were T. and J. (RN’s in the NICU), G ( a respiratory therapists in the NICU), and the Dr. J. ( the neonotologist in the NICU). The father said “all the moms and here is the real mom” (the real mom was the doctor) . Another guest, was a young female who looked of Hispanic descent. I asked her how she knew the family. She told me that Anna and her were old friends from Tampa (this is where the family had just moved from the previous

year, I think she may have been from Puerto Rico, also, I learned after the party, that the man in the first young couple had recently completed law school).

Anna and Alexa came shortly came down the stairs. I stood at the bottom of the stairs and videotaped the entrance to the party. The mother, with a big smile, on her face held Camilla facing away from her. She stopped in front of the couch. There were ooh's and aah's, smiles as everyone exclaimed over Camilla. There were comments about her curls, her hair, her glasses. Camilla looked away and did not smile. The mother told everyone about the food and offered drinks. Camilla had a humivent that was covering her tracheostomy (this is a protective covering that goes over the hole of the trach that filters air). The nurse came down the stairs after Anna and Camilla and sat in a chair in the corner of the room, in the TV area. She had a portable oxygen tank. She had a black notebook in her lap. The mother said to her husband, what should we get for Camilla to sit in, her seat? (at this age, she should be sitting independently but she needs support, the dilemma is that she has outgrown a typical infant seat.). The father left and brought back a soft infant bouncy seat that reclined. (She did not sit in the seat during the event). The mother said that she was sleeping through the night. The mother said that all they had to do was get up and give her treatments or change the pump and she didn't even wake up. (this isn't normal, may Camilla was sleeping through the night, usually when parents say this, it means they are sleeping through the night, but this meant the Camilla was sleeping through the night but not the parents). I noticed that the NICU crowd had gathered in an area of the family room away from the from the non-NICU party goers. JD was sitting on a couch in this area. Anna sat down beside her as she held Camilla in her lap. This was away from the TV area and faced the backyard and patio. She was talking to the other party members that were from the NICU.

The mother mentioned that she doesn't think that Camilla could hear on the left side. She continued to say that Camilla had passed her hearing screen in the NICU but that she may need to be re-tested. She said that the OT (this is the OT from BCW)

thought that maybe Camilla's neck was tight and she was working on that. Anna said that she loved the new OT but was having a difficult time finding a PT. The mother had chosen a PT from an agency. (from previous conversations and emails, I knew that the mother had not been able to get recommended PT's because they had full case loads, there are lists of therapists that have signed contracts to provide therapy services to BCW). Anna continued to say that the services coordinator from BCW had told her that if they didn't like the new PT that they didn't have to keep her. I told that I knew of a PT that may be interested.

The topic turned to the discussion of Synagis shots (this is a very expensive medicine that premature infants must have to prevent RSV, a respiratory virus that typically sends infants to the hospital, and could be fatal to fragile infants). Anna said that Camilla was so big now that she had to have 2 shots. One in each leg. The mother said that the nurses looked like "Nazis" coming towards her daughter for the shots. She related that she hated having to go for these shots. Dr. J. said "but they keep her well.". The mother talked about her visit to the neurologist. She said that he didn't have much to say. The mother said, "still waiting to see, maybe she will be OK." (I could see doubt on her face and in her voice, still a dream).

We talked about Camilla's glasses. The mom said that she didn't see how the doctor could tell that Camilla needed glasses (because she was an infant). He just said "she is getting glasses". (I wonder if there was anymore discussion instead of just telling the mother that Camilla was getting glasses). Someone asked if she had a hard time keeping the glasses on Camilla. The mom said that Camilla pushed them to the top of her head. She related that the eye doctor said that Camilla would get used to the glasses and wouldn't take them off when she realized that she could see better with the glasses.

G., the RT, kept calling out to Camilla "pumpkinnnnn" in a high squeaky voice. (this was a term of endearment used in the NICU by one of the RN's and G, is was picked up by others).

Anna handed me Camilla and went to put out the food. The food consisted of egg rolls, a vegetable platter, a tofu and vegetable item along with wine, beer, and soft drinks. We talked about another family that had been in the NICU at the same time. She said that she hadn't heard from them in a while. Both of the mothers wanted to get together with their children but the other's child's father was very protective (interesting because I have heard that both fathers are very protective). They hoped that they could get together in the spring because they could meet someplace outside, in an open area with less chance of infection. Dr. J. agreed that it was better to wait until spring. JD continued to talk about the other family. She said that the other infant's father even made everyone who came into their home wash their hands because they might bring something in with them, touch something in the home, and leave it there. (the families are afraid of infection). JD talked about the weight of her infant as compared to the other infant. The other infant (a boy) weighs more. JD said "I bet they feed him BBQ."

The mother placed the food on a low table in this area of the room. The mother pointed out the vegetarian selection to JD. She returned to the kitchen as she provided drinks to the other guests.

I was holding Camilla during these conversations. She tended to push her body backwards, arms and shoulders were back. She did not reach or bring her head forward toward the pictures or others in the circle. Her head was typically to the right and not to the center. S., the OT, from the NICU entered the party. I handed Camilla to her. The mother still in the kitchen. She sat down on the floor with Camilla and began to actively play with her. She sat on her on the floor between her legs (I wonder if it was play or if it was therapy, difficult to ascertain, I know that she thought she was playing with her). Then, she stood Camilla on her feet on the floor. S. laid on the floor and let Camilla stand and sit on her stomach as she bounced her up and down. Dr. J. got up and turned Camilla away from S. so she that she faced the others at the party.

Camilla began to get tired and started to cry. S. handed her to me. The mother entered the room and said that maybe she needed oxygen or suctioned. Anna took Camilla over to the corner where the nurse was sitting. The nurse suctioned Camilla and put her on portable oxygen. Anna then returned to the group and sat back on the couch with JD to her right. I noticed that there was a playpen in the corner, filled with pillows. There was an infant swing with Mardi Gras beads hanging across the legs in front of the seat. While seated on the couch in her mother's lap, Camilla threw up all over her mother. The emesis was thick, milk-based and beige. It soaked the couch, mother's pants and blouse, Camilla's outfit, and hit the side of JD who was sitting beside them. People around the couch, jumped up. Some went to get paper towels. (it was too much, too difficult to wipe). JD did not appear to be distressed. She moved slowly as she helped to wipe up the fluid on the couch and on herself. Anna called for her husband to help. I looked at her face. She was not smiling, her lips were downward turned. She slumped down on the couch with her head tilted to the left. She held Camilla out away from her on the edge of her lap. I tried to joke that "this was a typical infant thing" (didn't seem to help, it was a sad moment, I felt that the mother would have cried if she could). She stood with Camilla and left the room. A friend came over and wiped up the couch. She later came back with changed clothes, both for herself and for Camilla.

The brother came down from upstairs twice. There was much coaxing to engage him by the other guests (the non-NICU guest, the women that worked with the mother). He covered his eyes when he was spoken to. He would eventually return upstairs. (He seemed to be shy).

Mom and Camilla came down the stairs with changed clothes. A new couple and infant had entered the party. This couple was Afro-American. They had little boy that they said was 11 months old. Anna and the couple begin to compare weights of their children. (I think this was the only thing to compare the didn't show how delayed Camilla is). Anna mentioned that Camilla was on the charts with a corrected age. ( I

didn't follow her conversation but I know that the family has been concerned about weight gain and perhaps this was reason she was so happy).

After Anna and Camilla had changed clothes, it was time for Birthday cake and ice cream. Everyone gathered in the kitchen area. There was a bay window and kitchen table. There were inflated pillows with ribbons hanging down over the table. The brother, was at the table. He was smiling and no longer covering his face with his hands. The family stood behind the kitchen table. The guests stood in a semi-circle around the other side of the table. The nurse stood off to the side on looked on from the family room.

The mother said, "First of all, I have something to say. Everyone here, had something to do with Camilla during her first year of life... We have our friends and from the hospital." Her voice began to break and she had tears in her eyes. A., the brother, was now smiling and blew out the candles to the cake. Camilla did not look at the cake. She did seemed to scan the room and fixate on the balloons. Anna said, "I want a group picture." She tries to get Camilla to hold a balloon but the ribbon slips through her hand. The nurse continues to stand in the background. The father takes the picture of the group.

The next event was opening the birthday presents. I don't remember Camilla leaving the room, but she was no longer present. Most of the presents were clothes. A group of us went together and got the mother a full body massage from a local spa. The father said "what about me". He and another male guest said with smiles that this was discrimination. The young couple had left but I don't know when.

Then, the party seemed to be over. Anna said, now that you know where we live – stop by and see us". The guest began to leave. (I hung around to talk to some of the other non-NICU guest, as I have typed up this expanded fieldnotes, I definitely have a feel for the two groups, as NICU and non-NICU.) The NICU friends talked about the memories we had over the past year with the family in the NICU. We wondered if Camilla would remember us.

I asked the last couple with the baby how they knew Anna and her family. Anna and her husband was present when I asked. They all laughed. The man said that he was the one that initially interviewed Anna for the company that she now works for. This was in Tampa. She did not go to work for his department. (there was some kind of inside joke that I didn't understand). Since then, they had both been transferred to Atlanta.

The party was over and everyone had left except for the last couple. The father and this couple, the personal friend had sat down on the couch in front of the TV. I went upstairs and found Alexa asleep in the crib and the nurse sitting, approximately 4 feet away from her. The notebook was still in her lap. I said good-bye to the sleeping Camilla and left.

APPENDIX F  
NVIVO MODELS OF CODING AND THEME ANALYSIS

## APPENDIX F

## Nvivo Models of Coding and Theme Analysis

This appendix includes NVIVO models that were used during the analysis process to visually represent the findings from the data. The process of modeling helped to discover patterns and relationships in the data. Multiple models were drawn through out the analysis process as the data categories were regrouped and interpreted. Modeling began after the first broad coding of each of the research questions and is identified with the word "broad" in the figure title. The model, identified as "final" in the title, represents the final model that represented the final results that were discussed in this paper. A listing of the figures are as follows:

Figure 1. Impact on family broad (see p. 211)

Figure 2. Impact on family final (see p. 212)

Figure 3 Perceived needs broad (see p. 213)

Figure 4 Perceived needs final (see p. 214)

Figure 5 Support availability broad and final (see p. 215) The categories stayed the same from the broad to the final analysis

Figure 6. Member perception broad (see p. 216)

Figure 7. Member perception final (see p. 217)

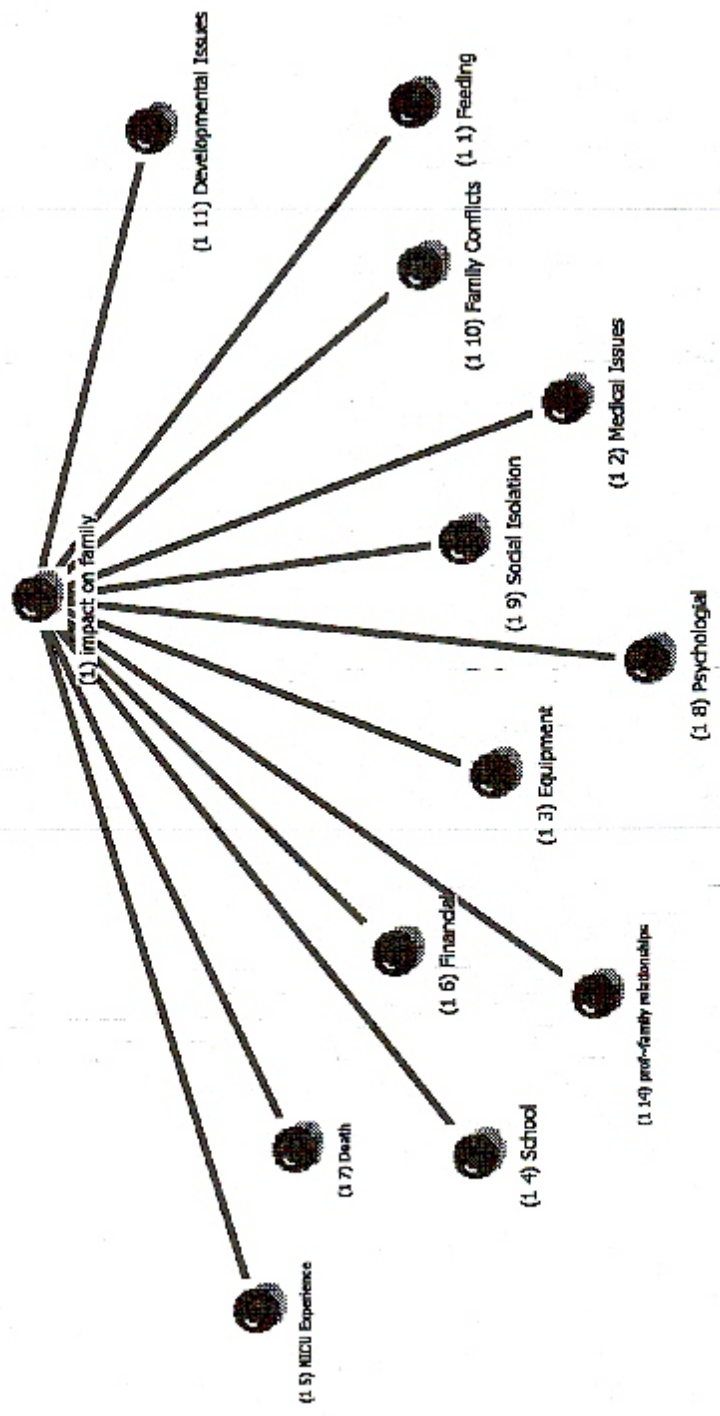


Figure 1: Impact on Family Broad Theme

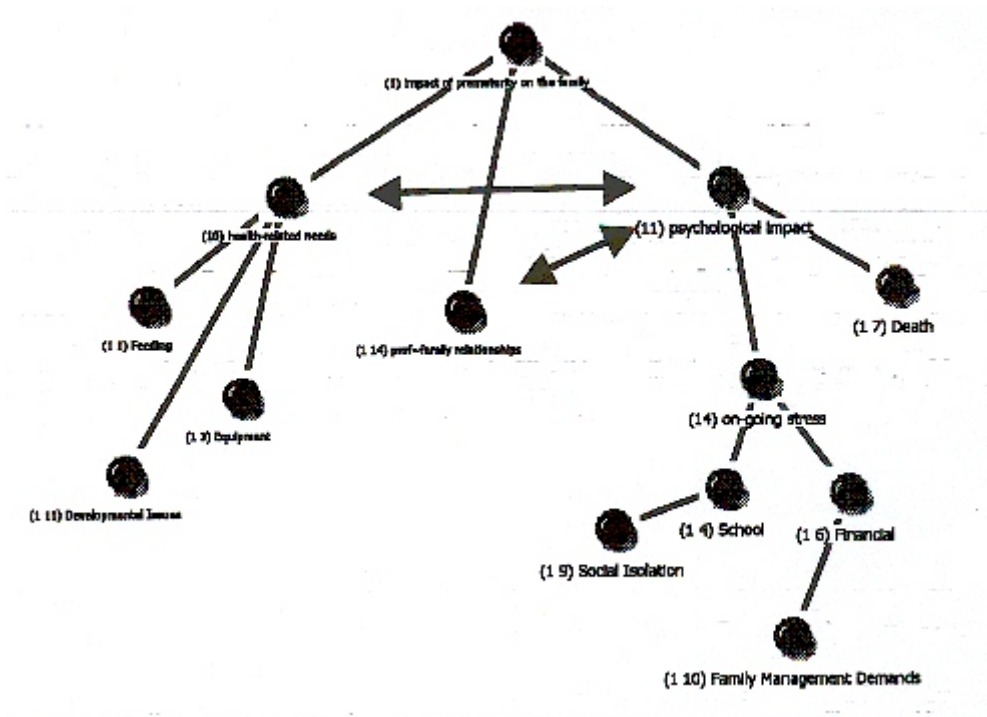


Figure 2: Impact on the Family Final

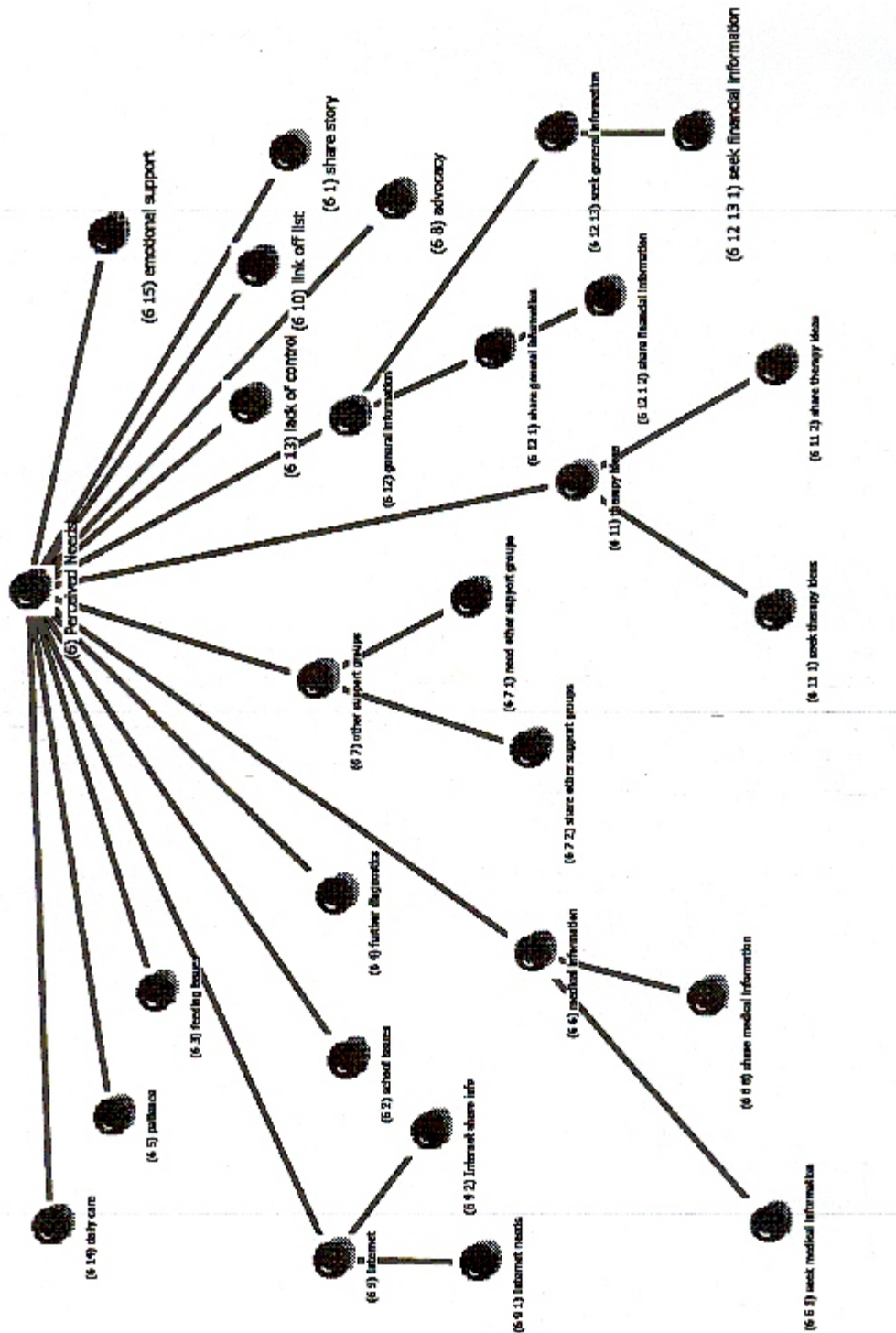


Figure 3: Perceived Needs Broad

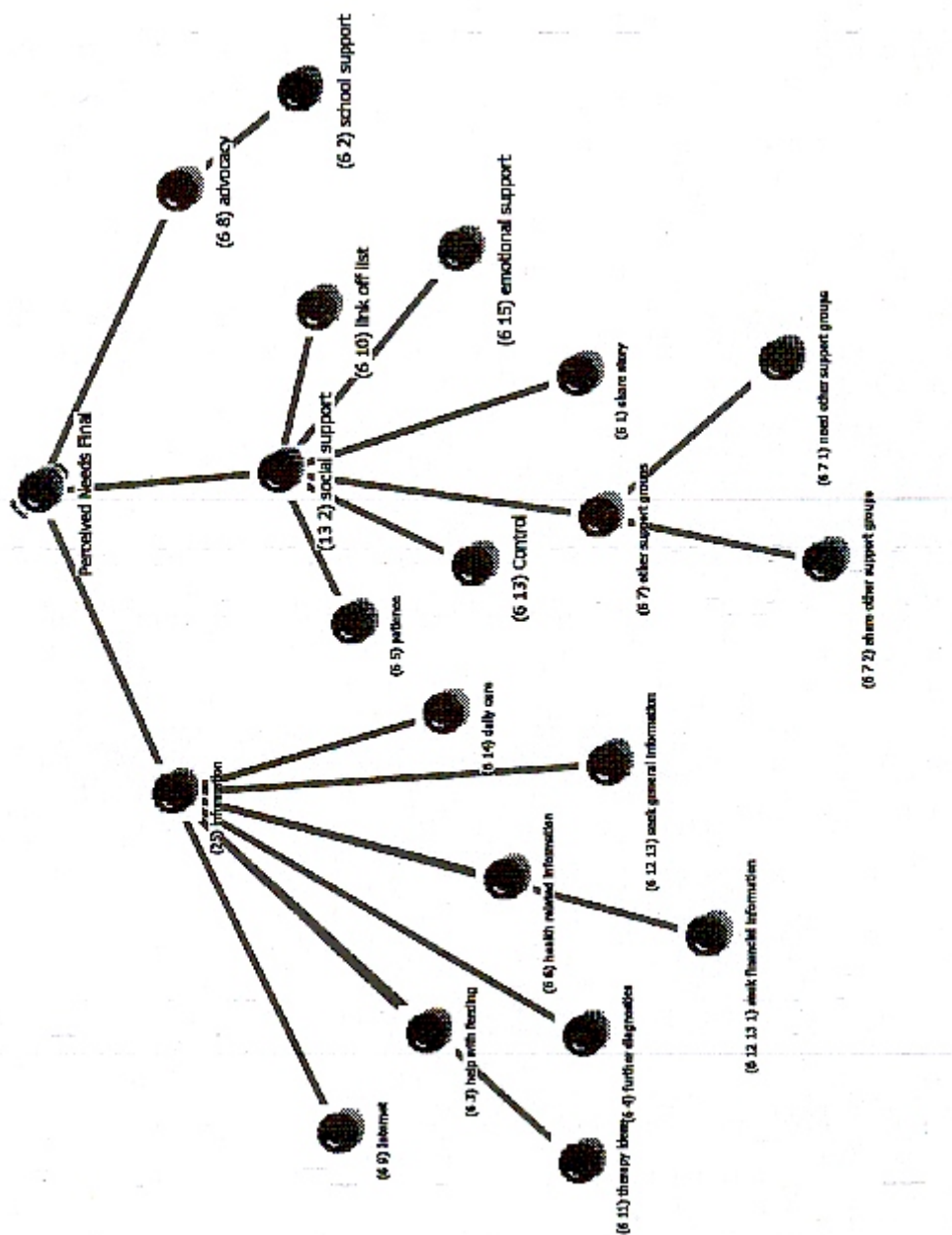


Figure 4: Perceived Needs Final

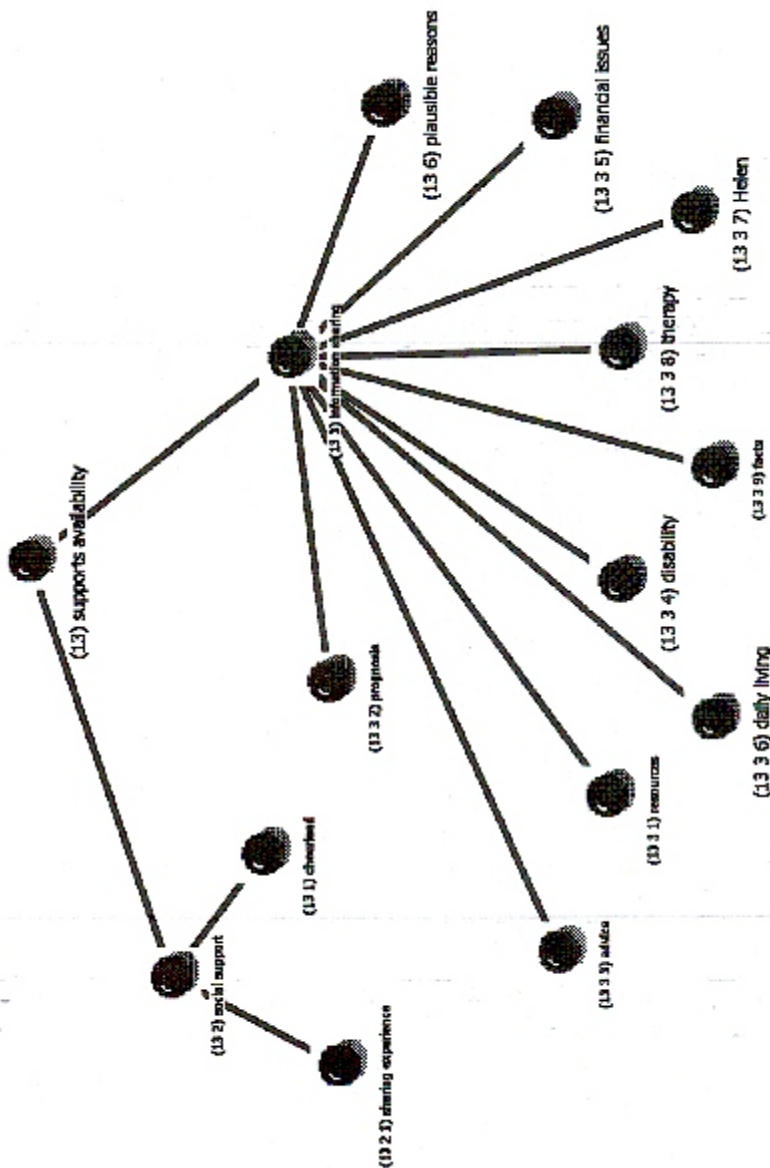


Figure 5: Supports Availability Broad and Final

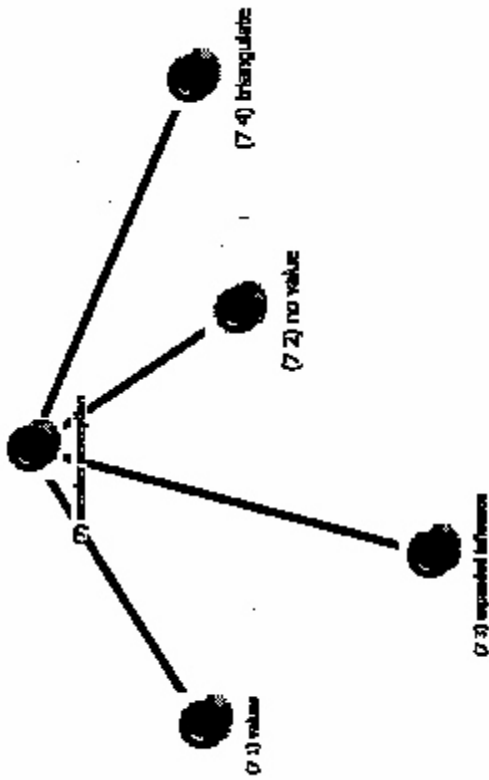


Figure 6: Member Perception Broad

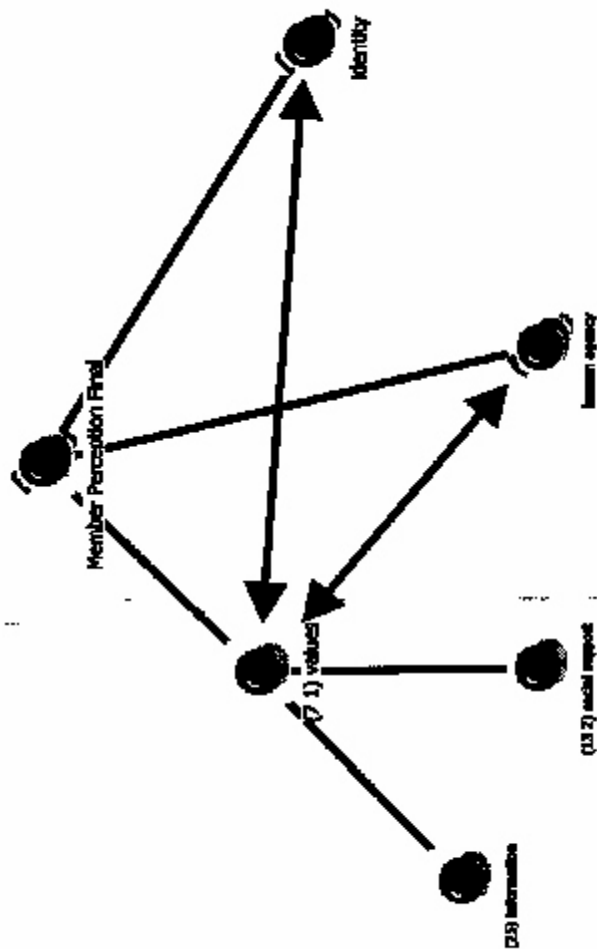


Figure 7: Member Perception Final