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Mothers as life-agent strategists in neonatal intensive care nurseries

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Mothers as Life-Agent Strategists in Neonatal Intensive Care Nurseries

by

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Degree Conferred: . . . .

Dedicated to:

Angela Kathryn Smith

Amy Khristen Smith

My Daughters

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Abstract

Mothers as Life Agent Strategists in Neonatal Intensive Care Nurseries

The purpose of this study is the discovery of the emergent process and the exact nature of the work performed by "survival agents" in neonatal intensive care nurseries, where the lives of critically ill newborns experience extremely high survival risks. In this study, parents emerged as significant actors who play an important role in working closely and directly with the medical care staff and conjointly performing those multiple tasks which enhanced the physical survival of the infants, while preserving their emotional integrity survival through the minimization of traumatic emotional scarring. Neonatal intensive care nurseries, as highly complex, technologized environments, by the nature of the work involved, create numerous conditions that threaten the very lives they were developed to save. This study explored the variety of strategies parents and staff members developed in order to enhance each infant's total survival, physical and emotional.

Though the last 15 or 20 years, medical technology has increasingly improved the chances of survival of these infants, yet very limited recognition has been given to the reality that in order for this survival work to occur and be totally beneficial, it must go hand in hand with specific parental and family involvement. This study identifies the exact nature of the work required to enhance the infants' total survival.

This study was conducted in a major metropolitan university hospital, in which there exists an internationally acclaimed neonatal intensive nursery for critically ill newborns, many of whom were premature and of extremely low birth weight.

This study consisted of families of 57 infants who were interviewed extensively in the neonatal nursery over a three year period. These infants were diagnosed as having a variety of cardiovascular conditions, none of which were considered curable. Consequently, each infant that survived would require life-long medical care and treatment as chronically ill individuals. These infants and their families were studied from birth until each infant was discharged home. Lengths of stay varied from several days to one year. Several infants died in the nursery without ever having been discharged home.

This study indicated that even though mothers emerged as the primary survival agents for these infants in this particular sample population, there were those instances when some mothers did not spontaneously assume the survival agent role and its varied tasks. Some mothers eventually assumed the role, others never quite took it on. When they did not emerge into the role, someone else ultimately moved into the role. Survival work, in those instances, was done by fathers, grandparents, and/or nurses and other medical care staff members, including some physicians. In other words, the survival work usually done by mothers can be shared by or shifted to others. Who ultimately does the work is immaterial to the work being done by someone. Whoever does it cannot do it unless supportive resources are available within the nursery as well as the home. A major factor tends to be how families and staff members are able to negotiate the division of labor required to successfully carry out the work basic to each infants' survival.

Numerous policy issues were formulated regarding neonatal care, the moral and ethical dilemmas experienced by parents and staff and recommendations for programmatic considerations were formulated. The efficcacious use of resources and quality of life issues emerged as concerns requiring continuous assessment and discussion.

I. Introduction

The family, the home, and the hospital are rationally seen as the primary interactants in the care and treatment of sick children. Each individual component is seen as representing a social system or parts of social systems. Each has its own rules, rituals and ceremonies, each with purpose and structure, all of which are basic to its existence, development and performance. Each has its own built-in jurisdictional boundaries, with guidelines determining roles and responsibilities.

The hospital is one of many social institutions designed to take care of children outside of their own homes and families. Developing strategies to negotiate the transfer of responsibilities for care is basic in the interactions that take place between family members and the hospital functionaries, as they relate to the care of sick children who require hospitalization.

The stress of physical illness and subsequent hospitalization affects millions of children each year, most under the age of 4 years, and most cared for in pediatric units in general hospitals or university-based teaching hospitals. Therefore, it is particularly relevant to determine the true nature of the social context in which this care is provided.

A. Discussion

Many years ago, illnesses were basically treated at home by family members and close family friends. Sick children were never expected to be separated for any appreciable length of time from their families and familiar surroundings.

Whenever hospitalizations were unavoidably necessary, at least one family member and sometimes grandparents and significant others would spend time at a sick child's bedside helping in one way or another.

As hospitals and modern medical techniques for the treatment of illnesses and injuries became more sophisticated and increasingly available, children were less often nursed and treated at home, but became more vulnerable to separation from significant family members and placed in hospitals for the treatment of their illness and injuries. Nowadays some children, especially those experiencing chronic illnesses, are repeatedly admitted to hospitals and for varying lengths of time, depending on various variables, including type of illness, treatments, variability and extent of symptoms.

B. Introduction to Problem

During the last decade, great strides have been made in the early diagnosis and treatment of children with debilitating congenital cardiac defects. Children now born with heart malformations are exposed early to numerous and elaborate mechanical techniques that are utilized by highly technically trained professionals in the accurate assessment and definition of previously undiagnosable, therefore untreatable, cardiac defects.

These innovative techniques, including cardiac catheterizations, angiocardiography, echocardiography, etc., together with increased clinical diagnostic skills, now insure optimal conditions under which cardiovascular surgeries can be performed and curative measures sustained. Improved medical-nursing management has favorably altered the prognosis of many of these congenital disorders, and children who were previously defined as "inoperable" or "incurable" ar being offered open-heart surgery as a means of enhancing their quality of life as well as increasing their long-term survival.

Several recent surveys on the incidence of congenital diseases of the heart and the circulatory system have been conducted throughout the world. These surveys have demonstrated a fairly uniform incidence of about 6 to 8 per 1,000 live births. It is likely that congenital diseases of the heart are present in about 1 or 2% of all infants.

The severity of the cardiac lesions is however, quite variable. In many instances, the malformation does not produce any significant interference with circulatory physiology and children may live a normal life span with no related symptoms. Yet, it has been estimated that about half of the children are destined to die before the age of 15 years, if the defect is not palliated or corrected. It is important to recognize that approximately 80% of all the deaths occur during the first year of life. Because of the technical difficulties involved in surgery and in the performance of cardiac catheterizations in infants, there has been a tendency to neglect young patients and to concentrate on treating and correcting defects and malformations in older children. However, with the development and continued perfection of surgical procedures, including heart, heart-lung transplantations, by-pass and hypothemia, children of all ages are receiving therapeutic interventions that hopefully increase their chances of survival.

In my work with children with severe congenital malformations of the heart, most of them have been diagnosed with conditions that will not spontaneously correct themselves over a period of time. Other cardiac conditions correct themselves after several months and others remain problematic for variable periods of time after birth. Some conditions are basically left alone, with the hope that good basic pediatric care will sustain these children while the heart mends itself; others are treated medically over a period of time until the heart makes the necessary adjustment or correction.

The children with whom I work are most often diagnosed at birth or during the first two to three months of life and must be sustained medically because surgical intervention at that particular time would be fatal. These children are usually premature and/or of low birth weight, posses immature lung development and would need to grow and develop enough to sustain the complicated surgery necessary for their survival. The question often arises regarding whether or not some children will survive long enough for surgery to be performed; unfortunately, many do not survive and death occurs quite early.

Despite these remarkable therapeutic gains in pediatric cardiovascular surgery, the impacts on children of cardiac disorder with which they were born, and to which they and their families must begin to adjust in their infancy, are diverse and tremendous. Children with congenital heart diseases face numerous and varied experiences in their efforts toward emotional and social adjustment to a chronic, long-term physical condition.

Parents of babies diagnosed as having severe cardiac diseases are early and routinely encouraged to become familiar with chronic nature of the condition, and are cautiously instructed to follow medical advice without fail. Cardiac centers usually maintain elaborate, up-to-date equipment, as well as the ability to attract reputable medical and surgical practitioners. These centers are sometimes logistically great distances from many families, but due to their level of competency, most are referred there for diagnostic evaluations and/or treatment.

C. Statement of Problem

What is the nature of the multiple interactions that take place between family members and the children with cardiac defects? What is the nature of the interactions that take place between parents, family members, and hospital functionaries? To what extent do these interactions influence these perceptions and encourage the emergence of family styles?

In my study I would like to look beyond the parent-child interactions and determine the extent to which other structural and interactional variables are significant determiners of parent and medical staff behavior and perception. What is the nature of the wider interactive world of infants with congenital heart diseases who will have corrective cardiovascular surgery?

In my work with these types of situations, especially with newly diagnosed infants, my on-going involvement with the patients, their families and the medical teams, allowed me to concentrate on the emerging illnesses at the earliest points in the children's lives and to explore the changes in life situations and relationships as the illness develops. My observations and interviews were conducted in the intensive care newborn nursery of a major metropolitan university medical center.

Chronic illnesses can be seen from this perspective as a major kind of disruptive experience. The structures of everyday life and the forms of knowledge which underpin them are disrupted. Families of chronically ill infants are forced to recognize the worlds of pain and suffering, threats of death and other experiences that most other individuals view as very distant possibilities happening to other people, certainly not to themselves. It has been my experience, based on observations and interactions with families, that goals, plans, and aspirations have to be re-examined, reappraised, and renegotiated. The development of a chronic illness such as cardiac defect seems bound to produce biographical disruption.

The anticipated birth of a long-awaited baby and the subsequent joy that the birth brings are brought to an abrupt halt when parents are told that their baby has a congenital heart defect, whether mild or severe. The meaning of these two events, the new birth and the disclosure of the condition, provides major shocks to the family and its relationships. Parents and other family members are required to rearrange their personal and social support network around this new set of circumstances as well as their identities as parents of a chronically ill child rather than of a healthy child.

Some chronic diseases are especially characterized by potentially fatal medical crises. In order to actually prevent these crises, and to minimize their potentially fatal effects, family members and sometimes the patient, must organize their lives for crisis management, in the hospital as well as in the home. They must literally construct and maintain necessary organizational arrangements. After a given crisis, they may find it necessary to reconstruct or improve these arrangements.

Many of the cardiac disorders are serious, dangerous, and life-threatening. They are considered life-long, long-term, never-ending; the child's condition may improve, but the condition basically remains the same. The heart, once imperfectly malformed, can never be perfect. Everything done after the diagnosis is designed to make the heart function as normally as possible given its original construction.

Parents therefore walk a tightrope between hope and despair, normalcy and abnormalcy, making the best of a basically bad situation. Parents have to come to terms with a painful truth--that the healthy, normal child they longed for, and planned for, does not really exist.

Meanwhile, the staff's primary interest appears to be that of keeping the children alive, by all means and at all costs. One primary way they attempt to ensure this is by laying down a specific medical regimen, outlining what has to be done medically and what must not be done otherwise. There are consequences to both sets of behaviors. The central theme emerging is the reality that the infant's life literally hangs in the balance and lies primarily in their (medical) hands. Lurking in the immediate background and basic to the hospital staff's behavior with parents is that the former expects specific parental behaviors in relations to the child and the intensive care nursery environment, and other staff members.

Physicians do not primarily concern themselves with the psychological-emotional aspects of care-giving; their concentration is medical-physiological, without conctrated focus on emotional advice. Consequently, there can be a strict, rigid division of labor between those who provide emotional-psychological support to families and those who do not, but focus primarily on the patient's physical survival. Social workers, psychologists, chaplains, and others are often delegated or expected to be responsible for the emotional integrity of the children.

In summary, even though they do not themselves necessarily focus on emotiol issues, physicians demand/expect exceptional performance on the part of the human environment to assure the best biomedical intervention.

D. Background of the Problem

As a professional social worker in a University hospital setting, I encountered numerous families with critically ill children suffering from severe congenital cardiovascular problems diagnosed at birth and oftentimes terminating in early death. My initial involvement with families usually occur in the Outpatient Pediatric Cardiology Follow-up Clinic, where children who have survived the early neonatal phases of the illness have been discharged home in the parents' care, and are subsequently followed by their local pediatricians and then by the outpatient clinic team. The clinic staff includes pediatric cardiologists, clinical nurse specialists, clinical social workers, and a variety of others, including EKG and Xray technicians, with special interests in the children's continued care and treatment.

The results of a preliminary survey conducted in 1979, suggested to me that most of these families experienced numerous psycho-social problems as they attempted to cope with the burdens and demands placed upon them by the cardiac conditions and the medical care management needs that continued into the home and became the unique responsibility of the family, primarily parents, and none possessed any medical-nursing experience. Although parents were told early that they would face many problems, some requiring major adjustments in life styles, no one specifically addressed what these problems were, nor did anyone attempt to prevent their occurrence.

How do parents constructively tolerate the child's prolonged illness and hospitalization? In order to understand their total experience, I extended my clinical responsibilities in 1980 to include the Neonatal Intensive Care Nursery where all infants with emerging cardiovascular problems are initially admitted for diagnosis and treatment. I discovered that these cardiac conditions are quite complex and complicated and as such become a major factor in the mangement process. Therefore, my curiosity was heightened about the types of problems parents encountered in the management process and the actions taken by parents and others to resolve them.

Although this was my primary focus when I embarked upon my project, the specific problem explored in this study emerged only after careful and cautious examination of my initial interviews, observations, and several consultations with my faculty advisers. The main problem under study was to discover parental techniques for controlling a severe life-threatening chronic illness in their newborn infants, protecting themselves and the infants from all sources of harm, while at the same time attempting to maintain a sense of normalcy in everyday life activities. How do they walk that thin line between normalcy and abnormalcy, maintaining a balance in all aspects of their lives?

STATEMENT OF THE PROBLEM

Considering the serious nature of chronic congenital cardiovascular diseases in infants and the psycho-social consequences associated with managing chronic illness regimens, major efforts in this study would be made to discover the necessary tasks which parents and families must perform in order to enhance the infant's survival against the threats of mortality and physical and/or emotional morbidity. These tasks must address the psycho-social interactions that occur between and among all of the participants involved and the social setting in which these interactions and management takes place.

A limited review of the literature suggests that minimal attention has been given to the everyday living experiences of these families from a sociological perspective. This study is ultimately intended to supply new knowledge about management strategies utilized by families of new-born infants with severe congenital cardiovascular problems.

THE RESEARCH DESIGN

The presentation of the research components of method, findings, and conclusions is designed to reflect the psycho-social perspective of Glaser and Strauss (1967). The application of their point of view envisions that infants with a chronic congenital heart defect and their families have a combination of organizational, physiological, psychological and social problems that require investigation. This perspective also detects their realities in coping and managing the chronic disease and the regimens prescribed for this management. The interactionist perspective provided a basic framework for guiding my initial observations and interviews for analysis. The setting for the study was the NICN of a large teaching university medical center within the San Francisco Bay area. The sample was comprised of 63 families and the majority of the data was collected by indepth interviews and intensive observations, and 20 years of direct experience with families with chronically ill children.

INTERACTIONIST PERSPECTIVE

According to Fisher & Strauss (1978) a major theme in the symbolic interactionist perspective is the relationship of social process and freedom of action to social constraints. The individual is seen as an interactive agent involved in an on-going process of shaping or molding his or her environment and dealing with the encountered problems within the limitations imposed by structurally determined conditions. Simultaneously, the structural conditions are in process and betweeen them and the shaping process there is an interactive effect as well as singular consequences for each. Each person relies on others for information, for alternative models of action, access to various options, and cooperation in action. The perceptions and actions of each interactant become important conditions under which the other actor's assessment and actions are carried out. The actions that an individual takes as he or she confronts encountered situations are based upon the meanings that the individual attributes to these situations which usually include persons and things. The assigned meanings derived from past social interactions are generally modified through an interpretive process (Blumer, 1969).

IMPLICATIONS FOR THIS STUDY

When applying this perspective to the problem under study, the parents are visualized as taking an active, participating role in the management of their infant's chronic congenital cardiovascular defect. This management takes place within the limitations imposed by the structural conditions within the neonatal intensive care nursery and those created by gender roles in society and by the role of medicine and technology. Other conditions are created largely by the nature and severity of the infant's condition, the state of the family's behavior and the intrasystemic action of one upon the other.

The settings within which this management occurs are the hospital (the focus of this study), the family's home, and the follow-up pediatric cardiology outpatient clinic. The structural-organization conditions of these environments impose a new set of conditions that will affect the family's management. The family's style and management process will also affect the organization of these various environmental contexts.

The management behaviors the family adopts and that appears to be associated with such behaviors, evolve from the meanings that are derived in part from past complex interactions. These include their interactions with the medical-nursing teams, and significant others, including other children at home. As the parents examine these new meanings, they themselves become modified and transformed in accordance with their past and present experiences, attitudes toward the heart defect and their future plans as a family. There are numerous past, present, and future facets of the family's biography that they bring to the new event of the birth of a child with a chronic congenital heart defect. In addition to coping with the present reality of the child's condition and state, the family must cope with the combined force of these multiple facets of their lives.

THE RESEARCH METHOD

The means adopted for exploring the management of the medical problems and the psychosocial processes encountered by families in this study, is the investigating approach of Glaser & Strauss (1967).

The primary task of this study is that of generating a theoretical explanation for the psychosocial processes that occur in the management of a congenital cardiovascular problem in neonates that both emerges from and is grounded in the data.

A. THE METHOD

My major methods of gathering information were extensive interviews and intensive observations. These allowed me to "enter into" the world of the families I was studying and it also allowed me to form a picture of reality as it is perceived by the interactants within the setting. The reality that molds their definitions of the problems to be managed, which shapes their subsequent behavior, is observed within the context in which the behavior takes place. The constant comparative method allows for the examination of the interactions around these problems as well as the comparison of responses to the problems as they unfold. I was then able to grasp the subtleties of the situation and obtain insight into behavior which is not seen when data and analysis is obtained by a more static method (Schatzman & Strauss, 1973).

Grounded theory generates a theoretical scheme that explains behavior by identifying the basic processes of interaction as problematic situations within the social settings under study are encountered by the researcher. Rather than searching for the frequency distribution of events, the purpose of this method is to delineate the conditions under which certain events occur, the conditions under which they vary and their corresponding consequences. The data is handled by qualitative analysis and the predictive power of the theory generates hypothese rather than verifies them. Theory derived in this fashion is constantly developing by means of modification, extension, and revision of new and available data.

In the interactionist perspective, behavior evolves in response to the meanings derived from an ongoing process of interactions of self with others within the existing conditions and modified by a uniquely individual interpretive process which bears upon the individual's past and future. By entering the world of individuals under study and observing their behavior as it unfolds within the surrounding conditions, explanations for that behavior can be derived that enlighten one as to their specific responses to situations, the meanings attributed to them, how these meanings are formed, and the consequences of these meanings are formed, and the consequences of these meanings.

In the literature, models for this method can be found in the work of Glaser and Strauss (1965) and (1969) on terminal care and in Fagerhaugh and Strauss (1977) and Strauss et. al., (1985) on pain management. For example, Glaser and Strauss examine the experience of dying and the management of it by the patient, the family, and the health team. They offer a theoretical scheme to explain who knows what about the probabilities and the time of death for the dying patient that they term the "awareness context", and Fagerhaugh and Strauss emphasize the theoretical problems, associated with pain management, that are involved in the interactions between the patient and important others within the setting in which management occurs.

B. THE SAMPLE

Setting. A large teaching medical center located on an urban university campus in the Palo Alto Bay Area provided the setting for this research study. This facility provides a wide range of medical services including nationally known cancer research center, cardiac surgery (including heart transplants and heart/lung transplants) and a federally funded premature intensive care nursery. It is well known for its up to date technology and its advanced medical management techniques. Parents are attracted to this hospital from across the country and foreign countries as well.

Gaining Access. A vital step in a research investigation is negotiating access to one's potential sample population. This was not a difficult task because I automatically interact with all patients admitted to the NICN especially those infants with congenital heart disease. Nurses on the unit introduced all of the new families to me and I proceeded to work with each unit, depending on the problem, their need, and accessibility to my intervention. I informed the parents of my interest in a particular group of newborn infants and their infants seemed appropriate and accessible. Fourteen families declined to participate, over a four year period, and their wishes were respected. The nurses on the unit became invaluable allies during my initial contacts on the unit, and as such they were able to share their concerns about the families and their particular individual problems. All observations and interactions were done in the NICN or other areas of the pediatrics ward.

C. DATA COLLECTION

This study is based upon the constant comparative method designed by Glaser and Strauss (1967) and Glaser (1978) to generate a grounded substantive theory. Their model requires that the data collection process be controlled by the emerging theory. Collecting, coding, analyzing, and deciding what further data is required and where it can be found, must happen concurrently. Glaser and Strauss (1967) label the last type of action "theoretical sampling".

Interviews. I conducted 79 interviews with fifty-seven families, which varied from one to two and a half hours in length, with parents. The initial interviews occurred within ten hours after each infant had been hospitalized. In some instances, this initial interview occurred with fathers, because most infants were in other hospitals and transported to our hospital, leaving their mothers behind to recover from the delivery. Consequently, fathers accompanied the infants via air ambulances or Lifeflight helicopters or they drove themselves in, depending upon the distance between the two facilities. In some instances, troublesome symptoms did not appear until several days after delivery, and in those instances, mothers and fathers were able to accompany their infants in transport, and I scheduled interviews with both parents as soon as possible, and within ten to twelve hours.

I was able to conduct these interviews at different times, in different places, under different conditions, with different participants. Because I could establish flexible hours, I could interview parents on the weekends, and in the evenings when I needed to see both parents together or when a parent visited during the evenings after work. I interviewed parents individually, together, sometimes with other relatives and other children. I observed parents' interactions with othe team members, other parents, and in various places (cafeteria, chapel, waiting room, outdoor patios, in the corridors, etc.). I attended NICU rounds daily and when grand rounds included data on clinical management of specific infants in my sample. I attended nursing rounds and psychosocial rounds where each infant's progress was discussed at length, with respect to problems, concerns, alterations in management and treatment, etc. When some parents failed to visit their infants to see if there were transportation problems, child care problems for other children, illnesses or any factors that prevented visitations.

I observed couples at their infant's bedside, when they were alone and away from their infants, and when they were with nurses and/or physicians or technicians. I also arranged periodic conferences with the nurses to compare observations and to gather any information pertinent to each infant's situation and condition.

Data Recording. None of my interviews were tape recorded. All interviews were hand written verbatim and in process form. They were later typed and sorted. The interviews were initially unstructured, undirected. As the data focused and categories emerged, the interviews became more structured, allowing the expansion of properties. The enormity of the issues involved in the NICU would not allow for the exclusion of subjects important to parents; therefore, they were allowed and encouraged to discuss anything important to them.

Fifty-three families were included in this study. They represented a variety of socio-economic and educational backgrounds.

For thirty-seven families, the sick infant was their first born; twenty-six of those were only children; three household were single parent families headed by women; thirty-six families had one or more other children.

Validity. The frequency of my contacts with parents provided me with opportunities to verify earlier observations within the context of any changed conditions. I would also during additional or subsequent interviews paraphrase their previous responses and reintroduce the same materials for their further comments and considerations.

Controlling for Researcher bias. As a professional social worker with twenty years of clinical experience, I have interacted with many individuals experiencing many difficult and stress-provoking conditions. I have learned how to be objective and how to pull back or move back from the situation and compare and contract what I've heard from one situation with many similar or different situations. This comparative knowledge eventually became the base for a grounded theory of interactions.

Data Analysis. The constant comparative method, established by Glaser and Strauss can be divided into four stages: (1) substantive coding; (2) theoretical coding, the establishment of relationships among categories; (3) delineation of theory, reducing substantive density, and establishing the boundaries of the theory; and (4) writing the theory that emerges from the end products of the earlier stages.

Substantive Coding. The first stage of the process consists of open coding. The data is read, line by line and each event is coded as a category and written in the margin. As each incident is coded into a category, it is compared with others. By making these comparisons, one begins to generate ideas about the theoretical properties of each category and how these clusters of categories coded are linked together. The linkage could well be the conditions under which it is enhanced or minimized, as well as relevant conditions and consequences.

While coding, one needs to constantly ask a set of questions that will identify the major problems articulated by the participants of the study, the techniques they use to cope with these problems, and the effects of interactions and structural conditions upon the two.

Open coding fractures the data which allows for the emergence of its empirical nature and renders it more abstract so that apparent unrelated categories can be related. It also directs the process of theoretical sampling, it allows for the verification, densification, expansion, and saturation of categories.

Theoretical Coding. This is the establishment of hypothetical relationships, or linkages, among categories. Data are woven back together by theoretical coding into a conceptual scheme that can be used to explain patterns of behavior. As coding continues, the unit of comparison changes from comparing incident to incident, to comparing incident with properties of categories. This process is aided by the utilization of a set of concepts referred to by Glaser (1978) as theoretical codes, which sensitize the researcher to possible relationships that may exist among categories. Clusters of categories are then identified.

As the process of building connections continues, the framework for a grounded theory emerges. Initially the categories appear somewhat hazy but they begin to become more integrated and the theory more pronounced as the analysis continues. After a theme develops, a commitment is developed after verification by means of repeated theoretical sampling, more structured interviews, and making comparisons with available literature.

Theory Development. Once there is commitment to a theoretical scheme, the task becomes one of delimiting the theory to that scheme so that two major requirements of a theory, parsimony and scope, may be achieved. Delimitation occurs at both the theory and category levels and is comprised of three steps.

The first step is the reduction of categories. As coding continues, underlying uniformities among the categories or their properties are noticed. These uniform characteristics help to consolidate several categories under one generalized heading.

The second step is the establishment of boundaries of the theory. Categories that neither fit nor extend the theory are deleted.

The third step includes saturating the categories so as to give density to the theoretical concepts. After the theoretical scheme is established and the theory is trimmed down to a workable size, it is then outlined and studied so that categories which require further development become obvious. If further development seems necessary, the cycle of theoretical sampling is repeated. Saturation occurs as new incidents are compared with incidents already coded and it is noted that no new qualifications are being added to the category. Coding into the category need not be done unless certain incidents will contribute to clarification of the theory. Coding continues if there is discovery of an incident which adds a new dimension to a category.

Memos. Writing memos permits advancing beyond description of data to that of theory building. An idea occurs while analyzing how an incident coded into a category may relate to other incidents coded into that category and therefore developing its theoretical properties. These ideas are written down as a memo contributing to the shaping of the emerging theory. Memos deal with abstractions that are embedded in the data and they are written at the time ideas are generated so they are not lost while generating new data. By sorting them from time to time, integration of the theory is enhanced.

Writing the Theory. When the fieldworker is convinced that the theoretical framework is cohesive and systematically formulated, it can then be articulated and put into written form. The organization of the memos forms the basis for the outline that guide the final writing.

How parents manage the problems associated with chronic, life-threatening cardiovascular problems in their newborn infants is explored and formulated in a prospective field study based on the constant comparative methods of data analysis, developed by Glaser and Strauss (1967) and Glaser (1978). This method presents theory as process which evolves over time and gives direction to data collection and analysis. Its purpose is to explain what is happening in the social setting of a hospital-based intensive care nursery where management occurs. Data from forty-six families, including parents, sblings and other relatives, and attending health care team members, were gathered primarily by interview and observation.

The next chapter will establish the theoretical scheme that emerged as the study unfolded and the specific experiences of critically ill infants and their interactions with parents and hospital staff members became more precise.

II. Overview of the Theoretical Scheme

This study examines in great detail the multiple experiences of newborn infants with congenital cardiovascular diseases, their families, and the clinical care givers in a major metropolitan teaching hospital. As the study developed, a scheme emerged centering around the conjoint management efforts of parents and nurses who were dedicated to the survival of each infant within the context of a neonatal intensive care nursery. Such nurseries are highly structured, technologically sophisticated settings that are organizationally very complex and specialized within the larger hospital. The nursery has itw own organizational structure with associated rules and obligations, and its own operating procedures and standards for functioning as a self-contained medical "community". Specific relationships are molded so as to facilitate the shaping of each infant's treatment course and moving each infant toward as successful an outcome as possible. Into this environment, critically ill infants, and the parents are abruptly thrust without any particular preparation on what to expect or what is expected of them.

Survival work develops around the overt/covert action taken on by parents and hospital care providers within the neonatal intensive care nursery. Though the birth of an infant with severe medical problems impacts greatly upon each and every family member, in my particular study, mothers emerge most frequently as the primary member who undertake the survival work and tasks, with fathers and other family members, as well as individuals from outside the family, such as friends and neighbors, proving her with back-up supportive work which is necessary if she is to be successful in her survival work.

There are those few instances when some mothers cannot or choose not to undertake this function, and it may then be done by fathers, older children, and grandparents. This study identifies the variations that may exist when individuals other than the mother takes on the tasks deemed basic to the infants' overall survival. In most instances, however, it is the combination of mothers and neonatal intensive care unit nurses who became the basic survival agents working on behalf of the critically ill newborn infants who had severe cardiovascular problems.

A survival agent is conceived in my study as any individual who, upon recognition of the serious medical nature of the infant's life-death struggle, commits himself to undertake at all costs and under any conditions those tasks that would ensure, to the best of his abilities, each infant's chances for surviving those conditions that threaten its very existence. The survival agents become life strategists, who consciously manuever themselves into action plans that facilitate behaviors among all workers, family and staff alike who may influence any positive chances for survival.

Survival work therefore centers around two major conditions that are present at all times. These conditions are: (1) activities that maximize and/or ensure the chances of each infant's physical survival thus physicians and others diagnose and prescribe and the nurses do the medical-nursing work; the parents do some of the medical-nursing work too, especially at home. (2) activities that minimize and/or prevent developmental/emotional trauma. These activities tend to be the primary domain of the family (mother) members. Nurses are there doing some of this latter work because of their legitimate authority and license to practice as nurses; mothers are there to do their work because of the legitimate nature of their biological/biographical relationships to the infants.

Therefore, survival agents (mothers and nurses) in this instance, join forces to accomplish the short and long-term survival of each infant. It is through this joining of forces that a dynamic set of interactions emerge between these "natural" survival agents and in relation to which they develop their work strategies and take on specific tasks relative to survival. As these interactions develop over a period of time through shared tasks, a "crossing over" of tasks develops, wherein to some extent under certain conditions, each agent will "license" the other to do a certain amount and kind of the other's work. Nurses do not expect mothers to become nurses, nor do mothers expect nurses to become their infants' mothers; however, by assessing, locating each other always in relation to infant's condition within the trajectory experience, the survival work as a whole emerges. License to do each other's work can be revoked at any time that one is convinced that the other's work efforts are not commensurate with the infant's needs. In other words, mothers and nurses must convince or prove to each other that their individual and combined work efforts are appropriate, and together they enhance the infant's survival chances.

Infants within neonatal intensive care nurseries are considered high-risk babies, who can be identified by a myriad of characteristics, diagnoses and prognoses considering the type and extent of the defects. There are also certain factors present, which, if left alone and allowed to persist, and go untreated, can often lead to major disabilities and/or certain death. Therefore, all efforts are marshalled to prevent problems from developing, and this is primarily accomplished in the hospital through cautious, expert monitoring by a variety of personnel and the utilization of highly sensitive machines and other devices.

Meanwhile, parents of these vulnerable infants experience major biographical interruptions in their initial parent-child interactions, because they recognize how profound an impact these interruptions can have on their infants' present and future development and growth, emotional as well as physical. Mothers and nurses especially share the challenges of enhancing each infant's total survival, beyond the present and obvious world of the intensive care nursery. Together they share the work, the tasks, and the satisfactions of keeping the infants alive at all costs <u>and</u> simultaneously preventing emotional scarring.

Apropo of the latter goal, Mercer (1977) defines parenting as a composite of observable behaviors that evolve as a process over time. These behaviors include parent's ability to share self, to give to, to care for, to love, to caress, to touch, to enjoy body contact and interaction with, to protect, to have concern for, and to voice a need for continued relationship with their infant. Mercer feels that it is the emotional facet that pervades the socially and culturally defined patterns of rearing children. The emotional quality in parenting enables the child to grow and develop into physically and emotionally healthy individuals. Yet the organizational conditions within neonatal intensive care nurseries that support and sustain physical life can further interrupt the natural attachment and bonding experiences that have been proven to be so basic for the formation of parent-child relationships. Klaus and Kennell (1976) present evidence of the significance of the neonatal period to the attachment between parent and child. They argue that the attachment process can be profoundly disrupted by infant malformation, prematurity and separation from the mother at birth. Nurses value good parent-child relationships and a great portion of their work effort is devoted to enhancing the development of healthy individuals through the medium of mutually satisfying parent-child interactions, for example, rooming-in privileges, and liberal visiting hours arrangement.

Strauss et. al., (1982) coined the term "illness trajectory" to refer not only to the physiological unfolding of a patient's disease but to the total organization of work done over that course, plus the impact on those involved with that work and its organization. Many different kinds of skills, tasks and relationships emerge as the workers (mothers and nurses) within the setting go about their necessary activities. The "illness trajectory" concept therefore allows for the analytical ordering of the varieties of actions and events that take place, as a variety of workers attempt to control and manage illnesses, such as congenital cardiovascular disease in infants and young children. Mothers are concerned about how these illnesses impact upon their infants and how they may come to mediate some of the attendant stresses and strains.

In the field of medical sociology and the study of medical work, much effort has been made to study such prestigious professionals, such as physicians, nurses, and others. Strauss (1972), Freidson (1970, 1972), Olesen and Whittaker (1968) and Mechanic (1978) document how these professionals establish relationships with clients. By contrast, my concentration in this study is upon the significant work that mothers of critically ill infants and clinical nurses do together as lay and professional workers with a similar and basic focus but from somewhat different orientations.

A "balancing" act develops between mothers and nurses as they weigh the available alternatives for controlling and managing the illness, in terms of the outcome. They make conscious choices as they interact more with each other and as the illness itself unfolds. They learn how to make adjustments in their work efforts, and they learn to realign those efforts as dictated by the changes, positive or negative, in the illness trajectory. Mothers and nurses are constantly assessing and identifying each risk factor that occurs, based on vigilant responses to the multiple objective cues emerge from all sources. This line of action work is continuous and always in response to the particular phase of the trajectory.

This dynamic interactional work that takes place between mothers and nurses becomes a meshing, blending or synchronizing of efforts at managing an illness where the risk factors are such that the death of the infants is seen as a major and primary reality. This interplay between mothers and nurses within the controlled and structured setting of the neonatal intensive care nursery seeks to organize their efforts to the end of minimizing emotional trauma and developmental delays while maximizing each infant's chances of surviving with identities intact.

Corbin (1981) states that in crisis situations where the risk probability is higher, more of the responsibility for managing the situation must be assumed by the health team members. Greater effort on their part is required than when the situation is less critical. In the cardiac care setting, the interactional work between mothers and nurses must be such that they each are able to locate each infant in relation to the particular phase of the illness trajectory presentation, and determine whose work efforts are most appropriate to that particular phase in time. Each must be cognizant of the relevant physical and temporal cues at each phase of the illness trajectory and based on their awareness of the presence of risk factors and promote the work effort commensurate with that particular phase.

The management strategies and tactics associated with the tasks of risk minimization are determined by each worker's perception of the risk levels at any given phase in the illness trajectory. If the nurse views the risk level higher than the mother does, in order to bring about the necessary change in the mother's management effot she must first bring about a change in the mother's definition of the risk level. Nurses recognize the importance of the mother's work efforts being compatible with the infant's needs. There are critical periods or junctures in each infant's illness trajectory where the nurses' tasks of providing physical survival care takes precedence over the mother's biographical/developmental work, and vice versa. Their own interactional work is a basic condition for this conjoint effort of illness management.

Two types of work are going on simultaneously: (1) illness trajectory work as performed by nurses and other care givers and (2) developmental/emotional work performed by mothers primarily, but others when necessary. As part of their illness trajectory work, nurses provide physical care activities including washing, changing and dressing, also participate in clinical diagnostic/treatment work with other medical professionals, as they determine the cause/effect realities of the cardiovascular situation. Based on their findings, nurses administer medications and other treatment tasks.

Concurrently with these nursing activities, mothers actively assess their infants' state at each phase of the illness trajectory and perform developmental/emotional tasks specific to their perception of their infants' needs. Their biographical trajectory assessment relates to their own awareness of the potential impact that management/ treatment tasks could exert their infants' normal growth and development and the extent to which setback complications later on could jeopardize their emotional integrity. Mothers actively engage themselves with their infants by stroking, caressing, holding them while they undergo certain diagnostic/treatment procedures. Their goal is to minimize trauma and emotional scarring as diagnostic/treatment tasks are being performed. Some procedures are painful and uncomfortable and mothers use themselves to buffer or mute the effects upon their infants' growth and development, emotional as well as physical.

Both mothers and nurses can license each other to perform tasks normally within their domain by giving each other permission to carry out their tasks when the situation is appropriate to do so. For example, as the infant's health improves, mothers with nurses' permission take over tasks such as bathing, changing, and feeding the infant. By virtue of the biological fact of giving birth to the infants, each mother's biographical trajectory legitimates her being there to actualize her claim to the child. On the other hand, nurses by virtue of their technical training and medical-nursing expertise have legitimate cause to be there and to do those tasks specific to the infants' medical needs.

Mothers and nurses are not always focussed on the same things. There are times such as during difficult procedures that nurses become so deeply absorbed in the physical tasks that they mainly see them as objects, to be worked on rather than with their human characteristics of feeling pain or discomfort. For if they saw each infant as a "baby", many of the treatment tasks would be difficult to carry out. On the other hand mothers can focus on the actual and potential impacts each task has upon the infants and are therefore oriented to sparing them as much as pain as possible through comfort and sentimental work activities. Mothers discover that just "being" there with the child is one part of their work, however, "doing" for the child accomplishes more on both short and long-term bases. The reason for this is as follows.

As the illness trajectory unfolds and nurses become more aware of an infant's problems and condition, based on their previous interactions with children with similar problems, they are able to make trajectory projections about an infant's proximal and distal outcome or overall problems to overcome. As mothers and nurses interact around infants' illness, mothers become aware of the seriousness of the situation and begin to develop their own biographical projections of their infants' life span. They know that if the child survives work has to be done on a preventive level to minimize emotional trauma and promote emotional integrity. Just as both perform tasks to prevent intellectural damage by providing objects such as mobiles and colorful tops to stimulate intellectual growth, they also perform sentimental work and comfort work that nurtures each infant's emotional psychological state. Whereas nurses concentrate on the here and now reality of each infant's physical survival, mothers project themselves and their infants' biographical identities beyond the present situation into the future, hoping that their child's emotional/psychological wellness is not minimized by the present traumas experienced by the cardiac condition or the treatment regimens basic for their physical survival.

Nurses and other health care members depend a great deal upon machines that are accurate and precise. These machines, as life-support tools, occasionally malfunction therefore jeopardizing the safety and survival of these critically ill, machine-dependent infants. Nurses monitor these machines for accuracy and error, and their work efforts are further monitored by mothers, who sometimes move in and bring error and safety factor problems to the nurses' attention.

Risk balancing in the division of labor between work efforts of mothers and nurses suggests that the inappropriateness of certain kinds of work done by someone at a critical juncture in trajectory can have damaging, traumatic consequences for the infants. It becomes imperative that the interactional work that occurs between mothers and nurses has at its base their working together to shape the trajectory so as to actualize the most successful outcome possible.

The next section will provide specific information about congenital heart disease and the variety of cardiovascular conditions that infants and children may experience.

III. Congenital Heart Disease in Infants

Congenital malformations of the cardiovascular system are among the most frequently occurring, clinically significant anomalies in living newborns. According to data recently collected in both Europe and North America, a serious form of congenital heart disease occurs in one of every 125 live births. Based on this incidence, in the United States alone, an estimated 32,000 infants are born each year with some form of congenital cardiac disease.

Congenital heart disease, defined as a congenital cardiovascular anomaly that results in death or necessitates cardiac catheterization or surgery within the first 12 months of life affects about 25% or 50% of these infants. Morbidity and mortality are highest in the first month of life. (In this study, infant refers to a living human from birth to age 2 years; neonate or newborn to a living human from birth to age 4 weeks and a young infant to a living human under the age of 1 year). If these lesions in infants are left untreated, 50 to 60% of these babies die during the first year of life; fully 30% die within 30 days of birth.

Since 1938, when the first corrective operation for a congenital cardiovascular defect was performed (Gross and Hubbard, 1939) advancing medical knowledge and technology have resulted in what has been termed "surgical cures" of many previously fatal or grossly incapacitating congenital cardiovascular diseases. Although a great many advances have been made over the past few decades in the diagnosis and management of congenital cardiovascular diseases, the single most important factor in the survival of these infants is still early detection and recognition.

The diagnosis of critical congenital cardiovascular disease in the newborn may be extremely difficult and can be complicated by the profound circulatory changes that take place in the heart and lungs shortly after birth. Prior to 1960, palliative and even curative surgical procedures were occasionally performed during early infancy. However, with few exceptions, surgical management of congenital heart disease was attempted only in older children who had survived the critical first few years of life.

During the 1960's, advances in the treatment of congenital heart disease were made chiefly in three areas. First, as the techniques of cardiac catheterization and angiocardiography were developed and refined, definitive diagnosis of congenital cardiovascular disease became possible even in the smallest infants. Secondly, established closed-heart surgical procedures were applied with success in younger patients, and new techniques for palliation were being perfected. Thirdly, sophisticated techniques for monitoring the patient during surgery and improved methods of postoperative respiratory support were developed.

In the distant past, a great deal of emphasis was placed on the importance of the clinical differential diagnosis of congenital heart defects. However, in many instances an accurate diagnosis was not made until additional information could be obtained from sophisticated diagnostic studies. Thus, once a newborn infant is now found to have cyanosis, respiratory distress, cardiomegly, or congestive heart failure, prompt referral to a center where appropriate diagnostic and surgical facilities are available is indicated.

Even after the decision has been made to refer a critically ill newborn to a cardiac center, time often remains an important factor in the patients' ultimate survival. A rapid and safe means of transport from the community hospital to the medical center must be available. Once the infant reaches the cardiac center, an accurate anatomic and physiologic assessment has to be made as soon as possible. The infants' condition may be only temporarily improved, if at all, by the various treatment measures undertaken.

In spite of numerous improvements, management of congenital heart disease in some young infants remains severely restricted because for them open heart surgery is still a hazardous procedure. Thus surgical procedures in young infants remain somewhat limited to those in which circulation is not interrupted or is only interrupted for a few seconds.

Within the described limitations, curative operations can be performed with increasing success with certain kinds of lesions. In infants with other defects, palliative procedures are used when possible to prolong life until the infants are older and a cardiopulmonary by-pass can be used during surgery to correct the defect. However, for a significant number of lesions, neither curative nor palliative procedures are possible. Many infants cannot be treated and ultimately die.

However, the past decade has witnessed remarkable accomplishments in pediatric cardiology, including the introduction of newer, innovative diagnostic procedures (echo cardiograms), the application of improved methods of medical management, and the implementation of imaginative surgical techniques, many of which have become particularly applicable to the newborn infant with heart disease.

Rashkind and Miller (1966) demonstrated that cardiac catheterization could be therapeutic as well as diagnostic when they introduced the ballon catheter for atrial septortomy, a procedure which has become revolutionary in reversing a frequently fatal outcome for newborns with transposition of the great arteries.

Through Stranger et. al., (1974) and work, diagnostic capabilities have been further advanced through the development of echocardiography, a non-invasive procedure which has been effective in separating the cardiac from the non-cardiac and in establishing a definitive diagnosis in many newborns and children with heart diseases.

Improvements in operative techniques and peri-operative management during the past decade have led many cardiovascular surgeons to a more aggressive surgical approach to many cardiac malformations in neonates. To date there has been markedly improved survival rates in most age groups undergoing surgery.

Cyanosis and congestive heart failure are the principal findings in the newborn with critical congenital cardiac malformations, and it may be only after a few days or several weeks that a significant heart murmur (sound) focuses the origin of the distress on the cardiovascular system. Cardiac failure, as defined by Goldblatt (1962) and Engle (1963) is the inability of the heart to pump sufficient blood to satisfy the metabolic demands of the body. Early recognition of heart failure in the newborn is often difficult because it may be confused with other disease entities.

Listed below are several major coronary conditions experienced in infancy and early childhood.

a) Transposition of the great vessels: cardiac catheterization is essential for diagnosis and at that time balloon atrial septostomy is indicated at that time.

b) Tetrology of Fallot: the major anatomic abnormalities in tetrology of fallot are the ventricular septal defect and hypoplasia or atresia of the pulmonary outflow tract. Cynosis is the most significant clinical feature and its severity depends upon the degree of pulmonary obstruction. The infant's breathing pattern is usually undesirable except in the most extreme forms.

c) Hypoplastic Left Heart Syndrome: this includes various combinations of aortic valve atresia and vitral valve atresia. Infants with this severe form are critically ill within a few days of birth. They appear ashen, are in marked cardiac failure.

d) Pulmonary Artresia with Intact Ventricular Septum: this malformation consists of pulmonary valve atresia associated with an intact ventricular septum. The infant with this malformation is usually critically ill in the first week of life with cyanosis and right-sided heart.

e) Total Anomalous Pulmonary Venous Drainage: the pulmonary veins are connected to a systemic venous site rather than to a left atrium. Two groups of patients: those with obstruction are usually critically ill in the newborn period whereas those without tend to develop signs of congestive heart failure as vascular resistance diminishes later in infancy. The newborn presents in the first week of life with cyanosis and tachypnea.

f) Ventricular Septal Defect: VSD may be the cause of congestive heart failure as pulmonary vascular resistance diminishes in infancy. These defects are small and only by the systolic murmur (sound) at the left sternal border, first noted at the time of the routine six-week p.e.

g) Patent Ductus Arterious: may occur as an isolated anomaly; may exist as the only source of pulmonary blood flow in an infant with a critical cyanotic cardiac malformation, or may complicate the course of a newborn with hyaline membrane disease.

h) Coarctation of the Aorta: may occur as an isolated primary cardiac malformation or may be associated with one or more of the following: aortic steriosis, PDA, VSD, etc. The more complex combinations of which coarctation is a part present earlier in infancy with signs of severe cardiac failure.

This discussion of major defects as been limited and is by no means complete. It only suggests the variety of presentations that occur in infants with major cardiac problems, each of which offers challenges to all members of the health care team, in terms of early definitive diagnosis and immediate treatment regimens. The medical management has to recognize that there is a problem, to do something very promptly to relieve the symptoms that one sees, then to proceed to definitive diagnosis and then to use the best judgement possible about whether medical management should be continued or whether surgical management combined with long-term medical management is the next thing to do.

Summary

Most infants with congenital cardiovascular lesions that are potentially fatal within the first year of life can be treated successfully by palliative procedures or by hemodynamic correction of the defects. The real key to success in the management of neonates and infants with congenital cardiovascular disease that is ordinarily fatal in the first year of life is the realization that when such a patient is cyanotic, demonstrate signs of congestive heart failure, or both, immediate attention is required. Definitive diagnosis can be made safely and accurately by pediatric cardiologists. Only after such thorough evaluation can a suitable plan of therapy be determined. In most instances surgery will be necessary and an extended period of hospitalization is usually anticipated.

Medical Technology in Neonatal Intensive Care Nurseries

A highly trained team consisting of pediatric cardiologists, neonatologists, pediatricians, diagnostic radiologists, cardiovascular surgeons, pediatric cardiovascular nurse specialists, social workers, and technicians, all skilled in the management of critically ill infants are usually available around the clock in these intensive care units.

In the newborn with congenital cardiovascular defects, a definitive diagnosis is often difficult to make solely on the basis of physical examinations, chest x-ray examinations and ECG.

Echocardiography (in particular two-dimensional echocardiography) has been extremely valuable in the differential diagnosis of congenital cardiovascular disease.

Although echocardiography is valuable for the demonstration of structural abnormalities in a newborn with congenital cardiovascular diseases, it cannot provide precise, detailed anatomic information, especially as regards the presence or absence of associated defects. It is thus the combination of a careful, detailed physical examination, various non-invasive studies and data from a cardiac catheterization which enables accurate diagnosis.

Conservative management of a cyanotic infant in an attempt to avoid cardiac catheterization generally only delays the acquisition of definitive anatomic information and, as reported by Stranger, et. al., (1974), it may actually affect adversely the infants' chances for survival.

In the early 1960's, cardiac catheterization was undertaken with great trepidation owing to the high mortality. Over the past two decades, a great deal of knowledge and experience has been gained in the care of the critically ill newborn. Although cardiac catheterization in an extremely sick infant may involve considerable risks, Porter, et. al., (1978) believes that the likelihood of death from the underlying cardiovascular malformation is usually greater. Thus it is generally felt today that in the hands of a skilled team experienced in the care of critically ill newborns, no infant is too sick to undergo cardiac catheterization and subsequent surgery.

Current methods of investigation of infants with congenital cardiovascular defects involve the use of complex techniques and equipment, which not infrequently exposes infants to discomfort and risks. The advantages of employing a technique that is safe, provides reliable information and may be repeatedly used are obvious and accounts for the popularity of echocardiography, a traumatic technique.

Echocardiography utilizes ultrasound as a non-invasive means of discovering the anatomic realities of the cardiac malformation. Echoes are displayed on a screen and a transducer is placed on the infants' chest and in various positions. The unit is portable and when the data is used in conjunction with the clinical, radiologic and electrocardiographic data, Chesler et. al., (1971) have found the method to be helpful and a rapid auxiliary technique prior to cardiac catheterization.

Cardiac catheterization is the ultimate diagnostic tool used before cardiac surgery is performed. It is the most definitive measure of conditions, and as an invasive procedure, there are risks about which parents are informed prior to its use. The procedure involves passing a venous catheter into a femoral vein in the groin via an incision. The procedure is possible in infants less than 48 hours of age, and it is easily manipulated in the newborn with minimum discomfort to the child.

Once the catheter has been inserted into the heart, pressures within the heart can be taken, as well as pictures of precise anatomic abnormalities, the presence or absence of associated defects, and the severity and significance of these abnormalities. It is primarily a diagnostic procedure but it can also be a therapeutic procedure for some defects. The acquisition of a maximum of angiographic data during a cardiac catheterization is desirable, but some critically ill newborns have such dynamically unstable conditions, and cardiac catheterization may represent considerable stress that may be poorly tolerated. Neches and et. al, (1973) states that a rapidly executed yet efficient cardiac catheterization that follows an orderly protocol eliminates unnecessary steps and anticipates potential difficulties is essential. In this way, once sufficient diagnostic information has been obtained, appropriate management decisions can be actualized.

IV. The Neonatal Intensive Care Nursery

This research study was conducted at a major metropolitan, university hospital center, which includes a 685-bed facility, and a regional Neonatal Intensive Care Center with a 40-bed unit for high-risk infants sent from all areas of the entire state. The study was conducted through participant-observation techniques and non-structured interviews with the parents of infants and the hospital staff over a three-year period and one year of intensive observation of the neonatal intensive care center itself.

Within the last 20 years, pediatricians and other health care providers have become more and more aware of the fact that most newborns who die so so within their first 24 hours of life. Therefore, the reality of immediately intensive care for all newborn infants to prevent serious, chronic and possibly fatal illnesses has continued to emerge.

High-risk infants are infants who have statistically increased chance of dying or becoming seriously distressed or compromised in the newborn period of life. As cited by Corbin (1980) infants who are seen as predictably high risk include:

(1) infants born to diabetic mothers

(2) infants born to mothers who have bled during the first trimester

(3) infants whose mothers suffered premature rupture of the membranes for more than 24 hours before delivery

(4) infants born to Rh-factor mothers

(5) infants born to addicts or mothers who have injested drugs which affect the fetus

(6) infants born to mothers who have lost a previous infant or infants in the first 72 hours of life

(7) infants born moderately or severely depressed:

(a) infants with low Apgar scores
(b) infants with meconium-stained amniotic fluid
(c) infants with histories of fetal distress
(d) infants delivered by emergency C-section
(e) infants delivered by mid or high forceps
(f) infants delivered with tight cord around neck

(8) infants of low birth weight

(9) infants born with life-threatening congenital anomalies (cardiovascular defects)

(10) infants who are too large for gestational age

(11) infants delivered by Breech extraction

(12) infants born to mothers with preclampsia

(13) infants born to mothers with histories of infection during pregnancy

All high risk infants are observed and monitored appropriately after birth so that the common complications associated with their high-risk status may be recognized, prevented and treated before the infants become seriously ill and beyond the ability to survive.

Special Features of Neonatal Intensive Care Nurseries

Some of the special features of these units include the following:

(1) to provide care of graded intensity, which is determined by the nature and degree of each newborn's problem(s).

(2) provision of specialized monitoring for those infants defined as severely high-risk.

(3) always under intensive, continuous medical/nursing care.

(4) extensive detailed charting and reporting for findings, changes, etc.

(5) extensive testing by machines.

(6) extreme caution extended to prevent infections: scrupulous hand-washing techniques.

(7) all staff, i.e., physicians, nurses, students, technicians, housekeepers, parents, etc., must wear gowns and wash hands to elbows with antiseptic solutions before entering nursery or handling infants.

(8) extensive medical instruments, all located in unit, none brought in from other areas of hospital. Extreme caution in cleaning all instruments before and after each infant's examination.

(9) all personnel cautioned to keep away from nursery if they have a mild infection or cough of any sort. No staff admitted with signs or symptoms of respiratory infection, "cold sores", or any other communicable disease. All staff monitored for any of the above.

(10) Clinical Nurse Coordinator or nurse-in-charge has the major responsibility for insuring all infants' safety by insuring all nursery

personnel's adherence to policies to protect all newborns from infections.

It is estimated that about 6 to 10% of the 3,600,000 births in this country are diagnosed as preterm or term infants with major malformations, including congenital cardiovascular defects. Most of these infants do well: 75% survive and about 70 to 80% of those cared for in neonatal intensive care units require hospitalizations that can last from several days to several months and the complexity of care and management may vary.

During the last 15 to 20 years advanced diagnostic and therapeutic techniques have resulted in a new type of facility to care for high risk newborns. As new and improved methods for controlling infections were developed, there was no longer a need to have separate facilities for infants who shared singular characteristics of perinatal disorders. Consequently, all medically and surgically ill infants are housed in a common area whether they were premature, term, infected or noninfected.

It is apparent that this new approach exerted major impacts on nursery architecture, equipment and other component parts of the nursery. There was also a need for specially trained personnel from several disciplines who function so cohesively that lives are saved. These disciplines work together so as to minimize the development of any conditions within the unit that would threaten the survival changes of each newborn infant.

This special care for special infants includes an array of detailed activities that range from intensive close, one-on-one observation of infants with serious illness but do not require extensive therapeutic intervention, to intensive treatment of infants whose survival remains problematic and uncertain. The hospital setting where this study was conducted was designated as a federally-funded Regional Center to which infants from around the state can be transported for treatment unavailable in their local communities. As a Regional Center its functions also include the production of new information through research, education of personnel, the evaluation of mechanical equipment, and general education via in-service and seminar programs for personnel of referring hospitals.

This new technological revolution mentioned earlier exerted profound effect on the lives of newborns with a variety of conditions requiring life sustaining mechanical measures. Each decade of this century has seen dramatic reductions in infant mortality, particularly in the first four weeks of life. The most dramatic reduction as cited by Wegman (1981) has been since 1970 with a drop in mortality from 15.1 per 1000 in 1970 to 8.4 per 1000 in 1980. Most of this improvement and change cited in these rates was due to the development of the neonatal intensive care unit. Families were now offered increased chances and hope that their infants would survive, where previously no hope existed.

Infants who would not have had any remote chances of surviving several years ago are now being saved because of the application of the new knowledge gained about fetal and neonatal life and the medical world's increasing ability to utilize all measures required to save these infants' lives. This new technology, most often available in university-based, research-oriented teaching hospitals, combines the ultimate in sophisticated medical technology with a highly specialized multidisciplinary team who perform their tasks on a 24-hour, around-the-clock basis.

This particular neonatal intensive care unit is no different from other similar units. It is often hectic and congested, with great activity. It is extremely noisy, with a constant flow of people, in and out. Infants in the NICU are placed under extreme physical challenges, including being restrained by having their arms, hands and legs tied down to prevent them from snatching out tubes and IV lines as they move about on radiant warming tables or in heavy plastic isolettes that surround them and prevents maximum human contact.

Infants treated in the NICU are usually the smallest, the youngest, and the sickest of newborns. Whether they are treated for extreme immaturity or another serious illness such as congenital cardiovascular defects, long-term hospitalization is required in order to meet their multiple medical needs. By the nature of the NICU, acute-critical care demands a wide variety of extreme medical interventions for each of the infants.

Tracheal intubation tubes, catheters, chest tubes, gavage feeding tubes, tubes in the stomache, continuous x-rays, blood gas lines, suction tubes, oxygen analyzers, pressure gauge adapters, resuscitative apparatus, aryngoscope and blades and bulbs, spiral and scalp needles, arterial and venous catheters, feeding tubes, cut-down catheters, sterile drapes, opthalmoscopes, blood study kits, capillary tubes, ECG, EKG, nuclear scans, infant lumbar puncture tubes, exchange transfusion sets, and other discomforting procedures, all considered basic and necessary for treatment and survival are just a few of the sources of challenge facing all infants in this particular setting. This constant, continuous mechanical monitoring is especially intense and stress-provoking.

Upon entering this NICU, one is particularly impressed with the noise level and the extremely bright florescent lights that radiate from all corners of the nursery. Most of the infants are quite small, some weighing 3 pounds or less. Most have their eyes covered by heavy gauze which protects them against the intense lights. Most infant beds, cribs or isolettes are surrounded by machines for monitoring minute-by-minute all physiological parameters, so as to anticipate and prevent crises which may have adverse effect upon each infant's physical and developmental potential.

Each infant's bed is surrounded by machines for monitoring minute-by-minute temperature, respiration, apnea, heart rate and rhythm, inspired and expired oxygen and transcutaneous oxygen levels registered. Someone is always doing something to each infant.

Several studies have found that the most frequent care giving activity in the intensive care nursery is adversive handling related to carrying out technical medical procedures. Gottfried (1980) found in a study of the physical and social ecology of the ICN that infants were handled 16.7% of the time observed. Most of the handling was associated with medical or nursing care. Korones (1976) found that infants were disturbed an average of 132 times per 24 hours. A recent study reported that sudden loud noises in the ICN caused agitation and crying in infants, followed by an increase in heart and respiratory rates (Long, Lucey, and Phillip, 1981).

The NICN, if viewed as a high-risk environment, can create some negative effects on critically ill infants as a result of an inappropriate pattern of stimuli from a variety of sources, primarily mechanical life support systems and multiple inconsistent care givers. Critically ill children are sentient and as such interact with and respond to their social world of NICU. They actively participate in and they react to all aspects of that total environment. They provide definite behavioral cues to their reactions to their physical states, and they give cues through changes in facial expressions, tone, color, and fluctuations in respiration and heart rate. (Gorski et. al., 1980), and other studies indicate that preterm infants provide definite behavioral cues to their neuro-physiological stability, disorganization or distress. In another study, (Gorski et. al., 1979) stated that apnea, sudden changes in heart rate or respiration, even cardiac arrest, are viewed as possible autonomic responses to the NICU environment and activity. These infants are subjected to an environment where numerous people poke and stick things into them in an unpredictable and oftentimes variable manner. In other words, as Sander (1977) indicates, what happens in the NICU can be very critical and may have major effects on infants' early adaption and interactions as well as their responses to their environment and immediately surroundings.

Neonatal intensive care nurseries tend to apply their own criteria as to which risk infants they will accept. The NICU in which this study was conducted accepted infants whose birth weight was less than 1000 grams, as well as any distressed infant regardless of birth weight. These infants were defined as needing special care and the staff provides that special intensive care, through a variety of strategies. Although electronic monitors, mechanical respirators and other gadgets are utilized extensively, optimal outcomes are basically dependent on constant scrutiny of these infants by personnel and not by machines. This statement somewhat accepts the fallibility of machines and raises to prominence the direct observation skills of astute and talented nurses who ar able to detect even slight changes which machines cannot detect. It is only well-trained nurses who can detect quality of breath sounds, edema, pallor and early cyanosis, skin lesions that indicate infections, etc. The nurses develop systematic methods for quickly assessing each infant's state, determining the severity of the condition and activating whatever treatment regimens deemed vital to its survival. Therefore, the instruments utilized within the NICU are intended for use by skillful personnel and not intended to replace them.

Along with electronic monitoring this NICU had its own laboratory with its own specially trained group of technicians. This laboratory is self-contained, requiring no support from other areas. It is able to provide quick and reliable results on all biochemical parameters, including blood gas, blood glucose, electrolyte and bilirubin reults. This laboratory provides a definite support service to the NICN program.

Chest films are a vital component of the diagnostic tools utilized by the NICN staff. These films can be taken with minimal or no disturbance to the child. Films are made of the skull, abdomen, and extremities, and a portable x-ray unit allows free access to all infants whenever indicated.

Structural Components

The newborn intensive care unit contains areas designed for intensive, intermediate, and minimal care. Infants are admitted directly to these areas depending upon their particular state, or they can be moved from one section to another as they move along the illness trajectory. The infants in the intensive area are the most critically ill; they also require more mechanical monitoring, and they are usually attached to ventilators and respirators. The flow of traffic within their area tends to be dense and continuous. They remain in this section as long as they need ventilatory assistance and several nurses in attendance. Minimal care sections tend to be generally reserved for infants who are basically convalescing in preparation for going home. Mothers are required to remain with the infant in the hospital for 48 continuous hours before infants are released home, so that they may begin to take over more of their infant's care while nurses are available for guidance and instruction.

The "Romper Room" is a fourth area, somewhat misnamed because it is devoted to those infants who need intensive monitoring but are not expected to survive. These infants are maintained on numerous life-support machines, and the expectation is that their situation will remain the same until their hearts give out or a lethal infection will set in, and no one will have to take the responsibility for stopping treatment. The Romper Room is also adjacent to the Parent Room, which serves several purposes, including as a lounge-conference room for nurses when it isn't being used by parents.

The Parent's Room is small and close, with comfortable couches that are opened in the evenings into beds. This room provides privacy for mothers who need to pump their breast so the milk can be stored for their infant's use later; it serves as a conference room where "bad" news is given, especially when the decision is made to remove lifesupports; it is here where parents may hold for the last time their dying infants in the presence of ministers or priests; mothers who are too ill to travel may stay in the Parent's Room until their energy level improves. This room has a private entrance that allows exit without passing other parents attending their newborn infants.

Each level of graduated care has its own personnel according to its respective clinical skills and the clinical needs of the infants. Each infant is allocated a certain amount of space, while more space is provided for each infant in the maximal care area of the unit. Space between infants allows a conservation of nursing energy, minimizing walking distance between infants, the telephone, supplies, etc., which permits each nurse to care for the infant's multiple needs without leaving the area. Chart notes are written daily on each infant's progress, problems and any discharge plans, etc.

There are 15 sinks with foot pedals that are stringently utilized for hand-washing. Telephones are strategically placed throughout the unit with connections to the unit clerks who retrieve physicians, nurses, and parents whenever indicated. At least 12 electrical outlets are available to each of the maximal care units. A suction, 2 oxygen and air outlets are available to each crib or incubator-like crib. Each nurse is able to receive help if an infant experiences distress by pressing an alert button that is adjacent to each infant's crib.

Some infants are placed on a newly-designed "water-bed", that is used with those infants with apnea problems. The theory behind its development implies that the constant flotation action of the waterbed allows infants to sleep peacefully without stopping breathing in the absence of motion. This research project is just one of many that are physician-directed, but nurse-implemented. The NICN has its own research laboratory, where relevant investigations are managed. Monthly grand rounds in pediatric nursing gives the research nurses opportunities to share the results, as they are, with the staff.

There are no nurses' lounges or house officers' sleeping quarters; clothes are changed in the locker rooms that are provided on the unit. All ancillary services have their own areas or rooms off the central corridor of the unit. Unit clerks manage a very busy desk that handles all paperwork emanating from the unit; it receives all calls into the unit, including calls from parents and families of infants, receiving calls from labs regarding the outcome of tests, they arrange for treatments and studies to be done on particular patients at particular times. When changes occur in infants' conditions, these clerks call families and at someone's request they can strongly recommend that parents rush to the hospital; they page all social workers, chaplains, when indicated by anyone in the service.

This is a sizable conference room with an automatic coffee machine, a small refrigerator for the storing of food and baby's milk. It is in the conference room where patients are discussed and decisions are reached pertinent to each infant's needs. A social worker and a discharge planner facilitate the purchase of equipment, the scheduling of public health nurses for home visits and referrals to follow-up clinics.

The delivery room is located outside the unit and on the same floor. Newborn infants are often seen being transported either in the arms of a staff physician or in an isolette being wheeled by a nurse to the NICN. The nursery for well newborns is adjacent to but some distance from the NICN. Offices for the house staff are located in the wing where faculty doctors have their research labs and level III clerks type clinic and well children's reports, one of which goes to the referring physicians in the community.

Staffing

The NICN employs 220 nurses who work 3 shifts daily, and this number continues to be inadequate for the number of infants on the unit. Conferences between NICN staff and administration of the hospital are regularly holding meetings to determine how best to handle the staffing and monetary needs of the unit.

The staff consists of registered nurses, LVN's, nurse assistants, laboratory technicians, 2 social workers, 1 discharge planner, and 1 spanish translator, who works some evenings and 2 Sundays each month. The physician-in-charge is a full professor and a full-time neonatologist. His staff includes 2 other full-time neonatologists, 3 residents, 4 interns and a host of consultants, including 3 pediatric cardiologists and 3 cardiovascular surgeons. There are 3 post-doctoral fellows, one specializing in pediatric cardiology and the application of echocardiography to early assessment of congenital cardiovascular conditions. The Clinical Nurse Coordinator supervises 3 nurses who supervise nursing students and postgraduate nurse trainees. The unit relates to 12 schools of nursing in the area and these students rotate between the neonatal unit and the pediatric ward, rounding out their experiences by working with critically ill as well as basically well infants and childen.

The house officers on the NICN are responsible for the care and treatment of all infants in all nursery areas, including the Center for Premature Infants, Intermediate Care Nursery and the Romper Room. It is also required that all new house officers must be oriented to the unit before they begin their rotation.

Some of the infants are cared for by private physicians and the house officers are required to communicate daily and freely with these physicians about all aspects of care and treatment of their patients.

Many infants are being studied on approved protocols that actually jeopodize their survival and the house officers are encouraged to be cognizant of these protocols in order that optimal care can be given to the infants during the periods of investigation, hopefully minimizing as much trauma as possible.

The admission of infants to the NICN is carried out by the attending neonatologist and/or the newborn transport coordinator. As a center, every effort is made to accept any infants who require intensive care. When infants are transported into the center during the day, the senior resident and the neonatology fellow are responsible for physician coverage. The junior resident, at the discretion of the senior resident and with the approval of the neonatology fellow and the attending neonatologist, may be the transport physician. After 5 p.m. a voluntary transport physician on call will go on transports. In the event that no doctors are signed up, the neonatology fellow or the attending physician go on transport.

The neonatology fellow, clinical nurse coordinator and the senior resident (except if he/she is new) are responsible for orientation of senior house officers and medical students to the nurseries at the outset of their rotation. On the first day of the rotation, there are limited patient care responsibilities so that the orientation can realistically occur. This orientation includes the well-baby nursery, intermediate nursery, intensive care nursery, premature research center, Romper Room and delivery room areas.

Scheduled seminars are the responsibilities of the house staff and if it is not possible to attend, they are cancelled. The weekly combined OB/Anesthesia/Pediatrics conference and the monthly Perinatal Morbidity/Mortality conference is mandatory.

Attending rounds are teaching and not work rounds. The format is patient problem discussions or presentations.

Social Service

All patients in the ICN have a social service referral except those infants who are admitted for 24 hours or less.

Each patient must have a note from Social Service which includes a statement regarding the financial status of the parents. Social Service makes informal rounds with each doctor individually regarding their patients.

Summary

This is the organizational/structural context within which mothers and their critically ill infants ar thrust and the environment in which trajectory management work and parental survival work are done. The purpose of this section was to allow the reader access into the particular world of hospitalized infants with developing chronic illnesses and the technologized world that's necessary for their survival. This is a totally new world to families; it is frightening, overwhelming and so far removed from their ordinary, everyday existence. But it has to be dealt with in all of its multiple presentations. The birth of an infant, whether well or unwell, brings with it numerous changes and expectations, and there are consequences if parents shrink from their duties, just as there are consequences when mothers come forward to assume major survival work in behalf of their infants. They are given a special role in this strange, highly charged environment, and unless one has experienced it, the realities therein are not understood.

In this study, as indicated during interviews, when parents enter the neonatal intensive care nursery, they acknowledged feeling overwhelmed by the extent to which the infants' lives are dependent upon machines and monitors. As a result of advanced technology, survival is now possible for infants who would not have lived several years ago. With this new knowledge and new technology, new lives are extended and saved. More infants are being born with congenital problems requring long-term, expensive intensive care and the space required to adequately care for these infants become scarce, limited and overcrowded. Such an environment can become hazardous to these infants and the environment itself becomes a factor in the infants' survival.

The NICN, under these conditions, can become hectic and congested and the care tends to be less comprehensive and less individualized for these infants, whose lives are basically in the hands of a nursing staff that can become dissatisfied and frustrated by these conditions. Infants' basic human needs are sometimes compromised due to the restrictions of their medical conditions and the treatments required. Under these circumstances the environment may fail to provide the necessary sensory stimuli, including handling and touching by a consistent, caring care giver.

Physical-clinical survival is always the immediate issue and medical intervention tends to receive first priority. Families worry a great deal about their infants' short and long-term survival. They worry that something could happen to these infants presently but not manifest itself until much later on in later years. This equipment, the tubes and all other pieces of apparatus serve to remind families of the severe and often precarious state of their infants' conditions and the extent to which everyone depends upon machines and advanced technology.

Technological advancement is extremely costly, in human terms as well as financial. Concerns are sometimes voiced about health care costs to maintain a few low weight infants at the sacrifice of large numbers of children who should be receiving preventive care but the costs involved in neonatal nurseries use up the resources from everyone else. In the absence of guarantees that each treatment decision and each treatment intervention will save each child, critics of the present system suggest a more cautious assessment of who should receive care when the resources are limited. In this type of unit, it demands and extracts a great deal of labor and activity from parents.

Technology, though advanced and sophisticated, may save some infants from certain death, and consequently expose them to conditions sometimes worse than death, i.e., psychological and emotional trauma and its long-term overall impact on the total family.

Schechnen (1980) and Stavis and Krauss (1980) suggests that some infants, because of their overall physical conditions and their need for long-term care are at high risk of developing iatrogenic problems resulting from the intervention therapy necessary to ensure their survival. These problems include not only the physical side effects of treatment but possible psychological and behavioral.

The next section will focus on the significant experiences of real people, families who become involved in the hospital care of their critically ill children. The parental experience within neonatal intensive care nurseries is the basic and central theme of this study.

V. Observations of Parents as They Interact with their Infants and Staff

A. Parental Responses

As the birth of a child approaches, the entire famly, but mother-to-be especially, anticipates a normal birth, and she symbolically rehearses delivery and receiving a healthy, normal child, one that is bright and beautiful in every way. The mother-to-be anticipates experiencing an estatic euphoric feeling following the birth of the child, and a sense of pride and accomplishment. Coleman and Coleman (1974) and Biloring (1959, 1961) identify the psychological work that occurs during pregnancy as mothers and fathers begin to prepare for their infant's arrival.

The mother-to-be anticipates staying in the hospital for a few days, having clinical help with early tasks by the nurses, then eventually performing a wide range of tasks with the infant: feeding, bathing, diapering, cuddling, and so forth. She anticipates normal development and no complications of any sort. She anticipates arranging a family division of labor with each member of the household performing specific tasks in relation to normalizing the family after the new baby's entrance into the family. However, the mother becomes the central worker in this process.

Sociologically, the "bonding" that occurs is a fulfillment of the symbolic rehearsal of all of the above and so the proper assumption of the identity of "mother" who is prepared to do the tasks and to be a mother when the reality, more or less, matches the anticipation. Then she "can-do" or perform because of her preparation.

The foregoing introduction has been necessary to set the climate for the stress of having a critically ill newborn with a congenital heart condition.

Parental Reactions

The suddeness of the onset of the new infant's medical problems may account for both parent's feeling under siege, with mothers especially unprepared for social motherhood, even unprepared to accept the child and her own identity under these new conditions. Hence, the distancing, because she may want to avoid the pain of loss or she doesn't know what to do. She is totally unrehearsed and untrained. Mothers begin to feel incapable of any form of intervention during those early periods when she cannot accept and identify a role under these conditions.

The second and third points — doing and competence are conditioned by her observations and imaginery of highly technical work, in the sense that she cannot be a mother because she cannot act as a mother in the neonatal nursery until the nurses there show her how she can be a mother. Until she is gradually socialized through easy, concrete tasks, she remains a "may-be" or tentative parent. When she finds that she can do mothering tasks, and if the baby lives, then the "may-be" mother becomes a mother socially. The distancing is then replaced by acting and eventual committment to the infant and to the "normal" identity of mother. She sees herself gradually as competent and able to do things with and for her infant. "Can do" or performance of life giving activities can overcome "may-be". A role is identified, learned, and so becomes the basis for a mothering identity.

When parents discover that an infant is coming, there is dramatic rehearsal for that event, and when the infant is not as normal as expected, there is a sense of dread, ignorance, and incompetence which immobilizes any action. It becomes obvious that until the socialization process provides the acts and the competence leading to the identity (acceptance) of mother, one cannot be a mother without knowing how to act like one.

B. Parental Observations

As parents begin to learn to accept the diagnosis and the realities therein, they begin to spend more time with the babies but are also observed talking more and more with a variety of staff members. Many parents have been observed with prepared lists of questions which they pursue with staff. Parents ask additional information, in language they can understand and share with others. Sometimes the questions are answered; others are responded to in some fashion but never completely answered. Nurses are questioned and observed as they care for the babies, and parents tend to select and talk to those nurses who seem willing to be open and truthful with them.

Parents usually comment about all of the tubes and machines attached to baby, sometimes more, sometimes less. They have seen machines being brought to and from their babies, and they raised many questions about their purpose and if they might harm the children in any way. Parents eventually learn that their baby's situation is critical, complicated and serious and will require a long stay in the hospital. Most parents received that message most often indirectly by being in the environment and less by being told by the doctors or nurses.

Many mothers also learn from other mothers' experiences the realities and similarities they share, and as a result of these multiple exposures to their child's condition and the social environment in which that condition is treated, parents eventually learn the complexity as well as the enormity of their situation. No longer can it be viewed casually and as simple and short term, but rather extending over a long, indefinite, uncertain course, outcome unknown.

It has been observed that as parents begin to explore the environment and become more aware of its organization and operation, they begin to pressure staff more for specific information regarding the short and long term reality of the babies' condition and the basic ingredients for overall survival. It is during this period that staff becomes more concrete in its explanations. Once parents realize the severity, life-death reality of the situation, they become more fully aligned with participating in the enhancement of the child's survival. After numerous conferences with doctors and nurses where parents are allowed opportunities to discuss baby's diagnosis and hopefully to gauge the reality of the baby's abnormality, they are then able to begin to address others with the reality of the baby's condition.

Many parents are eventually able to address themselves and others at home with what is involved in relation to the hospitalized baby. Previous to this sharing of information, children at home had no information upon which to base their knowledge of the observed changes noticed in parents. Many siblings had not been made aware of the true state of the baby's condition. However, what parents often said verbally, did not coincide with what they did and how they reacted. After realistic explanations were given about the severe nature of the baby's condition, families were then able to construct the survival program of how the family will survive at home and how they would help the baby survive in the hospital. Just as they will need to cooperate and redesign their roles and responsibilities at home, someone would have to have to help the infant survive in the hospital because it could not do it alone. In giving up old roles and assuming new ones, new divisions of labor and responsibilities would have to be developed to match up with the severity and enormity of the problem.

In most instances, mothers remained the family representative with the baby in the hospital, with fathers and siblings assuming responsibilities previously performed by the mothers. Fathers divided their time between their jobs, the children at home, and the mother and infant in the hospital. Cooking, washing, shopping, etc., became chores now for fathers, and siblings were required to rely more upon each other, and in some cases were farmed out to relatives and close family friends. Mothers were interacting with their hospitalized babies, seeking information from doctors, nurses, therapists, and all others, monitoring and assessing the activities of all care givers and therefore totally immersed in the survival work in behalf of her child.

Initially, all families are unprepared and ill-equipped to manage the demands made upon them and the ill children. They have no previous cues around them from which to make appropriate actions and responses. As a consequence of continual interactions with those individuals responsible for the child's care, parents begin to comprehend more fully the complicated, critical nature of their child's condition. They are also unprepared for the long-term, protracted nature of the illness; that it will not disappear over night but may be their reality throughout the lifetime of the child. Most parents are unprepared for the absence of unreliability factors; the child may improve at some point but will never be completely well. The imperfect heart, unless it is replaced with a new heart, will always remain imperfect and incurable. Parents eventually learn, most often, on their own, that there will be times when the child will be asymptomatic and basically under control and manageable with minimal effort by doctors and others. However, the painful realities of the original problem hits them again, full force; when the child becomes symptomatic, and the cycle is once again in process. Many parents can identify their existence remaining in a "state of siege", without controls or means by which to interrupt the unfolding of crisis after crisis. The child's survival becomes more central and strategies are developed to minimize factors that could cause the child's death.

C. Central Theme

Parents and staff share the same reality, namely, keeping the child alive, at all cost. The staff's basic approach to enhancing the survival of the child is by scientific-medical means. For the parents, theirs is a more natural-biographical style, primarily using themselves as instruments and advocates. Once they fully comprehend the magnitude of the overall problem and they are somehow moved beyond some of the initial, primarily overwhelming aspects of the loss of a "perfect" child, parents begin to develop strategies for serving as their child's primary advocate. Without much direction from others, parents naturally move into this role, some with more or less trepidation than others.

The staff establishes a specific medical regimen, outlining what has to be done medically and can be done otherwise, i.e., parents unlimited visiting, periodic conferences to bring everyone up-to-date on progress or the absence thereof. The central theme emerging is that the child's life literally hangs in the balance and primarily in the parents' hands.

Parents establish as their goal (and primary objective being to learn how to cooperate and interface with the established regimen) to enhance the child's survival chances, as well as its quality of life under those conditions with minimal emotional scarring. The environment within which this survival care is given is highly organized with sophisticated invasive-noninvasive machines, numerous experimental drug protocols, complicated and potentially dangerous diagnostic/treatment procedures. Into this area, most parents view themselves as "David confronting Goliaths en masse". What do they have available to counteract anything in that situation?

Families visualize consciously using themselves as their child's basic non-medical survival instrument. Many of these babies, have never been home; they were transported into specialty hospitals where crisis oriented care keeps them alive. Natural parenting has been interrupted by the child's illness and hospitalization, which can be for variable periods of time, depending upon the exact nature of the illness and the availability of medical treatment commensurate with the problem.

Parents stake out their parental claim to the child by defining their basic task as being with the child as much as possible and for as long as possible, without interfering with the work of doctors and other staff members. If they are truly going to be their babies' advocate and protector, they can only actualize that role by being present, alert, and responsive to the toal environment, which includes staff and all others working with their children.

Monitoring and assessing the children's behaviors and reactions, as well as those of all providers of care, becomes a basic part of parents' survival work. Even though babies are surrounded by and attached to a variety of life support machines and numerous nurses and technicians, parents are able to develop deep emotional attachments with their babies and consciously work toward establishing affectional bonds with their child and learn a great deal about their needs and moods and all special things that make each child uniquely each couple's child.

While doctors and other professionals treat the child's medical needs on a continuous basis, they do move on to other patients, while parents tend to focus on their individual children and remain a constant force for it. Parents become thoroughly attuned to each child's unique attributes and consequently, they serve as excellent historians of the child's reality in the absence of the staff's continuous, uninterrupted presence.

As parents remain at baby's bedside, as the illness begins to manifest itself, parents are exposed to most of the crucial problems. This exposure experience assists parents in recognizing the multiple realities as they exist for their particular child. They see the baby's reactions; they observe staff's responses, and they apparently store away each experience as a primary cue for reactions that they learn will occur again. This information is learned primarily by observation and direct interactions with doctors and other staff people.

VI. Learning About Survival Work

Mr. and Mrs. Dahl had been married for 5 years and both had established meaningful careers and the time seemed right for them to start their family. Both came from large families, and they were the only ones married who had not produced a child for the grandparents. Mr. Dahl entered a graduate program close to home, and their plan was for the infant to be born toward the end of Mr. Dahl's second and final year before graduation. Mrs. Dahl continued to work, and as they had planned, she became pregnant toward the middle of his final year.

Everyone was estatic and relieved when the pregnancy was announced during a family reunion dinner at Thanksgiving. Mr. and Mrs. Dahl were quite excited and looked with great expectations for the day when the infant would be born. Mrs. Dahl remembered her pregnancy as an uncomplicated experience and one which she enjoyed immensely, except for the initial morning sickness episodes.

> I can't recall when I felt more alive and more vital. My doctor said my health was perfect and that the pregnancy and the baby would be wonderful. I did all the right things: I ate well and properly, I exercised daily, slept well, and I gave up all of my vices, including chocolates and an occasional glass of white wine. My husband didn't drink so he was pleased when I became very virtuous and gave it up. As I look back, it was a wonderful time. I felt beautiful and I loved the whole world.
>
> (Excerpt from field notes, Mrs. Dahl, 1979)

Mr. Dahl, though not as demonstrative as his wife, acknowledged that all things seemed well with them during the pregnancy, with no major complaints.

> We were very happy then; maybe I should say we were happier because we've always had a fine relationship, but this period of time was different. Both of us were relaxed and everything was great. We had been alone so long that the idea of a little one around seemed great. We were ready for a baby and a baby we were going to have. I've always like children and I'm called the favorite uncle of some of my nieces and nephews, so I assumed I would be a favorite father, too.
>
> (Excerpt from field notes, Mr. Dahl, 1979)

Both had begun to anticipate the baby's birth and they shared the excitement of planning for the "perfect" baby, with blonde hair, blue eyes, and everything else in place, where they should be. They were society's definition of the perfect couple in every way. They were a good-looking, well educated, healthy, clean living, career-minded couple with everything going for them. Therefore, they went through the entire pregnancy expecting to have a normal, healthy baby, just like its parents. Mrs. Dahl sewed all new clothers for the baby and one of Mr. Dahl's brothers who had his own carpentry shop helped him paint the baby's room and they refinished the crib Mr. Dahl had had as an infant. Both men took great pride in this activity mainly because they had drifted apart during the years for no apparent reason, and the anticipated birth of the baby brought them together again.

Mrs. Dahl stopped working during her sixth month and spent the remaining months before the infant's birth getting everything perfect for its arrival. They spent money that they didn't know they had; gifts came from far and near, and their friends gave them an all-expense-paid trip to Reno for 3 days, which they thoroughly enjoyed. When they returned home, their friends had pained their house for them, engineered by Mr. Dahl's brother, the carpenter. The acts only confirmed for them that they were loved by many people and their anticipated infant had provoked those expressions of love.

> We were overwhelmed and we basked in the warmth that our family and friends generated around us at that time. Our close knit group of friends were very generous to each other in many ways, so the expression was not unusual, but the extent of it was overwhelming. We were brimming over with love and gratitude. We felt blessed and special.
>
> (Excerpt from field notes, Mr. & Mrs. Dahl, 1979)

As intelligent, educated individuals Mr. and Mrs. Dahl were aware that even the best of circumstances "imperfect" babies do happen, but not to anyone in their circle of friends. There were healthy relatives on both sides of the family; both of Mrs. Dahl's maternal grandparents were alive and in their eighties, and Mr. Dahl's paternal grandmother had died recently at the age of 79 years. One nephew had asthma and was somewhat restricted, but not limited in any important areas. They were basically from a healthy group of people. Mrs. Dahl's mother was 43 years old when her last child was born, and she and that baby, who is now 19 years old, are both fine.

> We never questioned that we wouldn't have a normal, healthy baby, all of the odds were in our favor. We did all of the right things, had all of the right conditions for a perfect baby. Even my doctor and his staff almost overwhelmed me with assurance that we would have a fine healthy baby; I wonder now if they know something they didn't tell me, but I doubt it.
>
> (Excerpt from field notes, Mrs. Dahl, 1979)

During her eighth month, as she grew heavier and getting around was somewhat more difficult, Mr. and Mrs. Dahl were summoned to her doctor's office where he informed them that the last set of X-rays indicated the presence of triplets!

> We couldn't believe it. There were no multiple births on either side of the family. We cried for joy, but when we finally came down out of the clouds, reality hit us. Three babies, not one, but three, all at the same time. We were in a daze when we left the doctor's office. We couldn't believe it; it was too much. We drove home more slowly than usual that evening and that could explain the heaviness I felt. We called my folks and they called others and before we knew it, the house was full of friends. We had so much more planning to do now. Three babies and just the two of us. How would we manage was our first concern. Jim was still in school and we needed more room. It was overwhelming at first, but we gradually settled down and we were able to approach the situation more rationally.
>
> (Excerpt from field notes, Mr. & Mrs. Dahl, 1979)

By all standards, Mrs. Dahl's pregnancy was normal in every way. The new awareness that she was carrying triplets excited everyone, including her doctor, who had never delivered triplets before. Everyone become more cautious in their care of her and Mr. and Mrs. Dahl themselves modified their behaviors and activities somewhat so as not to overexert her in any way. Mrs. Dahl's mother spent a week with her assisting in last minute preparations for the triplets' birth.

Mrs. Dahl checked into the hospital three days before her due data and she spent those days undergoing more tests and basking in all of the special attention she received from everyone. Their plan was for Mr. Dahl to be present during the deliveries and when the time arrived, he accompanied his wife into the labor and delivery room, where he remained throughout the experience.

> I tried not to be nervous and lose my composure, but you don't have three babies all on one day, at one time. My wife looked beautiful going into delivery and we both prayed that she and the babies would be fine. I thought I might faint, but I didn't, especially once it started. The nurses were excellent throughout; they knew I was nervous and they talked me out of it in no time. One in particular acknowledged that this was the first multiple birth she had attended and I guaranteed her that this would be my first, second, and last.
>
> (Excerpt from field notes, Mr. Dahl, 1979)

The deliveries were uncomplicated, with each infant born in rapid succession. Each one weighed less than 5 pounds but appeared to be fine. Mrs. Dahl was fine throughout, talking and crying with her husband who was a paragon of strenght. He was able to briefly hold each infant before passing it on to the receiving nurse. They delivered three boys, each making very loud entrances into the world. Mrs. Dahl briefly glimpsed each infant, asking between tears if they were all right. Her doctor reassured her that they were fine.

> It was a beautiful experience. We had three healthy boys; we weren't alone anymore. Can you imagine that? Three babies all in one belch. My prayers were answered, they were fine. There were tears in my husband's eyes and I don't think we could have loved each other more than we did at that moment. we had done it just fine and we were happy beyond belief. They took the boys away and I apparently fell asleep for the next four hours. I was exhausted but elated.
>
> (Excerpt from field notes, Mrs. Dahl, 1979)

The neonatologists in the ICN had been called to the delivery room once the infants were born. Each had experienced some respiratory distress and the second and third infants rallied forward while the first born presented several problems and required extensive diagnostic procedures. Mr. Dahl had been informed that something was wrong with one of the infants and they needed more tests to determine the exact of his problems. Mrs. Dahl remained sound asleep for five and a half hours after the triplets' delivery and knew nothing about the infant and his problems. This left Mr. Dahl alone to carry the awareness that all of the children had problems, but one in particular was critically ill.

> I was stunned. That's all I can remember. I was numb and things didn't seem real. I couldn't cry but I felt like I wanted to. When I finally saw them after delivery and my wife was taken to her room, they still looked fine but the doctors and nurses were very busy with two of them. I had been told about their breathing problems but I had been reassured that they would be fine. But when they started rattling off about one of them being critically sick and it might be his heart, I was stunned. Then I thought about my poor wife; she had already gone through so much and after the shock of finding out she was carrying triplets, she

> really put out a lot of energy to make things right. How could I tell her that one of them was so sick that he might die? I just wished that by the time she awakened we would have some good news instead of the bad news I had been given.
>
> (Excerpt from field notes, Mr. Dahl, 1980)

The field worker sat in on a special meeting that was called to determine the appropriate action to take with the first born infant. His condition was rapidly deteriorating and some decision had to be made soon regarding what to do. Medicine was discussed and orders were written to begin to administer them immediately. However, it was decided that surgery was indicated by all of the symptoms and a heart catheterization would have to be done in order to pinpoint the problem. The team was reminded that only Mr. Dahl had been acquainted with the infant's problems, and Mrs. Dahl remained unaware due to her state of exhaustion as a result of the deliveries. It was decided to wait for a short while and discuss the infant's problems with the parents once Mrs. Dahl has awakened.

> I knew something was wrong when I awakened and found my husband and all those people standing around looking at me. It was a dreadful feeling and the silence was overwhelming. I remember my husband sitting down on my bed, putting his arms around me and my first thought was that all of my babies had died. I started crying before they said anything and what they said me cry more. I felt sorry for one doctor because he was struggling so hard to find the right words. I could feel the tension in my husband's body and I didn't know what to say to make it better. He was trying so hard to be brave and I knew he was about to break.
>
> The head doctor said that two of my babies had

some respiratory problems and were greatly improved once the medicines were started. However, the other infant, who weighed the smallest, had some symptoms that said that a heart condition was present. My reaction? I felt like someone had slapped me in the face. The more he talked, the more frightened I became. He stated that there was only one procedure that could save his life, but they needed to do the cath first and then decide what was the best course of action. The surgery they were proposing would only serve to keep him alive until a more bonafide procedure was developed.

We were told all the things that could be wrong with my infant's heart and the one thing that stood out was the finality of it all. It would be good if it worked, but terrible if it didn't. We were told all of the risk factors in doing surgery on an infant so young but they would go slowly and cautiously.

We could hardly wait for them to leave my room and once they did, my husband and I fell into each other's arms and cried. I couldn't seem to stop. My poor babies. Why did this happen? What did we do wrong? And then I thought about my nine hour year old son who was about to have surgery and I cried some more. My poor husband needed as much comforting as I did, but he tried his best to comfort me but I couldn't stop crying. I hurt so bad for my babies. I wanted to jump up and run out of there but I couldn't. One of the nurses came in and offered to wheel me down to the nursery before they took my baby to surgery. We got there just as they were about to shave a portion of his head in order to start an IV. I started crying again and apparently I bit my tongue or lip because my mouth started bleeding and everyone became concerned and they quickly wheeled me back to my room, where I remained until one of the nurses told us we could go back to the nursery.

The triplets were separated because of their respective states with my critically ill one in the more intensive part of the nursery. He seemed overwhelmed by all of the machines and wires attached to him, but he still looked good to me. The others slept a lot, while he seemed always jerking and moving about. The nurses indicated that his heart was beating so hard and fast that he jerked almost constantly. The procedure was arranged for late that morning and I remember asking myself the same questions, why did this happen and what did I do wrong? The doctors talked to me and tried to focus the reasons elsewhere but I kept coming back to me and my behavior and I felt worse.

The procedure lasted six hours instead of the projected three hours. Apparently he experienced some problems and they were required to move more cautiously and more slowly. However, while they were cathing him, one of my other babies started having greater difficulty breathing and a crowd assembled around his isolette. We kept the social worker (the field worker) busy running back and forth between the cath lab and the nursery, keeping us informed each step of the way. I kept thinking, why is this happening to us? What's next? They were able to stabilize him and he returned to being fine and not in any particular imminent danger. We were to learn later that he suffered some minimal brain damage but not to the extent that he would have problems.

However, my baby in the cath lab had experienced a major assault to some major arteries and we were told that as a result he had experienced two cardiac arrests and that they did not know the extent of his brain damage. If I didn't faint, I came close to it. I couldn't believe all of this was happening to our babies. We knew that there were risk factors you take when you have children, but we took extraordinary precautions and still this happened. I couldn't believe I was hearing what I heard. If two of our three sons would have problems like these for the rest of their lives, then these were wasted pregnancies if all we were going to have was one healthy child. I felt sad and defeated and cheated from having all of my children normal and healthy.

The doctor came back and defined the exact cardiac problems as well as the specific brain damage that my infant had sustained. They acknowledged that his situation was more critical and the next twelve hours would determine if he possessed enough surplus strength to survive. They mapped out the next few days and what they would be doing for him. The other tow babies were rapidly improving by the fourth day and we could see this improvement each time we saw them, but kept thinking about my other poor baby; what was going to happen to him? How would he get through the next week, the next few days? Would he live and how would he

> live? Did he have the strength to do it or could he give up and die? My tears started again and the more I tossed these questions around in my head the more my heart ached.
>
> (Excerpt from field notes, Mrs. Dahl, 1980)

These field notes present a dramatic and oftentimes typical presentation of events that precede the work that mothers eventually discover as basic to their infants' survival. Their great moment arrives but is short-lived because the infant is discovered to be critically ill and possibly terminal. Because the infant is born manifesting defect or disease, the parents experience a wide range of feelings and reactions as they adjust to the birth of a less than "perfect" child.

The birth of a sick infant is almost always precipitous and unexpected and it interrupts the natural establishment of the long-awaited relationship with the infant. The "perfect" baby that they hoped and planned for and had every reason to expect, is not only "imperfect" but one they will eventually learn may not live or may have numerous chronic problems if it survives.

When parents such as Mr. and Mrs. Dahl find themselves in such situations involving a child who is critically ill they are completely unprepared and ill-equipped to comprehend and manage the multi-faceted dimensions that emerge. Most parents acknowledge that during the initial phase when the message is first given that their infant's heart is imperfect and that it will need to undergo extensive care and treatment, they themselves experience many intense feelings as they wrestle with the overall implications, both immediate and distal. The looming fact remains that presently they're dealing with a serious and complicated condition that will not go away and one that will require great amounts of concentrated effort of management.

The literature, (1) Mattsson, 1972; (2) Nathason, 1970; (3) Korsch, 1961; (4) Turk, 1964; (5) Tropaner, 1970; (6) Blom and Nichols, 1954; and (7) Quint, 1969, extensively documents the reactions parents have to the birth of an a typical child and the theme that emerges concentrates on the appropriate and natural reactions experienced by that event. Most of the parents in this group admitted having little if any previous knowledge about the mechanics of the heart; most took it for granted as a major, life-dependent organ, never thinking that a child of theirs would experience problems associated with its malfunction. Most understood it to be a condition most often experienced by people who were well advanced in ago who developed problems as a result of the aging process. However, relatively soon as the infants' birth, these parents are compelled to understand the pervasiveness of the condition and that experience is now theirs.

Mr. and Mrs. Dahl's world came crashing down around them when the announcement was made that two of their infants were ill and that one in particular possessed problems that threatened his life and whose care would require extensive, long-term care within a major facility hundreds of miles away from home. As they journeyed happily through the pregnancy expecting to have a beautiful, normal and healthy baby, somewhere there lurked in their consciousness the reality that there were risks to the contrary. They were shocked and in a state of suspended disbelief that what was happening was really happening to them. In one quick series of moments, events emerged that drastically crashed their past and future with the present.

> This couldn't be happening to us; we didn't deserve this; it was so unfair. I could remember these things going through my head as I looked at all three of my babies. I couldn't say anything but I sure cried a lot. I was numb. I felt like a sleepwalker must feel, and even now, that feeling of sadness can be overwhelming. I didn't know how to take care of one baby, and we had three; I didn't know what to do for a sick baby and I had two, one of whom could die. I think I cried even more as I thought of all the things I would have to do and I didn't know if I could do any of them. We thrashed about for days, struggling with the newness of everything as well as the immediate crises of two sick babies. I questioned if I wanted the responsibility, as much as I wondered if I could do it. I know we breathed easier when they told us that the second baby was responding well to the treatments and that he and the third one would be discharged home to us. I was happy and sad at the same time, relieved and distressed at the same time; two babies are going home with us, who will stay with the other one? We couldn't leave him in the hospital, yet we couldn't take him home. I think when we recognized what that meant I decided then that my focus would be on him, and my husband and mother would have to take care of the others. He looked so helpless and all alone, but he would have me to help him through whatever is required.
>
> (Excerpt from field notes, Mrs. Dahl, 1980)

VII. Recognition and Acceptance of the Serious Nature of the Condition

At some point in time after the birth of the infants, some mothers begin to get the message that the infants are critically ill, and that no amount of wishing or denying will cause it to go away. At that point, they really don't know what they're really up against because they've never been up against anything like this before. What are the conditions under which their levels of awareness are achieved? How do they gradually come to understand the extent and proportions of what was to become their ultimate reality of being the parents of a critically ill, damaged child?

Parents are required to "accept" the fact that their infants are critically ill, and a major task for them is the "letting-go" of their pre-birth fantasy of having a normal, healthy child. Accepting is not static but happens in degrees, phases and stages; therefore it is dynamic and continuous. The infant in whom so much has been invested are not well and the chances are great that they will never be completely well, even if they survive. These parents also have to go through a "letting-go" process of their own self images as parents of normal, healthy children, and the assumption of the identity as parents of severely chronically ill children. These acts of self-image, relinquishment occurs under specific conditions as parents begin to recognize that the situation will not "pass over" and that the dimensions of these children's conditions are critical, life-threatening, and chronic in nature.

"Accepting" and "letting-go" occurs through projections, reflections, and reviews which may be backward, forward, or comparative. As the realities of the child's medical identity continues to unfold these parents begin to relinquish or "let-go" of the fantasy child that doesn't exist. This fantasy imagery can include a bright, beautiful, healthy, agile child, who will be strong and sports-minded with potentials for being superstar material; as a child who will have a coming out party or a daughter who will get married in her mother's wedding gown; a son or daughter who will make them grandparents. These emerging realities of the diagnosis continues to confront these parents as they receive information and develop an understanding about the present as well as the future dimensions of their child's ultimate fate.

Parents continue their "letting-go" activities as they naturally compare the new infant with either their other children or the children of friends and relatives. As they recognize the deficits and limitations within their infant's physical-medical situation, they raise questions about its future, such as will it ever walk, will it be happy and loved by others, and if the child outlives the parents, who will take care of it?

"Accepting" and "letting-go" come about as mentioned above, in part through backward reviews wherein parents review the pregnancy and issues surrounding that experience. "If only we had waited", "the timing was all wrong", "if we hadn't had this child, maybe it wouldn't have happened", are just some of the questions raised and comments made reflecting a backwards look in an effort to understand and explain the experience of having a chronically ill child. Some parents express feelings of guilt and self-blame as means of explaining why it all happened.

Many parents recollect the bright moments in the pregnancy as well as the guilt and blame areas. Of course, there are ranges and variations in all of this. Some pregnancies are described as beautiful and positively eventful, while others were recollected as being troublesome, uncomfortable, unwanted and overall troublesome. When parents were encouraged to recollect the pregnancy period, some were able to remember the "normal child" behaviors that occured in utero. They could remember the first and subsequent moments of active, vigorous movements of the child and how fathers usually enjoyed that shared moment of discovery. Other parents remembered little if anything pleasant about the pregnancy experience but rather they tended to focus primarily on the discomfort and misery.

Particularly poignant were those recollections or flashbacks to instances in family histories where cardiac conditions were known to exist. Immediate and distant relatives were reflected upon with comments relating to variations in their conditions and the mode of expression experienced by each person. Most were reflective comments identifying the known presence of certain physical conditions. However, some parents were very verbal in their feelings of anger, blame, and guilt that emerged solely in relation to their present situation.

Conditions That Bring on "Accepting" and "Letting-Go"

"Accepting" in the form of coming to terms with the reality of what it is can be painfully initiated during that initial period of mother-infant separation immediately after birth, or in those instances where there is no separation but the diagnosis and treatment occur in the setting where the birth event occurs. Regardless of the logistical arrangements, some time soon after birth an announcement is made that something is wrong with the infant and it isn't perfect.

Many mothers suggest that certain inadvertent cues which, when reflected upon later, suggested something was wrong. These behaviors on the part of health care team members aroused suspicion in these parents that all was not well. Some mothers vividly recalled how the infants of other mothers were brought to them at various times during the day, while these mothers had to go to their infants, and for shorter periods of time. Many mothers experienced "by-pass" activities wherein staff members playing "hopscotch" with their rooms, avoiding them and going on to someone else's room. Ultimately as these mothers became more and more suspicious, many were relieved when the announcement was made that the infants would be transferred to another hospital for treatment. This period of uncertainty ushers them into a state of limbo until they are able to discover why such behaviors are occuring around them and their infants. These are some of the conditions that ultimately lead parents into "accepting" their altered state of parenthood by a newly emerging re-definition of their infants.

Parents acknowledge beginning to feel as though they were functioning in a "state of siege", overwhelmed by factors and conditions they didn't understand and without any means of protecting themselves from an unknown force located within the highly structured and extremely organized hospital environment. They feel overwhelmed by everything that begins to happen to them in such a relatively short period of time. What was originally seen as having promises of joy and satisfaction turns into an awesome nightmare.

What the parents are required to "accept" varies according to severity of the infant's illness. Some cardiac conditions in infancy and early childhood may only require monitoring and occasional visits to local pediatric cardiologists for annual assessments and out-patient clinic visits. There are other cardiac conditions treated with specific medications which allow them to live relatively unencumbered or to "buy" time to grow and develop so as to enchance survival during and post-operatively. There are those infants whose cardiac problems are such that only after a series of surgical interventions will they be able to survive, long or short-term. In all instances, there are no guarantees that any of the children will survive. Each parent will be required to accept and understand their own individual realities and discover how they will manage themselves, the infants, and all other individuals important and significant to the entire family unit.

Some parents accept literally everything that they are told and proceed to structure their activities along the areas and issues defined. Some other parents accept certain aspects of what they're told, while some parents only that which they believe. This can have important consequences. Thus Mrs. Marshall heard everything that the three physicians told her about the serious nature of her baby's condition. They questioned his abilities to be sustained beyond the age of one year. She reminded them that she and her husband had waited seven years to have their infant, and she would not give him up without trying. She did not believe their prognosis of death by the age of one year. Her efforts to disprove them started then and much to everyone's amazement, the child responded to some aspects of treatment, experienced only three hospitalizations and lived to reach his thirteenth birthday. His mother was given total credit for his surviving as long as he did, based on her refusal to accept the original devastating pronouncement.

For some parents acceptance comes before the final announcement and diagnosis, whereas others get to the point of acceptance somewhat more slower. Concurrently with parent's "letting-go" their fantasy child's image, the environment gives cues that assist mothers in coming to terms with their baby's reality. One mother states that she finally "got the message" when she saw her baby's isolette surrounded by several pieces of omnious equipment. When she compared here baby with other babies in the ICU, no other baby was as overwhelmed with machines as her baby. That gave her the new awareness and the new identity of a parent with a critically ill child with an unknown future, medical or otherwise. When the "letting-go" and the "taking-on" turns for some parents depends on how much time they've had in between denying, getting information, and how much work (letting-go) they've done.

When parents do "take-on", they've received a trajectory projection medically as well as biographically, and they put these two together, make their connections and go from there with their management role(s) and life agency. The mother's trajectory scheme includes the physician's projection, her perception of the patient's trajectory projection, her degree of agreement, or disagreement with it, and her own definition of what she is going to do about it. She then becomes this life-promoting, life-enhancing, life-sustaining agent for her child.

The tremendous magnitude of the problem cannot be heard. Rather it must be experienced, observed, and witnessed.

The machines necessary to sustain life as well as assess states and conditions are multiple and varied. Parents usually comment about all of the tubes and machines attached to baby. One mother stated that she became more aware of her child's condition when after observing her child for several days, she noted more tubes than after his first surgery. The number of tubes denoted to her the seriousness of her child's condition.

Another mother said that she had commented to another mother that when she saw several technicians wheeling pieces of equipment into the nursery that the baby needing all of that equipment must be seriouly ill. She later learned that it was her own infant and it was at that point that she recognized that they had a real problem that was critical and that the staff's skills were being tested as they struggled to keep her child alive. She and other mothers received the message most often indirectly by being in the ICN environment and less by being told by the doctors, nurses and other health professionals.

Many mothers also learn from other mothers on the unit the experiences and realities and similarities that they share. As a result of these multiple reality exposures to their children's conditions and the social environment in which that condition is treated, parents eventually learn the complexity as well as the seriousness of the situation. No longer can it be viewed casually or as simple and short-term, but rather extending over a long, protracted indefinite, uncertain course, outcome primarily unknown.

As parents begin to explore the environment of the ICN and become more aware of its organization and operation, they begin to pressure staff for more specific information regarding short and long-term reality of the babies' condition and the basic ingredients for overall survival. Staff then becomes more concrete in its explanations; once parents realize the severity, life-death reality of the situation, they become more fully aligned with participating with staff in the enhancement of the child's survival. After their levels of awareness are increased, mothers are then able to begin to address others with the reality of the babies' overall condition, as well as outcome possibilities.

Conditions that delay parents' understanding the doctors' trajectory of their child's condition include the following:

1. The technical language used in the unit could be very remote from the parents' level of comprehension.

2. The complexity of the situation is such that it eludes some parent's comprehension.

3. Ambiguity and uncertainty remain potent in the ICN.

4. With all of its knowledge and skills, ICN sometimes cannot locate exactly where a particular child is, in terms of repairability, i.e., it is easy, complicated, difficult, sizable, small, large, etc.

5. The issue of believability - some parents cannot <u>believe</u> that <u>their</u> child is as seriously ill as it is defined by the health professionals.

6. Symptom specificity - sometimes problems are so multiple that staff can be unsure if it is primarily the heart, the lungs, or both.

At some point, there is some breakthrough in one or more or all of the above, and parents begin to harness their resources and begin their survival work. They ultimately accept the trajectory projection, the interventions of the health professionals. They then have to learn what they have to do and decide how they will do it given their overall understanding as well as their specific biographical situations. They basically recognize that the babies cannot do it alone, their help is mandatory and necessary.

At this time, what parents and staff think about this child's condition come together and a division of labor in terms of who does what and how, can be defined and acted upon. It is possible that at other times during the course of the child's illness each will perform tasks normally done by the other, yet they will negotiate who's tasks most meaningful at that particular juncture of the illness trajectory. They come to view themselves as team members working towards the same goal which is, the total survival of the child.

The next section will identify who becomes a survival agent and the process by which the tasks are performed.

VIII. Who Becomes a Survival Agent

A. The Process

Who other than doctors and nurses can become and what does it take to be a survival agent? In my study, two major properties emerged as significant factors leading to the assumption of survival agent tasks. The first property is the acquisition of an adequate information/knowledge base. Before anyone can rationally or intentionally decide to become or not to become a survival agent, he/she must have acquired sufficient and substantive information that will assist them in making a decision. Dewey (1937) and White (1974) for instance believe that having the proper amount of information is a prerequisite for action and a necessary component for coping.

In this study, some parents possessed some basic information, some had specific information, and others possessed no information about sick children and what happens to them, whether over the long or short-term. Some parents, through their other children's illnesses, or through media such as television coverage and newspapers, possessed varied amounts of information, but none to compare with that relevant to what they are presently absorbing. White further believes that the more acute and expansive the acquired information, the greater the number of options and choices one can make. Mr. and Mrs. Jones typified how information helped them reach a decision about themselves as survival agents:

> I think we read everything we could find on our infant son's heart problem. My wife went to several libraries and checked out all of the books on children with heart problems. I read some things at work and I talked with our pediatrician almost daily until he was blue in the face. The questions kept coming and the more we read the more scared I got. One of the cardiologists arranged a special meeting with us and we kept him busy for almost two hours with questions and special concern about his chances for making it. We saw a TV program about heart disease and children. There were three parents on a panel and they all seemed as comfortable and confident while we felt so scared. I couldn't see us ever getting to that point. But the more information we got, I could be more realistic and I had more control. Something had to be done, we couldn't stay scared forever, so we decided that come hell or high water, we would do it. Those other mothers did it and so could we. Af first, we didn't know what, but at some point we realized that kids with heart problems need a lot of help. His heart was complicated and he could die, and we didn't want that. Even if he wanted to live, he couldn't do it by himslef, so we had to get involved and help him make it.
>
> (Excerpt from field notes. Mr. & Mrs. Jones, 1981)

A second property that impacts on the assumption of survival agent tasks is that of <u>commitment and dedication to the infants</u>. In my study, commitment refers to the ability and/or willingness to place the infants' survival above everything else. The ultimate in commitment is when the infant's survival is so important to parents that nothing else matters to them, especially their own personal comfort, needs, and careers. Many parents were quick to understand the serious complicated nature of their infants' cardiac condition and their responses indicated an almost immediate relinquishment of themselves and their needs to those of their infants. Everything else was placed on hold or in abeyance.

> We had waited too long for this baby to lose him now. I had lost two babies before this one; each died when they reached a certain weight too heavy for me to carry them and I would miscarry them. I decided this time when I got pregnant that things would be different. We talked it out and I decided to stop working during the 4th month of pregnancy since the 5th month had always been the times I lost them before. We had bills from the other hospitalizations and we were close to paying them off, and we needed my salary to help make ends meet, but this baby was more important, so I stopped working and stayed home to safeguard the pregnancy. Of course, my husband agreed because he wants this baby as badly as I do. Now that we have him and he's so sick, we are now having to agree again how we're going to get him through the rough times we know he's going to have. The only way is for us to put him first, after God, of course, but nothing else matters. So get used to seeing me here because I'm not going to leave here until he's able to go home with me.
>
> (Excerpt from field notes. Mrs. Munroe, 1982)

Commitment and dedication became full-time or sometimes part-time, costly activities for those parents who were determined to take very active parts in their infants' care and survival. This unconditional acceptance of being actively engaged and not passively sitting by watching others supporting their infants was a major condition that contributed to the assumption of the survival agents' tasks and it contributed greatly also to the positive outcome chances for each infant's survival.

Some parents were very slow to grasp the overall significance of the severity of their infant's condition or the part they could play in their infant's survival chances. Some therefore minimized their interactions with their infants as well as the professional caregivers (nurses especially) within the NICU. Some parents did not have an avowed stake in their infants, nor in their survival. In the absence of making a "claim" on the child, parents left a major portion of the work that the mothers did if committed and knowledgeable, in the hands of nurses, who in addition to their own nursing work, were then challenged to hook the mothers into the care activities of the nursery through a variety of strategies that will be discussed in another section of this dissertation.

However, this should be said here; within this study, two groups of parents existed in the sample population: (1) those parents who very quickly and without reservations connected with their infants and hooked themselves into the activities of the NICU and consciously designated themselves as significant interactants with all others similarly engaged within the structural context; and (2) those parents who, for various reasons, were slower at understanding, slower at accepting, who were holding themselves back and not certain if they really wanted to get involved; and as a result, had to be "pulled" into the contextural arrangement somewhat assertively by those other "natural" survival agents in the NICU, the nurses. Physicians also recognize along with the nurses, the significance of parental involvement in the overall interactional scheme of parent-child relationships. Therefore, by consent of all others within the NICU, nurses aggressively pursue those parents who are tentative and reserved in their actions and dominantly involved in the dynamic reality of their critically ill newborn infant's fight for survival.

Parents who are tentative, holding back, fit into the "maybe" category of those who sit and wait because they are not sure if they want to get involved. When these parents persist in holding back and not getting involved, one consequence is that someone else will have to take over that task. Nurses try very diligently to pull parents into the experience and take on the survival tasks. This entire technology essentially <u>requires</u> unpaid mother's servitude in order to function.

One example of the "maybe" parent is Mr. and Mrs. Leftcourt. Mrs. Leftcourt was an airlines stewardess with seniority due to her twenty years with the company. She became pregnant for the first time at the age of 39 years and was happy about the pending birth, having undergone aminocentisis and informed that she way carrying a healthy daughter, who would be delivered full term. Her husband was a 43 years old air traffic comptroller who looked forward to the baby's arrival. Mrs. Leftcourt acknowledged concern that she would need to return to work as soon as possible so as not to jeopardize her position with the airlines, especially her chances of becoming chief stewardess supervising over 50 other stewards and stewardesses. She had made arrangements for a live-in babysitter who would take complete charge of the infant during her absences. However, when the infant was diagnosed as having a severe heart murmur, Mrs. Leftcourt became hysterical and unable to be consoled by anyone. She would not visit the baby in the NICU, but chose to remain in her room. Mr. Leftcourt was torn between his emotionally overwhelmed wife and his critically ill infant. The nurses continued to visit Mrs. Leftcourt in her room and their attempts to persuade her to visit her infant were unsuccessful.

In the meantime, Mr. Leftcourt was observed watching his daughter from outside the nursery window and on several other occasions he was seen at the infant's bedside holding one of her hands and talking with one other nurse. Individual nurses worked with each parent, and on occasions one or more were seen talking to the couple in Mrs. Leftcourt's room. Mrs. Leftcourt remained in the hospital for six days recovering from a C-section and emotional exhaustion. The infant was to remain in the hospital upon Mrs. Leftcourt's discharge home. The nurses started taking Mrs. Leftcourt on walks around the unit, always ending up in the NICU. After several daily trips around the unit and into the NICU, some of her resistance relaxed, but she had not visited the infant since its birth. Mr. Leftcourt was invited into the NICU and he would offer information to his wife about the baby and eventually she started asking questions about it. The nurses didn't push but they were somewhat determined and persistent. The infant could not be held, but Mr. Leftcourt had progressed to the point where he was able to caress the baby and, though somewhat embarrassed, he would talk to her.

On one occasion, one of the tubes inserted in her left nostril and down in her stomach had become clogged, had to be extricated and replaced. The replacing of the tubes was visualized as offering some discomfort to the baby and Mr. Leftcourt asked and wasl allowed to remain in her room with the nurses during the procedure and together they comforted the infant while another nurse and physician replaced the tube. Mrs. Leftcourt, though she knew about the procedure, chose to remain in her room.

The nurses were continually amazed by her primary focus on everything but her infant. She complained often about having to face the fact that she would have to stay home with the baby because she was sure that no-one would want to take care of a sick baby, especially if it belong to someone else. She also complained about probably losing her promotion, which was never really promised to her but everyone had assumed that she was the most qualified one to move up the ranks to that position.

Mr. Leftcourt and the nurses continued to move Mrs. Leftcourt closer to her infant and on occasions she made some overtures that were interpreted as beginning connections. She started asking if the infant was experiencing any pain, if the infant had been given any of the milk she had pumped from her breasts, if any improvement had occured since its first of life, etc. These responses were encouraging yet no-one wanted to rush her, fearing that she might retreat if she felt pressured. By the sixth day, Mrs. Leftcourt was observed standing outside her infant's window for almost an hour, with her husband and a nurse pointing out certain features in and about the NICU. With continued support from her husband and staff, Mrs. Leftcourt began to establish some connections with her infant, and though she went home, leaving the infant in the nursery, she returned each day with her husband and eventually visited the baby alone; when the infant was discharged home seven weeks later, Mrs. Leftcourt had been completely "hooked" into her infant daughter's care and she was able to take an extended leave of absence from her position, which allowed her to remain home with her child indefinitely. She became completely dedicated to her child's survival and together she and her husband began a survival program that coincided with their infant's illness trajectory that was unpredictable. The infant experienced numerous readmissions to the hospital before she eventually developed a more manageable response to treatment. Her parents remained active participants in her care and the staff was thoroughly awed by the obvious changes that had occured in Mrs. Leftcourt's attitude and behavior towards her child.

Certain other conditions, as represented by the above discussion pertaining to Mr. and Mrs. Leftcourt, promoted tremendous variations in <u>who</u> can take on the tasks of survival agents. In most instances, a mutually agreed upon decision was reached between spouses as to how the division of labor would take place. There is a reality factor that all families face - there si a critically ill infant in the family, it needs a survival agent other than the hospital staff. Who will it be?

In my study, although there was a predominance of mothers who became survival agents, anyone can become a survival agent however, including a husband like Mr. Leftcourt, who marshalled his energies and emerged as the initial person in his family who could connect with, support, and act in behalf of the child during the critical phases of his infant daughter's emerging illness. Even though most mothers in my study emerged as active agents working for the survival of their infants, there are a variety of possibilities where individuals other than the mother are able to assume the survival agent's role, in part or as the major agent. These potential variations sometimes emerge in the mother's absence as an agent, i.e., due to mother's death or incapacity or unwillingness, and then the father may take over; or in the absence or death of the father, the mother and one or more persons may join forces and become a survival team; or in the absence or incapacity of both parents, then nurses and/or grandparents, older siblings or other relatives move into the agential role and function in behalf of the ill child.

In many situations, fathers and mothers worked in unison, with a very specialized division of labor agreed upon. When mothers did emerge as chief survival agents, they could not have done so unless they and others had not set up structural conditions that would allow and support such behaviors. For example, Mr. and Mrs. Jackson agreed that it was imperative that one of them remain in the hospital with their infant daughter to make sure that everything went well.

> Even though we never discussed it, we both knew that our baby needed someone to stay with her and help her through that process all babies like her have to go through. We agreed that I would stay in the hospital with her and my husband would take care of the other four at home. I called my mother who lives 25 miles away and told her how sick our baby was and I needed her to help us get through this. Both of my parents are retiredso they have time and they love our other kids so grandma coming to stay awhile was a treat and not a problem. My husband wanted us to not bother tehm but he needed my mother to get things in order so he could handle things. Because the baby was 6 1/2 weeks early, I hadn't planned how the house would function when I did deliver. My mother could get the house in order and then my husband could take over. Both were beautiful — my mother did the entire house, i.e., the laundry, some ironing, and she prepared a few meals and stored them in the freezer. When she left, it was completely on my husband, who really did a Trojan's job in taking care of the other kids, answering their questions about the baby, visiting me and the baby every day after work. He was beautiful and a real gem.
>
> He took extremely good care of everything at home, including cooking, washing, some ironing but not much. He would come to visit us in the hospital and there were times he would be so exhausted he'd fall asleep while we were talking. He never complained once about anything. He knew how I felt about everything and his loving presence was the tonic I needed when the baby would take a negative turn for the worse and I'd be scared that we would lose her. I know that I would not have been able to do it alone. I'm lucky and I'm just finding that out. He would take me home on the weekends and sometimes he would turn around and go back to the hospital where he would stay with the baby for hours or maybe all night long and then he would drive back home to us the next morning. That was the only way we could have done it and I know having my

> husband's support was a tremendous help, and I would have been a mess if I had been expected to do it all by myself.
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> (Excerpt from field notes. Mr. & Mrs. Jackson, 1983)

B. Summary

If it's true that anyone can become a survival agent, how is it that mothers tended to take on the management tasks as survival agents so frequently? What conditions made the assumption of this role possible? There are several broad structural conditions that may account for the occurrence of this phenomenon.

First, economics and finances tend to play an important part in this, primarily from the perspective that fathers' earning power continues to be far greater than that of mothers. In my study, most mothers who worked did so on a part-time basis; thus while already supplementing their husbands' incomes, they continued to spend, even on a half-time basis, relatively more time with the children than were their husbands. Because fathers' incomes were greater than the mothers in the majority of instances, it seems plausible that it would be more possible for mothers to give up their jobs and fathers maintain the family exclusively on his salary. When an ill child entered the family, mothers were more likely to emerge as the survival agent than the father. Where the division of labor within the family made this possible, mothers could assume the role more readily and without causing major difficulties that would threaten the economic survival of the entire family.

Some interesting observations in this study were made about certain fathers. Those who were unemployed/laid off, were self-employed or students, tended to spend more time in the nursery supporting their wives and infants to a much greater degree than did fathers who were employed full-time. Even though many fathers who were full-time employed were initially able to visit their infants during their extended lunch breaks, most indicated after a period of time they did not feel comfortable nor were they any longer encouraged to continue that visiting.

Second, even though there tends to be a move toward a less traditional approach to women's roles and men's roles, there remain cultural norms that delegate men the performance of certain tasks, and women the performance of others whether they wish to or not. Even though many fathers help out and lend a great amount of support, it is still traditional for women to take care of the children and fathers to work outside the home. Sometimes anything to the contrary may pose problems for some individuals.

> Mr. and Mrs. Payne were the parents of three healthy children ages 7, 5, and 3 years old, when their fourth infant was born with a severe heart defect. This infant experienced a difficult, experimental surgical procedure, developed complications and remained in the hospital for four months. Mr. and Mrs. Payne stayed in the hospital during the infant's first three weeks of life. It was decided by the staff that they should go home to their other children and return in two or three days and resume their work with their infant daughter. Two days later, Mr. Payne returned, having left Mrs. Payne home with the other children. When we talked, he stated that once they arrived home, they decided that

> they would resume their typical division of labor: Mrs. Payne was a CPA who worked for a law firm; Mr. Payne was a playwright who worked at home and consequently had the major responsibility for the rearing of the children. It seemed logical to them that Mrs. Payne would return to work, her unmarried sister who lived in the same town (Carmel) would live with them and take care of the children while Mrs. Payne worked, and Mr. Payne would return to the hospital and stay with the baby. Mr. Payne stated that this arrangement had been established the entire 16 years of their marriage, and their own respective families never quite accepted or understood their style. On the weekends, Mrs. Payne and the other children would drive to the hospital for a visit and Mr. Payne remained with the infant until she was discharged home.
>
> (Excerpt from field notes, 1981).

Third, there is a cultural norm that suggests that even though both parents are responsible for the welfare of the infant, the reality remains that the mothers gave birth to the infants, therefore the mother is seen as responsible for her child. There is an expected cultural norm that mothers bear the majority responsibility for the infants even though fathers may help out. There are expected maternal roles as well as there are expected paternal roles that are defined and generally agreed upon. In the families that I interviewed, this is the way that they saw this occuring.

Fourth, there are some pertinent interactional conditions going on in the nursery, namely, that mothers are there, most of the time, and there are few if any forces that can get her to do otherwise. As a result of just being there, a great deal becomes hers as a consequence. Even though they may not address it directly, nurses and all others in the nursery relate to the value of having a parent or family member available, especially because of the emotional-psychological component that addresses the infant's biographical relevance to the family. The staff is willing to bring anyone that's available into the management work that's related to the infant's survival. In some instances, mothers and fathers remained in the hospital full-time, or fathers relieved mothers by coming in after work and spending the entire evening or a major portion of the evening. In those situations where the parental work of managing is shared, the staff related to the most available person at the particular time. In the majority of situations, the mothers and fathers sometimes worked in unison, with the division of labor distributed and sometimes agreed upon by the spouses in the experience.

Even in those instances when mothers took on a major portion of the survival work, it would be impossible for them to do this unless there were conditions set up that would allow or require it. If fathers did not manage the family members at home, mothers could not remain at the infant's beside with the regularity that emerges. Someone, be it a neighbor, relative or another child, stands in the background and supports the work efforts of the agent who remains in the hospital with the infant.

IX. Conditions for Becoming a Survival Agent

As mothers of chronically ill infants with congenital heart diseases interact with physicians, nurses, social workers, technicians and other hospital staff, they are constantly bombarded with the multiple realities and life and death within the intensive care unit setting. Parallel to the staffs' enactment of a trajectory projection scheme based upon the results of numerous tests and other diagnostic laboratory procedures routinely performed upon each infant, the mothers are able, through the information shared and the observations they make of the environment and its inhabitants, to begin to establish a biographical/developmental projection and scheme of what they can and must do in relation to their infant's overall needs as those relate to the medical/physical realities of its cardiac condition.

The illness trajectory scheme developed by the medical team and the biographical/developmental trajectory and scheme developed by these mothers interplay and intersect on a continuous, dynamic level. The medical work and the biographical work performed by staff members and mothers respectively, are developed around tasks that focus primarily on balancing the multiple risk factor by maximizing the chances of survival (staff) and minimizing biographical/developmental trauma (mothers). It is necessary for mothers to accurately perceive the degree to which their infants are at risk during each phase of the illness trajectory and simultaneously take action which enhances their infants' chances of physical survival while minimizing any emotional trauma from illness trajectory work that may have eventual impact on its future social-psychological development.

The next section will describe in detail: (1) the specific conditions and properties of the dynamic interplay that takes place during the interactions between the mothers of these critically ill infants and the attendant hospital staff; and (2) how mothers come to take on the work of survival agents and align their maternal management efforts with those of the health care professionals to bring about their desired mutual and respective outcome.

A. Illness Trajectory and Developmental Trajectory

Numerous factors, including the age and level of newborn development and the specifics of the cardiovascular condition present, determine whether or not a positive survival outcome can be achieved for each infant in the intensive care unit. In order for these multiple conditions to be controlled, they must be effectively managed in a conjoint effort of tasks sharing between mothers and the hospital staff. Neither can work independently of the other. The interactions that evolve between them have as their primary focus the development of a management scheme that defines the areas of work to be accomplished by each management person, commensurate with the levels of risks and type of trajectory or developmental task to be accomplished as well as the levels of skills of the individuals involved.

As mentioned earlier, Strauss, et. al., (1984) state that the term "trajectory" refers not only to the physiological unfolding of a patient's disease but to the total organization of work done over that course, as well as the impact on those involved with that work and its organization. Strauss further states that it is also a means for analytically ordering the immense variety of events that occur as patients, kin, and staff seek to control and cope with the illness.

The effectiveness of contemporary medical technology has led to infants surviving longer than they did five or ten years ago, leading to what may be called trajectory "stretchout". As a consequence, now medical, organization, biographical problems develop, which require newer and more expansive management problems for everyone involved. To deal with these problems, parents and staff engage in a "balancing act" in which every aspect of management is synchronized between them in order to maximize survival and minimize trauma, goals that each side will recognize.

Managing an illness trajectory begins when the definitive diagnosis has been made and the physical problems identified. Once the diagnosis is made, the physicians and others develop an understanding of the illness and its potential course. As a result of its combined experience with other infants with the same or similar set of clinical symptoms, the medical team is able to map out a trajectory projection and a trajectory scheme (the interventions) to manage the illness trajectory for each infant. This includes an understanding of the sequence of potential events and related activities to be performed.

Infants in ICU settings are totally dependent on physicians and other staff members for discovering significant signs and symptoms that denote problems and potential problem areas. This is very different from adults, who for the most part are participants in their own care and treatment, because they are able to identify changes in symptoms and to articulate them to appropriate staff members. This total dependency of infants requires continuous collaboration with and communication between all team members involved in care child, including mothers and other kin. The infant's total dependency upon the diagnostic accuracy and reliability of its care takers necessitates the work within the unit be organized in such a manner that it supports the efforts of the medical team. It also requires equally definitive laboratory/technical back-up.

Cardiac conditions in infancy require great flexibility in the medical work, they are often unpredictable. In most instances, this unpredictability requires that those engaged in the care of the ill child be flexible in their approach to management, and to make changes according to treatment regimens as necessary. This will likewise require a shift in focus of the work as well as a shift in who performs that work. Chronic illnesses are such that diagnostic locating and mapping are continuous and evolving. Not only is the condition rediagnosed, but the work of management may be reassigned based on the skills needed at that particular time. The plan of action is redefined and renegotiated as the illness unfolds and designated personnel redefine their tasks based on the change in the trajectory and any related contingencies that arise.

The mother's survival work in this division of labor includes monitoring virtually everything that's done to or on behalf of their infants; also monitoring the number and complexity of the tubes and machines used in a pediatrics ICN. As noted earlier, several mothers stated that they became more aware of the seriousness of their infant's condition when they really "saw" the number of tubes and equipment necessary to keep the illness trajectory and related problems under control. For example, Mrs. Mason had appeared somewhat oblivious to most of what was happening to her infant son in the ICN. She remained in the hospital most of the time, periodically going home for brief periods. The seriousness of her child's condition had been explained several times to her, having no apparent impact. I had attempted on several occasions to talk with her about the infant's slow progress and the doctors concern about his poor weight gain. Mrs. Mason persisted in thinking that everything was simple and safe and she took her afternoon break with another mother on the unit. As they were sitting and sharing their day's experiences, Mrs. Mason noted two technicians speedily entering the ICN with four large machines. She commented to the other mother that the infant who needed so much machinery must be in real trouble. They continued to sit until Mrs. Mason stated that it was time for her to return to her infant's bedside. She stated to me later on that day that much to her dismay, the infant who needed so many machines was in fact her own infant. From that point on until the child was discharged home four weeks later, her behaviors were appropriate to the child's serious condition. She talked more with the nurses; she asked more specific questions; she spent more time with her baby and less time doing other things; i.e., making coffee for the nurses, chatting with other mothers, taking long and frequent respite breaks. These then, are some of the survival work consequences of being brought into the necessities of it through the medium of the machines.

Leading to their willingness to act as survival agents in the following, most mothers acknowledge that once they are able to move beyond their initial feelings or sadness over the defect, they are able to see the struggle their child makes to survive. This also helps to bring them to awareness of their place in the division of labor. A crisis helps that awareness.

> John was my third child and each one was a difficult birth. I heard the doctors when they said he had a heart problem, but, then all of my children had something; one has asthma; one catches colds all the time, and the other one is in and out of the doctor's office because she's always having accidents, cutting something or other, so I thought John was like the rest; he would outgrow it and be fine just like his brothers and sisters. But that all changed for me when I saw how hard he has to struggle for breath. When

> they removed his respirator just for a few minutes so his throat could be cleared, he turned blue and looked horrible. My first thought? It's true; he is sick and he could die. We were in for a time and I know it was serious and shouldn't be taken as lightly as I had. It scared me, but it sure opened my eyes.
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> (Excerpt from field notes, Mrs. McCohee, 1982)

Other conditions that lead to awareness include the fact that during this period that mothers eventually "received" the shocking information that their infants' cardiac problems are such that its ultimate survival is of concern to the total staff and that they had work to do to ensure their child's survival. Mrs. Johnson called her husband immediately after she had witnessed her infant daughter's fight for breath during one of her pulmonary treatments. She stated that her child looked so helpless.

> She was so little and her entire body shook drom the experience of having that tube forced down her throat. I was so angry with the nurse who did that, but I later found out that it was necessary to do, or she could have had brain damage, or worse, she could have died. Once I got over the shock and calmed down, I called my husband and told him that he had to pack a bag for me. I wouldn't be coming home, she needed me and I had to help her and somehow I would figure out how. But at that moment, I had seen how frightened she became when they did that to her and I decided not to leave her but to help her as best I could.
>
> Excerpt from field notes. Mrs. Johnson, 1982)

The tasks they needed to do and how they are going to perform them emerge as the illness trajectory progresses, and in relation to the work of others. At this early stage, mothers are not certain about what the exact nature of their work will be; however, for the most part they accept the trajectory scheme as articulated by the physician. This recognition occurs as a consequence of their gathering of information through multiple interactions with staff and other mothers in the unit. Eventually, these mothers become more astute about their infants and the seriousness of their conditions. As they become more aware, they begin to realize there are specialized types of work for them to do for their infants that no one but they can do as developmental survival agents. And that the work they do in relation to their infants greatly impacts upon the overall outcome for each of their infants in the ICU setting. The types of work include tasks aimed at ensuring their child's social/psychological, intellectual as well as physical development. As such they become <u>development</u> survival agents.

Mothers become concerned about their infants' overall development. When they weigh the multiple risk factors that can compromise their child's development, from there they proceed to assess the degree to which their actions with and on behalf of their infants might benefit their present and long-term development and then take action that may prevent or minimize a developmental lag.

B. The Various Types of Mothers As Survival Agents

Mothers as survival agents are not alone in their efforts to enhance their infants' survival, proximal and distal. The health care team's illness-related tasks include the giving of appropriate medicines at appropriate times — carrying out technical procedures, i.e., x-rays, blood pressures, temperature taking, EKG's, EEG's, catheterization, echocardiograms, etc. Nurses' illness related work includes providing physical care and maintenance, monitoring and assessing infants' responses to all treatments, keeping records of all medicines given and each infants' reactions to them, and relaying pertinent information to physicians as it relates to infants' progress, improvement, deterioration, etc.

During the early phase following the infants' birth and the diagnosis of the cardiac conditions, nurses' tasks include feeding (in a variety of forms, depending upon infants' physical state). Many of the infants are very difficult to feed, and nurses have to gavage feed them by pushing nourishment through a tube directly into their stomachs via mouth or nose. The nurses have to be careful that they do not overload the infants as they push the fluids. In most ICN settings, one infant per nurse is considered ideal and mandatory, due to the infants' level of functioning and their overall high-risk status.

As the illness trajectory unfolds, mothers begin to establish some tasks for themselves to perform that are independent yet supportive of those performed by the health care team. As the treatments and diagnostic procedures continue and mothers perform the work of supporting their infants by comforting holding the child's hands during procedures and treatments. Caressing and loving their infants are tasks that mothers relish with delight and anticipation, especially when their infants have been restrained in isolettes and attached to numerous tubes and wires. Though some mothers are frightened by the tubes and hold back on comfort tasks, others will not allow restraints, lines and tubes to restrict or inhibit their comfort work with their infants. Because infants cannot inform staff or mothers when discomfort and pain occur, certain procedures and treatments are historically known to have been painful to older patients due to the kinds of treatments performed. It is on this basis that mothers will ask to be informed when certain procedures are to be performed on their infants. Some mothers will also ask to be present to comfort their infants when certain nurses or technicians have been scheduled to do certain procedures or treatments.

Receiving medicines through "shots" and taking blood samples via needles have been viewed as painful by most individuals. The development of arterial lines so that all medicines can be administered from one source, came about as the result of the recognition of pain and discomfort patients experienced by the previous act of numerous "sticks" before a successful tapping.

For some infants the trajectories become stretched out, therefore requiring more tests, more treatments, and the continuation of discomforting, painful experiences. Mothers of these infants tend to become concerned about the effects of these long-term, persistent episodes of discomfort. Their comfort work emerges as a specific task that they accept as theirs, recognizing that to some degree, nurses and others may also provide comforting actions to their infants, but the intensity is not the same because the infants belong to the mothers and not to the nurse or others.

Another type of work performed by mothers of critically ill infants in the ICN is focused on minimizing trauma, to the intellectual potentials or the infant. Mothers recognize that children in a normal environment require emotional/environmental situations that promote and stimulate their intellectual development. An infant who spends much time in an ICN, most of all a child whose illnes trajectory may be streteched out indefinitely is at risk of having the intellectual developpment neglected to some degree. Mothers of these babies move into action by attempting to make the environment more intellectually stimulating by providing cassette taped music that is comforting and soothing. They also build multicolored mobiles and attach them to their infants' isolettes. Mothers have also brought in tape recordings of their own voices or those of the fathers and siblings reading stories to the infant. These mothers also ask the nurses to play these tapes, including the ones with music, at certain times of the day or evenings during the mothers' absence.

Mothers also use brightly colored infant blankets as another course of intellectual stimulation for their infants. Mrs. Johnson was very adamant in her request that she be allowed to change her infant's isolette everyday, especially replacing the blankets, which were always handmade but always a different color. Her two other children, seven and eight years of age, had been stimulated in this fashion as normal children without contingencies. The staff was willing to support her request and the isolette was always colorful and cheerful.

C. Shifting Divison of Labor

The organization of tasks involves recognition by mothers and staff members of those tasks which are more appropriately performed by one as opposed to another because of the nature of the work associated with that specific place in the trajectory phase into which the infant's care has moved. Strauss (1984) indicates that since trajectories extend over time, they have phases. As a result of the medical staff's experiences with hundreds of patients, they can anticipate the overall work that needs to be done, beginning from point of diagnosis through to various therapeutic interventions. Strauss further states that a trajectory point sequence is reached whenever a decision is made as to what should be done and when. The trajectory point cluster has a sequential ordering and an organizational base that allows them to be carried out.

During the early diagnostic phase, physicians and nurses perform specific tasks to determine the exact nature of the infants' cardiac state. They utilize all types of diagnostic machinery to assist them in arriving at a definitive diagnostic, as well as to determine what treatment modalities they will have to activate. Most infants are critically ill during that first state of the illness. Therefore mothers tend to leave medical and physical tasks involved in care of their infants up to the staff while they perform the tasks of comforting and supporting their infants. Mrs. Jamison and Mrs. White are examples of two usch mothers.

Mrs. Jamison acknowledged that the nurses were more skillful at doing the numerous tests her baby needed four times daily and she could comfort and console him later on when every treatment was complete, while Mrs. White insisted on remaining with her infant during his treatments, holding his hand and talking softly and reassuringly to him so as to distract him from what was happening to him.

Most nurses align their actions with the mothers' by recognizing the mothers' plight and completing their tasks as quickly as possible so that the mothers can proceed with their comfort work.

Some mothers could not tolerate being present during certain procedures and would ask the nurses to take over their usual tasks of comforting and talking to their infants during these procedures. This would occur especially if they felt the nurses cared about their babies. For example, Mrs. Bacon and her infant's primary nurses had become very close during her infant son's eight months' hospitalization. Mrs. Bacon was most comfortable when these particular nurses were on duty. These nurses had demonstrated to Mrs. Bacon that they cared greatly about her baby, and as a result, she was not reluctant to leave him in their care.

When the nurses feel in control of the infants' condition and sure of the mothers' abilities, they usually encourage mothers to spend more time visiting their infants and taking on some of the responsibilities for its physical and medical care. Nurses attempt to meet mothers wherever they are in relation to their assureness levels and their ability to "take-over" the specific management tasks. As the infants' condition continues to improve, the nurses give more and more responsibility to the mothers, including feeding, bathing and where possible, changing and dressing the infants.

However, during crisis periods, when the infants' conditions were out of the control of the medical staff, mothers are forced to retreat into the background while the staff moves forward into the foreground to perform necessary life-saving work. The trajectory work at those points involved redefining the illness status and establishing new tasks to be done based on new diagnostic findings. Some mothers, those who are not frightened of the physical situation, or the infant, are encouraged to resume their work activities with their infants, while other mothers are encouraged to retreat until better control is achieved and the infant's physical condition is more manageable and stable.

For almost all mothers the intensive care nursery experience is a new one. Nurses take on the task of "molding" mothers into their roles as parents of chronically ill infants with serious heart problems. Nurses monitor and assess mothers' capacities and skills and then, based on their assessment, provide experiences that will enable mothers to learn their management tasks gradually in some order or sequence. With assistance from the nurses, mothers gradually become comfortable entering the nursery with all of its overwhelming, noisy machines, meet their babies for the first time, touch its finger, gradually moving to its hand, then its body; learn to watch what's going on for information that will be useful later; learn to ask questions.

Later when mothers gain a level of confidence and skills, they are further brought into the survival agent role by further assistance and support from nurses. Mothers are gradually able to hold their infants comfortably and administer some forms of treatment, even if nothing more than putting liquids in the feeding tubes so as to enhance weight gain. In other words, parental readiness to take on more tasks or the desire to relinquish all or some taks is monitored and assessed and handled accordingly. Timing is quite important; if staff feels mother is unready for the next level, and she insists that she is; if mother feels unready but staff insists that the time has arrived, then a compromise decision has to be reached. Parental readiness and trajectory phase have to be in synchrony. It is on this basis that some determination is made as to who does what tasks, when those tasks will be done, how and with what consequences. There is a continuous "balancing" going on, wherein every aspect of the illness management effort is focused on organizing the medical work of the staff with the parental work of the mother so that everything meshes together in the infants' best interests. This balancing act, which includes the workers' monitoring and assessing the appropriateness of each other's work, is supported by a continuous, purposeful interaction between mothers and staff. This interaction work is dynamic and necessary.

Mothers also assess and monitor the nurses in their work with the infants. They look for evidence of competency in nursing skills, their ability to manage the safe use of the life support machines, and their ability to interface with the physicians in reporting and charting the infants' responses and reactions to treatment interventions. Mothers also assess and monitor nurses affectional responses to the infants and the extent to which the nurses connect with each infants emotional needs. Mothers assess nurses' emotional attachment activities with the infants, and they can therefore determine which nurses are better at the technical work or not so skilled in the emotional work.

Even though the unpredictability of congenital heart diseases remains a major management problem, the dynamic interplay between trajectory workers (mothers and staff) has at its focus "shaping" the trajectories so as to maintain some elements of control through a division of labor of tasks that enhance the survival when there is a thorough understanding of the illness trajectory and the sequences that will unfold, in problematic situations contingencies occur which interfere with and upset the balance achieved.

When mothers take on the work of participating in the management of the trajectory they are usually sharing in the shaping of the trajectory and when problems of deciding or discovering which of several options to take, mothers may have a significant impact on the decision reached. Strauss (1984) points out that since particular decisions about options at critical junctures points can profoundly affect the shape of the trajectory, it is well to think of these decisions as potentially very fateful. As an example of a mother's role of shaping trajectory is seen in the case of Mrs. Baker who under conditions where she felt the physical survival of her infant was threatened took on the role of the child's advocate and negotiated with the staff a change in trajectory schemes.

Mrs. Barker's infant son's condition had been extremely problematic from the very beginning. She had decided quite early into the trajectory scheme that she would go all the way with her baby, doing everything necessary to help him and the staff help him survive. As the trajectory unfolded, it was determined that only one surgery procedure was available for his condition and it would be used as a last resort, when all else had failed. Several drugs were offered and used and the baby responded well but without any major changes in his overall state. Mrs. Barker spent all of her time with her baby, relieving herself only for brief walks outside the unit or trips to the toilet and cafeteria. She was very helpful to the nurses in caring for her baby and they allowed her to assist them in changing his dressings and sometimes in repositioning his numerous lines and tubes. It had been decided that after several drugs had been used, the infant's situation would be re-evaluated and any changes would be indicated at that point. The child's condition had worsened and Mrs. Barker knew it, and in fact had mentioned to the nurses that she thought that the newest drug had been started too soon before the previous one had been given adequate time for the appropriate response. When the nurses shared this with the physician, it was his opinion that Mrs. Barker was unable to make such an observation, nor was it her place to evaluate the situation. When Mrs. Barker was informed of this, she proceeded to invite herself to one of the case management meetings, having been alerted by the nurse that the meeting was being held. She apologized for intruding but did not apologize for standing up in behalf of her baby, whom she thought was not being treated fairly. It was obvious that she knew her child very well; she was quite astute about how the course of treatment had been established, and she was concerned that her comments were not at least listened to, since she had been included in all aspects, seemingly as long as she went along with the decisions reached. She unfolded for staff all of the reasons that had previously given to trying her baby on the drug regimen and her copious notes verified the plan of action leading up to the critical point of when they would no longer work. The newly proposed surgical procedure was considered a last-ditch effort after all medications had been exhausted. It was Mrs. Barker's thought that stopping the medications without knowing if the last one would work or note seemed to be compromising her baby without giving him all of the chances he had. She understood if the medicine worked, it would get the desired effects and even though he would have to be on them the rest of his life, that appeared to offer more hope than the surgery, which had not been used before and the immediate benefits could only be speculated.

The nurses assisted Mrs. Barker in her role as child advocate by interjecting that they had noted some improvement and promising changes in the baby's condition; with each new medication his strength improved and his lung capacity increased to the point that he was able to tolerate being disconnected from the respirator for longer periods (Mrs. Barker had begun to hold her baby more now that he could be on room air longer without problems). The nurses joined in with Mrs. Barker in requesting that they allow the baby more time on the medicines and reserve the surgery for a later time when everything else fails and Mrs. Barker wishes to go for the procedure.

The physicians were divided in their opinions on how to proceed; some thought that the longer they delayed the surgery, the slimer the baby's chances of handling it because of other problems created by prolonged use of the drugs; others thought that if the meds worked, the certainty of his survival for a longer period of time could enhance his chances for an improved quality of life for a period of time. Mrs. Barker stated that she and the family understood the reality of their child's chances forwere small and that he could not survive with the number of problems with his heart and lungs. For them, surgery was seen as another painful experience without any measurable benefits that the surgery would work and his problems would be resolved, then they would have no trouble making the decision. They knew that they were going to ultimately lose him; surgery would possibly hasten that reality, while the medicines could prolong his chances for them to have him a little longer. They wanted him at any cost but not at the expense of increasing his agony and not his quality of life.

The final decision was to monitor the baby moreclosely on all medications and to check his reactions and overall responses to them. It was also decided to move more cautiously while assessing how smoothly the infant adapted himself to the regimen. Mrs. Barker informed the staff that she had noted that her baby always experienced two straight days of elevated blood pressure before he would ultimately reject the medicines. She wondered if smaller doses would extend the period of time he could use the medicines. It was her opinion that the dosages seemed extremely high, considering his history of drug intolerance. The chief resident concluded that they should have a conference with the pediatric pharmacist and discuss more fully an individualized drug regimen that could take into consideration the comments made by Mrs. Barker.

What are the general points then brought out by Mrs. Barker's case? Managing an illness or biographical trajectory involves the organization of numerous tasks by many individuals. Mothers, as one set of primary workers along with the staff, in the management of tasks relating to the overall survival of their infants, position themselves strategically within the ICN, in order to carry out the role of survival agents, as dramatized by Mrs. Barker's interactions with the nurses in the unit. She assumed an active position in promoting her awareness of her infant's condition as she perceives it, an at-risk infant needing her advocacy and support in his behafl; this case also illustrates the division of labor and the sequence of tasks and the part that Mrs. Barker played in shaping the trajectory scheme along with the nurses and physicians. It also brings out the reality that trajectory work is closely linked with trajectory phasing. The two go hand-in-hand.

Mrs. Barker's work as patient advocate was just one more aspect of her work as a survival agent. Just as she aligned herself with the nurses as part of her strategy, she aligned herself with her child and defined her task as doing him those things that he could not do for himself. Her advocate work became a condition for his survival, just as his alignment with the nurses took on the same significance.

Mrs. Barker and many of the other mothers acted as survival agents through their continuous mother-infants interactions. These mothers monitored their babies so closely that they became finely tuned to their baby's needs. In doing so, they became sensitive to cues that only mother's astuteness and attachment to the child could detect. This ability to assess and interpret baby's cues is another condition for infant survival. Often, mothers shared their observations with the staff, recognizaing that they were deficient in those cues in which only she had established knowledge of through her identity with her child. By means of her sharing of this knowledge they were then able to participate in thos aspects of survival work that are normally performed by mothers. Thus, by each staff and mother sharing in their specific knowledge of the child's medical, socialpsychological needs, they both were able to share in carrying out tasks normally belonging to the other.

Mrs. Barker's level of awareness was such that she had processed the realities of her child's situation to the extent of knowing that all efforts made in his behalf were only serving to slow down his ultimate death. Her goal was to help the staff keep her son alive and well as long as possible, adding some quality of life to his existence through her bonding/attachment work, and a conscious use of herself as his primary link with his father and brothers at home and other kinfolks.

X. Biographical, Interactional, and Sentimental Work

Strauss, et. al., (1984) states that sentimental work is presently an ingredient in any kind of work where the object being worked on is alive, sentient, reacting either because it's deemed necessary to get the work done efficiently or because of humanistic consideration. Infants with severe congenital heart defects find their identities challenged and compromised from their first day of life because their illnesses require that they be separated from their loved ones, sometimes whisked away from their mothers soon after birth and hospitalized miles away. The problems do not go away nor are immediate solutions available.

The mother-child separation experience creates a new set of conditions for the child's existence and the mother's, along with the members of the family. In the presence of a severe chronic illness, numerous conditions previously unknown to most members of the family impinge upon it and a new identity of family of a sick child and a child with a cardiac defect emerges for them <u>and</u> for the child.

Identity work takes several forms. It includes sentimental work by the mothers of the infants whose emotional attachment and bonding to the infants defines the infants as primarily their, and the loving affection expressed is grounded in that reality. When mothers were observed doing their comfort work with their infants as painful procedures were being performed by nurses and physicians, their acts of love and affection were genuine and done specifically to express feelings that could only be transmitted by them as mothers.

Nurses also bring in pictures of their own children, and on occasions give to these mothers clothes and toys their own children had outgrown. This behavior had the result of furthering the nurses' own medical work with the infants via the mothers' support and compliance.

The biographical work performed by mothers is grounded in the awareness that there is more to their infants than a physical condition; the child also possesses a psychological/emotional that is their responsibility to protect and enhance. Most of these infants have families including brothers and sisters, grandparents, etc., and the parents have close friends who share in the family's overall biographies. Mothers visualize their infants as having families and being in need of some form of connectedness. Their chronic illness and long-term hospitalization created a biographical interruption which mothers attempt to overcome by their presence and sentimental work tasks. The biographical information that the mothers posses causes them to act differently since after all they and their infants share the same identities.

One form of biographical work is identity work. For most mothers it has special importance. Mothers recognize that their infants could suffer permanent psychological trauma as a result of the long-term illness and its contingencies.

Thus, Mrs. Stone was certain that her child needed her presence in order to survive the ICN environment. She could remember her own early hospitalization as a five-year old, and the trauma she experienced then. Her hospital stay was only three days, but the memory remains vivid in her mind to the present day. Her baby had already spent four weeks in the hospital, and he had been poked at and stuck so many times his little arms looked like a pin cushion. Being with him and helping him through the bad times was seen as one of her basic reasons for staying in the hospital with him.

Because the infant's psychological self is so threatened, these mothers view themselves as primary in developing for these infants a healthy identity while experiencing the realities of their illness and hospitalization. When mothers engage in identity work it is accomplished through their close relationships and identification with their children. This work takes on special significance because of the nature of the relationship between mothers and their infants; this is very different from the staff's somewhat distant and removed perspective, when the identity work is done primarily to enhance their trajectory work.

Mothers actualize their own identity work with their infants by establishing real and symbolic images and connections for their infants that identify their basic family, its members, and the importance each has for the other. Mothers bring in pictures of the father and other siblings at home, and pictures are taken of the infants and sent home to the family. In most ICN units, there are age restrictions placed on visits by well siblings; however, some mothers have been able to convince staff members that rules could be bent to accommodate their wish to enhance their infant's identity with other members of the family.

Mrs. Alden had mentioned several times to the nursing staff that she was concerned that her five-week old infant needed to have his two brothers visit him because he should have been home and he was long overdue. Mrs. Alden also was concerned that unless her sons saw the baby they would stop believing that he existed. Their baby needed their love and energy to grow on. The staff stood adamantly behind the rules and refused the visit. The nurses indicated that the baby was progressing well but slowly; however, within two weeks or so, he could be transferred to the next level of intermediate care, and there they would place his isolette next to the window where visitors could see him; the brothers could not come into the unit.

Mrs. Alden could not wait two or more weeks so she talked with the evening nurse who had taken care of the infant his first two critical weeks after birth. This nurse understood Mrs. Alden's concern; however, she could not alter the situation. She did remember that they baby's isolette was closer to the well-infants unit, which had a parents' room where mother could nurse their infants in privacy. The nurse suggested that over that week-end two infants would be transferred home and housekeeping would be cleaning those vacated stations and in the process of the shifting around, if Mrs. Alden's two sons and her husband were strategically waiting in the mothers' room, she would personally bring the baby in for a very brief visit, with all of his tubes and monitors.

This rendezvous was successfully carried out and the reputed visit was a complete success. Mr. and Mrs. Alden's two sons were able to see their baby brother in his illness reality, which made all that their parents had told them very real; they were able to briefly play with him, with some reservations because of his small size; they could comment on his resemblance to them or someone else in the family.

Mrs. Alden stated the following week that she was able to acknowledge that their brief visit with the baby meant so much to everyone, and especially the baby who seems stronger and more alert. She would credit this totally to the visit, however, she did believe that with her continued presence and interactions with her child, the feeling of connectedness (identity) must be there in his little being. Her sons had made cassette tapes of themselves singing and reading stories to him. She and the nurses agreed that it would be fine if they could play the tapes periodically for him. After several playings, they noticed that a certain kind of recognition occurred when he heard his brothers' voices. He knew them and they knew him.

Everyone's identity had been enhanced through the efforts of Mrs. Alden and empathetic nurses who understood her concerns for her child's proximal and distant identity.

Mothers can also be instrumental in promoting identity work by structuring interactions between infants and their fathers, who may wish to connect but be somewhat unsure about how to do it or if it has any significance or value at that point in the child's life.

Mrs. Morgan was concerned how her infant son's identity with his father would be damaged if she did not find ways to facilitate their relationship. This child's cardiac condition was quite serious, and he was required to spend five months in the ICN. Mr. Morgan worked days and spent his evenings caring for their three other children. Mr. Morgan would take Mrs. Morgan home on Friday evenings, and she would return to the hospital late Saturday evenings. When their infant was one month old, Mrs. Morgan discussed her concerns with her husband and decided that after he had taken the other children to school, he would join her at the hospital, and they would share in the care and the ultimate identity work necessary for their baby's psychological health. Eventually, Mr. Morgan became comfortable in handling and holding his son. It became clear to Mrs. Morgan and the staff that the baby knew Mr. Morgan had entered the ICN before he said a word. The baby would move around and make sounds that he only made when Mr. Morgan was around. Mrs. Morgan stated that were it not so beautiful, she could become jealous of the recognition that her baby was with his father. However, she's aware that he's of who and what he is to them, and that's the important thing.

Interactional work between mothers and staff members, especially nurses, is another example of the crucial division of labor that becomes a necessary condition for the survival of critically ill infants in ICN units.

The mother's work as life-agents includes working with the staff in such a manner that their infants are rendered more sentient and the staff is obligated to become more human in its interactions with and in behalf of those infants. As the mothers come to understand and accept the proposed medical trajectory scheme, they become more aware of their tasks as opposed to those of the staff and as their interactions become more routine they learn that they too must learn enough of the medical work so as to understand the realities of the illnesses present and to take on those tasks that comfortably fit into their abilities. The mutuality of their work tasks become clearer where staff is encouraged to be more human and more personal as they provide medical care, and mothers are encouraged not to become medical personnel but rather to increase their level of knowledge of the medical work to be done.

Mothers and staff share information back and forth between them as they interact in behalf of these chronically ill infants. Mothers share more biographical information about their babies and look for evidences of comfort work and sentimental work in the staff's interactions with the infants. Staff members share medical information, encourage parental involvement and participation in taking care of the babies, and look for parents to be able to understand when certain phases or critical junctures occur and the astuteness to understand which tasks are primary and who is the most skilled person to perform the tasks. The interactional work is continuous and dynamic, requiring communication and mutual respect.

XI. The Interactional Work of Mothers and Health Care Professionals

Something special and unique happens when the mothers and the health care professionals join forces to enhance the overall survival of these children within the highly structured, extremely technologized world of intensive care nurseries and units. This "something" is more involved than the mere mutual sharing of pertinent information; it involves more than just communicating facts and figures regarding the uses and the benefits of certain medicines; it is more than explaining intricate procedures and elaborate and expensive treatments.

What this "something" does involve is the coming together of individuals (workers) faced with a specific problem, who, by virtue of their respective investments and areas of expertise, recognize that their conjoint efforts present the greater possible set of conditions for the successful amelioration of factors that could greatly jeopardize the survival of infants with life-threatening conditions.

This interactional work that occurs between mothers and staff within the setting of the hospitals' intensive care nursery highlights the dimensions of management tasks and the problems that develop as they work to maximize the infants' chances of survival, while minimizing the emotional risk factors inherent within the cardiac conditions experienced by the infants. This management work is quite complicated and the conditions are so multiple that mothers cannot accomplish them along and they must join active forces with the intensive care nursery staff.

When critically ill infants and their mothers enter the health care system via the ICN, this natural interplay between mother's work and staff's work begins. It is within this highly structured setting that their organizing scheme develops, where strategies and tactics develop for managing the survival work that both must share. This joint management effort or scheme is organized within a setting that can make it very difficult for mothers to truly share in the managing efforts that they desire to actualize. This reality therefore requires them to develop strategies with the nurses so that their mutual work of minimizing the imposed risks through maintaining some influence over the overall outcome. The interactions between mothers and staff develop into a necessarily meaningful component of the management process.

One particular major condition within pediatric intensive care nurseries that supports the development of an interactional scheme between mothers and staff is the size of the staff and the staff's open-ended amount of time available to each infant. In other areas of the hospital, namely adult ICU, because of large numbers of patients and the short amount of time alloted each patient, the staff concentrates most of their efforts on managing primarily the physical aspects of the patients' illness. The emotional/psychosocial needs, though recognized as important and relevant, are generally neglected or seen as the supplementary of exclusive domain of family members and friends. In pediatric intensive care nurseries, the staff members as caring agents are relatively knowledgeable about and experienced in providing care to meet the total needs of patients, which include comfort and sentimental work.

A particular set of conditions where the interactional work of mothers and staff are most challenging is when those "maybe" mothers have to be pulled into the work of being survival agents. When these mothers falter in their assumption of those tasks deemed necessary for their infant's survival, there are dire consequences for everyone concerned. When mothers do this, they are basically relinquishing their rights to be their infants' survival agent. They are of course licensed to do this work by being the infants' natural mother. To abdicate that responsibility is to give that license to someone else, i.e., the husband, grandparents, or the nurse. Yet no one ordinarily can do the mother's work with the same degree of intensity, commitment or dedication. Others may find respite through other means but the mother's work as survival agent is continuous. Because nurses know how important it is for mothers to take on this work, they establish a variety of tactics to get them hooked into the process.

Mothers are under tremendous pressure to come to terms with some very difficult realities very soon after the births of their infants.

The infants are not what they planned for: they are not healthy and they are critically sick. Their plan was to have a healthy normal baby, with some minor problems, but nothing like their present situation, where it is still uncertain if their infants would survive. Mothers are required to reconcile and revise the biographical projection of their "fantasy baby" with the realities of their babies' situations. The infants are not what they expected.

Those mothers who cannot or do not readily "take-on" the tasks of a survival agent, retire to the fringes of the action and minimize their involvement with the infants as well as with the nurses.

> I couldn't go into my baby's room. That was terrible. I couldn't get my foot in the door. It cracked me up just looking at him through the window. He looked so pale, so helpless and he looked like he would die any minute. I know I should have been in there with him, but it was too hard, too frightening, and it was too soon for me.
>
> (Excerpt from field notes, Mrs. McCaskill, 1982)

> I know I was a coward and a sissy. I just couldn't bring myself to touch him. You know, we waited six years to have a baby, and look what happened. That's all I could think about; the wasted effort, the hopes we had of finally being a complete family. I may have been angry with him, I don't know. I do know that I couldn't put my hands on him. I cried a lot and I stayed away a lot. I know he needed me, but I couldn't do it. I know it was terrible of me and some of the staff didn't like me, but I didn't like myself either, but I couldn't do anything else.
>
> (Excerpt from field notes, Mrs. McKiver, 1982)

These and other mothers always came to visit their infants, and their initial stance also included putting distance between themselves, and the staff, especially the nurses who sought out the mothers, shared information with them about their infants, and solicited and encouraged their involvement, however miniscule it might have been.

In the mother's absence, who does the work that mothers do? In most of the instances where the "maybe" mothers were slow to move into action as survival agents, the nurses assumed their role, while at the same time they were developing strategies to get the mothers more involved. When the mothers did not do the work, the nurses made direct overtures to them, offered suggestions, demonstrated certain tasks, and if the mothers were still unable to perform, the nurses themselves would perform the tasks.

XII. Variations in the Assumption of Survival Agent Tasks

The survival agent role emerges once it becomes evident to a parent or both parents that a very delicate balance exists between the risk of death and the ultimate survival of their infants. Most parents eventually decide or are convinced to do everything in their power or ability to enhance their infant's chances for survival, physical as well as emotional. Most are not completely certain about the exact nature of their survival work, however in concept they somehow accept the interventions and the medical trajectory scheme articulated by the health care team. They begin to understand the day-to-day nature of the infant's existence and the uncertain nature of the outcome of the life-support techniques employed. Their next set of tasks include learning what the division of labor will be between them and the health care staff, given their overall capabilities, their specific biographical situation with their individual infants, and their specific task or work assignments as survival agents.

Mothers most commonly emerge as the central, pivotal persons representing the individual families involved in the NICU experience. While most fathrs tend to return to work soon after the birth of the sick infant, mothers remain most consistently in the hospital with their infants, going home occasionally for some respite for herself and to somewhat normalize the family/home situation, which may or may not include other children. However, she remains strongly and deeply committed and connected to the hospitalized infant. Under these new set of conditions with mothers absent from the home for extended periods of time, most fathers necessarily have to assume a more major responsibility for the day-to-day maintenance of the household and the other children if any are present.

Although mothers most commonly emerged as the primary life agent person, in this study there were variations in the degree to which mothers could take on the "life-agent" survival role. However, in those instances when mothers did not or could not because of her inability to comprehend the seriousness of her child's condition or the major significance of her active role in the situation, other persons were required to move in to take over this tasks, either permanently or temporarily.

A. Delayed Acceptance (Distancing)

Most mothers are convinced very early in the experience that their infant's condition is serious and life-threatening to the extent that there are no absolute promises that the infants will survive. Soon after these mothers accept the medical trajectory projection and identify the importance of their role in assisting the staff in its work in behalf of their infants, they quickly move into the NICU experience and develop their roles as survival agents.

It was also evident in this group of families that not all mothers are able to move into or take on the life-promoting agent's role. There are some mothers who decide after they are told the medical trajectory projection that more is expected or required of them than they can do, and they do not buy into or take on the role and its tasks.

First-time mothers who are new to their role as mothers and especially mothers of critically-ill, "imperfect" babies are most often in this category of being reluctant to take on the new identity and its accompanying tasks. They are basically overwhelmed by the unexpected development and are understandably insecure and unsure of their abilities and parent capabilities, least of all to a critically ill infant.

These so-called "may-be" mothers take on an identity of not being definite in their understanding of the depth and extent of their abilities or commitment to do what is required of them in relation to their infant's survival needs and the role they must play. Their reluctant, stand-offish attitude can be reflected in their initial resistance to fully learn about their infants' overall condition, and they manifest an approach-avoidance stance, phasing in and out of the situation, with episodic contacts with the infants and the staff.

Conditions that Contribute to Delayed Acceptance of Role

Unlike the other mothers who move quickly into the new set of conditions as defined by the medical trajectory projection, these "maybe" mothers have to be aggressively pursued and "pulled" into the action-oriented survival scheme. The most logical and best equipped persons to do this are the nurses within the unit whose primary function is to facilitate the medical management of the infants. The nurses also function as resources in assisting mothers in learning their function as survival agents. Nurses are also able to observe and assess the status of the situations and provide specific help and support that is critically needed by all mothers within the ICN.

Certain other conditions contribute to mothers' reluctance to accept the challenge of becoming a survival agent. Many mothers when they begin to understand and accept the medical staff's trajectory projection, cannot get beyond the possible death of the child as a result of the critical state of the condition and the infants' vulnerabilities. These mothers avoid becoming attached to the child and getting hurt when it dies. Their focus is on the possible death of their infants and their desire to avoid the pain that the loss would bring upon them.

Mr. and Mrs. McNeil were told six hours after their infant daughter's birth that two cardiac defects existed and that while certain aspects could be treated medicinally, if she survived, she would require two or three operations in the long-term future. Her present survival depended upon her ability to tolerate the medicines prescribed and the procedures necessary for maintenance. Upon hearing this, Mr. McNeil jumped up and ran out of the room, leaving Mrs. McNeil and the staff to continue the discussion. She suggested that the hospital keep the baby, do what was required, and when the time came, to let her die. Mrs. McNeil then proceeded to join her husband in the waiting room and they left the hospital. The infant's nurse reported that Mr. McNeil returned two-and-a-half hours later, retrieved their belingings, refused to look at their infant daughter or the attending nurses, and left the unit. Mrs. McNeil made this decision for them based on her husband's present behavior, plus knowing how he had reacted to the previous loss of another child.

Mrs. Brown was a young seventeen-year old mother whose infant son was born while her husband was on a tour of duty in Japan as a marine. Her infant was premature by two-and-a-half months and his cardiac condition was serious. The infant though small, appeared to be strong and somewhat more healthy than everyone expected. However, Mrs. Brown was unable to come into her infant's room for any appreciable amount of time without falling apart and rushing out, not returning for several hours. Her visits became less frequent and her face-to-face contacts with her infant shorter and shorter. She was overheard telling another mother that she was ready for her infant to die; she had alerted her husband, who was then seeking American Red Cross assistance in returning home.

Mrs. Rice's baby was transferred into the hospital three hours after it was born, and due to her own slow recovery, she did not join the baby until two weeks later. In the meantime, she was kept informed by phone on a regular basis, twice daily, by her infant's nurses, who also encouraged her husband to be specific as he described their baby and her condition as well as her progress, which was slow but steady. Mrs. Rice had not held her baby since its birth and everyone was anxious for her to do so; however, she was quite vehement in her refusal to hold or touch the baby. Her husband had become quite astute in his work with the baby but even his entreaties met with hostility and a continuing refusal to interact with the infant. She was observed crying a great deal, not talking with other mothers who were also aware of her predicament. The husband and the nurses remained patient and understanding and they continued to offer encouragement and emotional support as she struggles with her fears, as well as her awareness of the medical trajectory projection of the serious nature of her infant's condition and the uncertainty regarding its survival.

The data suggests that for Mrs. Rice, these became a set of conditions for overcoming her obvious reluctance to finally assume the survival role.

Also, mothers whol have had previous infant losses, i.e., miscarriages, abortions, etc., tend to "pull away" from the staff and also from their infants. They hear the medical trajectory projection, they remember their previous and sometimes continuing, unresolved pain, and they consciously have no desire to repeat them.

The data indicates that while most mothers never waiver in their original commitment and determination to be that necessary, dependable survival agent, some mothers do vacillate back and forth in their awareness level, as well as their ability to take hold and function as survival agents in their infant's behalf. Some go along for variable periods of time doing some tasks with their infants. They will marshall their energies and resources (and sometimes the fathers), begin to get more involved; and at some point something happens and they retreat and withdraw to be fringes of the NICU.

In part, this may be accounted for by the fact that as the medical trajectory develops over time, the infants' condition sometimes peaks and at other times drops. Many of these mothers acknowledged some difficulty "shifting gears" from one moment to the next. Many mothers withdrew when serious medical junctures were reached and the infants' condition worsened. Many would return when the infants' responded positively to treatment and the condition improved and the threat of death momentarily abated.

On another level, many of these mothers acknowledged that during those periods when their infants' condition seemed stable, they allowed themselves to think that the primary problems were being cured and they stood a good chance of having a future with their infants. However, when their infants' conditions exacabated, they had to shorten their hopes, long range desires and settle for immediate survival. This became too difficult to handle, consequently they retreated in order to salvage some of their biographical aspirations.

B. Joint Assumption of Survival Role

Most parents are convinced very early in the experience that their infants' condition is serious and life-threatening to the extent that there are no absolute promises that the infants will survive. Soon after these mothers accept the medical trajectory projection as well as identify the importance of their role in assisting the staff in its work in behalf of their infants, they jump right into the ICN experience and develop their roles as survival agents. As a result of having observed the activities within the unit and thoroughly understood the dynamics of the situation, they know what they are getting into, and they are willing to pay the price at all costs. They managed to over their fears of their infants' death and recognized that though the trajectory projection may indicate that the infants may die, until that time came, they would do everything possible to help them survive, regardless of what that required them. Their attitude became one of the "this baby's going to live if I have anything to do with it". For these parents, their commitment was total and without reservations. None could visualize any tasks beyond their abilities, capacities or condition.

Mr. & Mrs. Ethan agreed that they wanted their infant son to live at all costs to them and the staff. They agreed that Mrs. Ethan had no choice but to remain in the hospital with their baby and help him with all that they understood that he needed to experience; he couldn't do it by himself. Mr. Ethan returned to work and together they planned how to change their life style to now include their son, who needed special consideration from everyone, including his two brothers, ages ten and twelve. The Ethans were aware of the staff's concern about Mrs. Ethan's health because of a C-section delivery; however, Mrs. Ethan insisted that she was fine and that she would manage the long, protracted period of hospitalization her child would require. She was very adamant in her decision to remain in the hospital with her baby, helping him through all of the tests and procedures she understood that would be necessary for his survival. Though her health and the strain which the long hours placed on her energy continued to be of concern to the staff, Mrs. Ethan, with her husband's support, persisted in her total commitment to her baby. After the first three weeks of critical management activities where the child almost died on several occasions, Mrs. Ethan allowed her husband to take her home for an entire weekend, once it was medically certain that his present management needs were under control.

Mr. Garcia had been unemployed for about four months when his infant son was diagnosed as requiring immediate hospitalization two hundred miles away at a major metropolitan hospital. During their infant's six months' hospitalization, Mr. Garcia was offered three separate jobs, but he chose not to accept any at that time. Based on his understanding of the medical trajectory projection, he was definite in his determination that he should remain at his wife's side and jointly assist her in supporting their infant son in his efforts to live through the critical experiences that they understood were in front of him. They had initially considered leaving their two-year old daughter home in the care of the maternal grandparents, but the Garcia's chose to have her join them after the baby's first week of hospitalization, thinking that their infant son could die never knowing his sister, and through her presence with them, she too could get to know him.

Each parent in the NICN is bombarded very quickly by nurses and all other health care members with a large number of unpleasant facts and information. In a very short period of time, they are generally expected to understand and assume responsibilities that seem awesome, frightening, as well as impossible. They first have to get in touch with themselves and what it means to them, as well as this new, unexpected definition of their infants, themselves, and their new role expectations as parents of critically ill children. They are also concurrently faced with the realities of the infants' critical condition, and the confusing, ambiguous uncertain aspects of the illness and its implications for survival.

Mr. Garcia's unemployment situation was one condition that allowed him to jointly assist his wife in doing survival work in behalf of his infant son. He was also fortunate in having a large extended family that was able to provide financial support while he remained at his infant's side. Time appeared to be a major factor in those situations where a joint effort of survival tasks were shared between parents. Many other fathers commented that they wished to have been able to share more of the tasks with the mothers, but someone had to work and manage life that existed outside the confines of the hospital. Young fathers who were students at local colleges were also more likely to have the necessary time to spend with the mothers as well as the infants. Many employers were sympathetic to fathers' need to be with their wives and sick infants, therefore allowing extended visits during the day or postponing business trips out of town.

Another important condition that supported joint assumption of tasks was the degree to which fathers could project biographically with their critically ill infants. Some fathers were able to recognize the fragile nature of their infants' condition and recognized the urgency of getting bonded to and connected with their infants. Fathers today are less willing to relinguish their infants entirely to mothers without some activities of their own as the infants' father. Many fathers felt equally responsible for the infants and were never embarrassed by being seen holding their infants or taking care of them in some way, and will not allow themselves to be relegated to the sidelines.

C. Fathers and Others as Primary Survival Agents

There are those instances when fathers become the primary survival agent as a result of the mother's inability by way of her own absence, illness or because she had died. In those instances, the nurses continue to take on an active part in helping the father become what he has to be, even when they feel that his capacities and resources are not sufficient for the tasks at hand, except with guided support, encouragement and instruction.

During her fifth month of pregnancy, Mrs. Tomasini was diagnosed as having Hodgkins disease. Mrs. Tomasini would not allow the physicians to administer any medications for her illness and she was required an extensive three-month hospitalization immediately upon the delivery of her infant daughter. Six hours after delivery, the infant was diagnosed as having a congenital heart defect and was ultimately hospitalized thirty-five miles away from Mrs. Tomasini, ultimately requiring Mr. Tomasini to divide his time between his wife and infant daughter. During his daughter's two-and-a-half month hospitalization, he never missed visiting her daily for long periods of time. His employers allowed him to work part-time, reducing his salary, but he was able to maintain full hospital-medical benefits which provide full coverage for both his wife and infant daughter. The nurses took great interest in the situation and numerous case conference were held to discuss management strategies that would enhance Mr. Tomasini's abilities to take on the survival role in Mrs. Tomasini's absence.

When his wife was well enough, they would discuss their infant's condition and Mr. Tomasini would relay Mrs. Tomasini's concerns to the nurses. They tape recorded her questions and concerns and on two occasions two of the nurses visited Mrs. Tomasini and spent two-and-a-half hours talking about the infant and all aspects of her care and development since the diagnosis and the emerging trajectory. Mrs. Tomasini was concerned about her baby's ability to tolerate so much without her to offer support. The nurses were able to understand her concern and recognized that Mr. Tomasini was doing an excellent job with the cues and suggestions he acknowledged came from her. Mrs. Tomasini, with the assistance of her mother, completed a hand-made blanket with hearts and flowers and the names of all of the infants, relatives on both maternal and paternal sides. The nurses took numerous pictures of the infant and sent them to the mother via the father. The infant went home with the father at two-and-a-half months of age, three weeks before her mother was discharged home; however, Mrs. Tomasini died three months later. Mr. Tomasini continued to manage his infant daughter with great success. He attributed this to the fact that he had learned how to be a good father by working closely with the nurses and by sharing as much as he could with his wife before she became too ill. He learned early that he would have to take on a more major role in his child's care; more than either one of them had expected. His daughter was three years old when Mr. Tomasini remarried.

D. Strategies Utilized by Nurses to Pull Parents In

Mercer (1977) defines "parents at risk" as those parents who, because of a stressful incident occuring at birth of their infants, experience interruptions in their early parent-infant contacts and interactions. As a result of these early interruptions, their acquaintance, claiming and attachment processes, as well as their cueing-in to their infants' unique needs, are likewise interrupted. It is an obvious fact in the ICN that nurses there have as one of their goals the enhancement of healthy, happy parent-child relationships, even under conditions as controlled and strained as the ICN within the hospital environment. Nurses are concerned about the fate of these children, and because of this concern, when they see that mothers are not moving well into the survival role, that they begin to develop strategies to get the mothers in gear and moving. Nurses become as tenacious as mothers and their work shifts them to pulling in those mothers who say that they cannot do the work required of survival agents.

The fact remains that when mothers are unable to move into the survival agent's role, someone else has to do it. However, nurses know the significance of parents getting hooked in and, based on their extensive experiences with hundreds of infants and parents, they become very astute in getting this done. Fathers and sometimes grandparents temporarily take on survival-type activities until mothers are able to overcome whatever presents them from taking on the tasks.

Nurses are especially good at facilitating parent-infant interactions on a gradual, non-threatening level for those parents who are reluctant to become survival agents. They watch parents very closely, becoming somewhat knowledgeable about their concerns, their fears, and their overall attitudes about themselves as the parents of critically ill infants.

When Mr. and Mrs. McNeil refused to visit their infant, the nurses remembered that previous to the infant's diagnosis, Mr. McNeil had been observed holding and caressing his daughter quite lovingly. However, after the diagnosis had been made known to them, both parents stayed away, called several times the next day and came very late and stayed briefly the following day. Mr. McNeil would bring his wife to the hospital, but he refused to come into the unit. Mrs. McNeil would enter the ICN, stand back at some distance, observe the nurses in interaction with her infant, but could not approach or interact with the baby herself.

This behavior persisted over two or three weeks with both parents moving in and pulling away from the infant. Nurses became concerned about the parents' behavior and attempted to involve them more in their infant's care. Parents' visiting schedule remained unpredictable and unstable, with Mrs. McNeil calling several times each day to inquire about her child's condition and progress. The nurses decided to call her more often, rather than wait for her to call in. The nurses decided to ask the parents' permission to take pictures of the infant, commenting how pretty she was and how she had begun to improve as she gained small amounts of weight. These pictures were always given to the parents, who never turned them down and always seemed pleased to receive them. Their baby's primary nurse arranged a conference with parents and physicians so that focus could be placed on child's present condition compared with its original presentation and the implications for the staff's future planss as far as its care and management.

The father commented that the infant seemed to have fewer tubes in her and the nurse quickly commented that it was a definite sign of improvement, but it also made it easier to hold her. She was still a sick baby, but not as sick as before. Mrs. McNeil was quite direct in asking the nurse if all of this improvement meant that her baby was going to live and when the nurse stated that her chances of survival were greatly improved, Mrs. McNeil ran out of the room crying with her husband and two of the nurses in pursuit.

The following day both parents visited their infant for several hours, remaining somewhat cautious and reserved. They asked the nurses many questions about procedures and treatments and they spent a great amount of time sitting and watching (assessing and monitoring) the nurses and everyone else in the unit. One of the nurses informed Mrs. McNeil that their infant's highly infectious state had subsided and if they had some special toys or anything that they wanted to bring from home for the baby's isolette, they could bring them on their next visit. The following day Mr. and Mrs. McNeil brought in mobiles and Mrs. McNeil placed them herself above the infant's isolette. She stood closer to the infant with the nurse standing close to her with her arm around her shoulder.

The nurses started asking Mrs. McNeil to assist them in certain aspects of the infant's care, such as rubbing lotions on her body and placing clean diapers on her. It was during one of those seminars when Mrs. McNeil saw for the first time the numerous IV marks on the infant's body. She wondered how the infant could have so much done to it, and still be alive. She saw (cueing) this as a sign that her infant daughter wanted to live, and from then on, she proceeded to take on more activities in assisting the nurse in their work on her infant. She stated that she had had several abortions in the past, and this was the first baby she had wanted, and the fear of losing her was too much to consider. Both parents started asking for a projected date when the infant could be discharged home.

Therefore, nurses can be instrumental in shaping experiences that will give parents opportunities to become familiar with their infants and all aspects of their physical situation. They forge and mold these relationships between parents and infants in an environment that is foreboding and creates a sense of helplessness and frustration. Nurses have long been convinced of the value of healthy parent-child relationships and they monitor and assess each parent's capacities and they seek to cue them into activities that will have long and short term impact on the infants' development, emotional and physical.

> These parents looked so helpless as they watched all of us work with their severely ill infant. I knew that they were experiencing conflicts in what they knew they should be doing and what they were able to do. The main thing that I didn't want to do was to frighten them away, then we would really have problems. My experience led me to believe that they needed to have more direct contact with their baby and once they got to know her, how could they leave her or not come to visit with her. Once they got to know her, they would be "hooked" for life. They needed to have some concrete things to deal with, i.e., pictures, clothes, etc., and they needed to know that she could survive once she overcame that particularly critical phase of her illness. I knew that I could not turn away or run away from them and focus all of my attention on the baby. Through the years, I have been most successful with parents like this couple by running toward them and not running from them. I guess once they check me out, they usually become somewhat more assertive and they hold back less and move forward more.
>
> (Nurse interview from field notes, 1981)

Most of these "maybe" mother's self-esteem as mothers tends to be devalued and maligned to the extent that they do not feel that they can be survival agents because they are not good parents. Nurses know that in most instances these mothers have not had an opportunity to hold their infants, nor gain confidence in doing the primary care activities. Many of the mothers have great difficulty getting over their fears that the infants might die, consequently they distance themselves from the infants so as not to be hurt whenever death occurs. In general, the quicker nurses can "hook" parents in, the better for all concerned.

E. Summary

There appears to be an emergent continuum along which the "maybe" mothers move as they develop an awareness of the tasks involved and their abilities and/or desires to become survival agents. They tend to "pull away" from the staff and the information given them regarding the trajectory projection and the biographical projection of their anticipated actions. They also "pull away" from their infants, who then require someone else to assume the mother's biographical projection work. Fears of infants' death loom prominent in their concerns.

These mothers move then to a second level of involvement where they "withdraw" to the fringes, vacillate back and forth between some involvement and no involvement. It's during this period that mothers appear to be getting use to the idea that the infants may survive but they remain uncertain of the actions they can take to enhance the infants' survival. This "let's wait and see" phase suggest some beginning involvement with some obvious distancing.

As nurses become more assertive in their efforts to pull mothers into the tasks of survival agents, mothers take a "try it, maybe" stance with nurses gradually sharing tasks with them, showing them how to do their parental survival tasks within the trajectory scheme projection. It is during this phase of their becoming survival agents that mothers begin to believe that the infants might survive, and with the guidance and support of the nurses, these mothers begin to take on more and more tasks that they begin to identify as significant for their infants' survival with minimal trauma to their psychological selves. These mothers eventually move into the category of the "definites", those mothers who accept and recognize the relevancy of their involvement in the survival agents' role, which joins forces with the nurses in maximizing the clinical-medical survival of the infants, while minimizing development trauma.

In these and other instances, the ICN staff is able to appropriately intervene by providing mothers with specific instructions, support and guidance through the numerous activities relating to the infants' care, management, and ultimate survival. It is the staff's responsibility to prevent families from doing themselves in by helping them develop strategies that assist them in taking on and enhancing the overall survival of their chronically ill infants.

Therefore, even though mothers are primarily the survival agents in this study, there were those occasions when mothers didn't always easily and spontaneously take on this role and its tasks. When they didn't, someone else had to do it. Sometimes, taking on the role is delayed; in other instances, parents take it on jointly; and sometimes they don't do it at all and in those instances, fathers and others are required to take on the role.

The consequences are such that when any of these conditions exists, the work that they would normally do is shared by or shifted to others.

XIII. Ethical Dilemmas in NICUs and Directions for Policy

The data in this study essentially calls for a natural extension of the medical staff's functioning and a radical shift in the interlocking of hospital care and home (and community agency-assisted) care.

In a typical neonatal intensive care nursery in any urban community medical facility, hope is liberally mixed with uncertainty as numerous premature infants, some weighing less than two pounds, and others who are full-term or nearly full-term but are suffering from serious illness or birth defects, fight and struggle for their lives. Omnipresent cribside cardiac mothers inform a constantly hovering, listening, watching staff of the second-by-second reality of each infant's subtle medical and physical changes.

Dynamic and sophisticated advances in neonatology have moved so rapidly in the last fifteen or twenty years that more infants are surviving the neonatal intensive care experience, and though some of these infants continue to have only a questionable chance of survival, many will have some chances of reaching adulthood without at least one major handicap. Technology has definitely come a long way, but it can create it's own set of problems for these infants.

Fifteen years ago, infants of nearly full-term were suffering from severe lung damages as a result of being on respirators for extended periods of time. Present day advancements in the machines solved the problem for those infants. However, today tinier infants, those who would have died almost immediately after birth a decade ago, are now surviving but are encountering similar damage to their even more delicate and immature lungs. The damage cna sometimes be irreversible.

In my study, basic attention is drawn to the issue of infant survivability and the concentrated, intensive work successfully carried out by parents and professional health care workers, i.e., physicians, nurses, technicians, etc., to ensure each infant's chances of surviving the nursery experience. With special skills and modern medical technology it seems possible that intensive care activities saves the lives of many of the formerly unsaveable or questionably saveable infants. These successes often depend upon a technically complex system of care activities that provide temporary palliative support until a cure can be achieved successfully. Everyone takes justified pride in these accomplishments and improvements.

However, on the other side of this coin, there is the reality of the numerous difficulties faced by the health care community as it attempts to keep pace with technological advances, especially in those instances when inappropriate and prolonged application of medical technology does not benefit the infants involved. In other words, there are those critically ill infants where intensive care activities will fail in its efforts to cure them, and their lives will be clouded by permanent and severe impairment. Duff and Campbell (1976) state that parents, professionals and other lay people express considerable concern about the quality of life for these impaired survivors and the effects on their families. Campbell (1982) states that for most infants, treatment is continued to the limits of modern knowledge and technology; for a few, as doctors have done for generations, the prudent and compassionate course of action is to withhold or stop certain treatments in the knowledge that death and relief from suffering may ultimately result. Given the "success stories" and the "miracles" that reportedly occur in intensive care nurseries, what about those infants who had "heroic efforts" made on their behalf and who survived, but who were taken home by parents who couldn't cope with small lives?

Moral ethical issues promoted by advanced medical technology emerge most clearly in neonatology where the traditional medical ethic has been to act in ways that benefit the patient (infants) and do no harm, yet in many cases the prognosis is uncertain and in all cases the wishes of the infant are unknown. Who is the infant's natural advocates: its parents or the physicians-in-charge? In a capitalistic society, there is the bottom-line question: Who is going to pay the costs of "heroic efforts"? Who makes the decision? Should the decision be made by those who do not know the specifics or the particulars or do not have to live with the consequences of the decision?

Goodall (1984) states that it would be good if the advances of technology were to sharpen our focus on what life is really all about; if life is sacred, its sanctity only departing with the heartbeat or the flattening of an EEG? Or is human life to be valued primarily because it is given to us as a vehicle for caring relationships. If the latter, does it take priority in shaping these decisions?

Illich (1976) contends that the essential argument of the critics of the medicine and the so-called benefits derived from new medical technologies, is that if technologically based medically care were to be judged on the purely quantitative criteria of increasing longevity, then only a small fraction of the care delivered would meet the required standard. Most medical care is provided in order to relieve symptoms, improve mental health, restore functioning, or reduce pain/ discomfort. Such care is defensible only insofar as it improved the quality of life of patients and/or family or caregivers. If, as is argued, most health care must be ultimately evaluated in terms of the impact that therapy has on the quality of life, then these activities and procedures which produce the largest improvement in the quality of life should receive the most support.

There are several moral ethical issues that arise in the care and treatment of critically ill newborns, the most dynamic being whether to prolong life or shorten life, by passive or active means, and the conditions under which each occur. The following sections will identify four areas that address these moral dilemmas and policies that emerged as my study identified the management activities of survial agents in attendance to these critically ill newborns.

A. Efficacious use of Limited Resources

Fost (1981) states that it is not feasible to declare that all life is sacred and therefore warrants being preserved forever. He suggests that most of us can imagine some life not worth living, and intensive care units are increasingly populated for prolonged periods of time with infants whose prospects for meaningful life do not seem to warrant intensive care, or even minimal care. He offers as a justification for withholding treatment from critically ill newborns the claim that to use limited resources on a defective child is a misallocation of scarce supplies, personnel, and equipment. Everyone recognizes that all resources are limited and that to provide services for one patient deprives someone else. Decisions have to be made at some level as to how to distribute benefits and resources.

Many arguments may be offered as criticisms against withholding treatments from critically ill infants based on scarce resources. There is a need for clear, definitive public policies, rather than judgments arrived at by arbitrary and sometimes personal means. To deprive a person (child) of the fundamental right to life requires justification beyond personal preference. In pediatric situations, it is often the case where it's possible to treat the patient, but the issue is whether or not that treatment should be provided.

In my study, parents are the predominant survival agents whose only focus is their active role in the physical and emotional survival of their infants. Because parents are such a major force in this survival work, it is the staff's responsibility to allow as well as assist them in their survival work. Parents are constantly working for what is best for the child at all times; never is their focus elesewhere.

The conjoint survival work that parents and staff actualize is always focused on the ethical dilemmas that arise out of the emergence of the illness trajectory at critical junctures in the infants' illness experience and the technology utilized in it's care, treatment, and survival.

What are the implications for parents as survival agents when their infants' conditions are drastically shifted and severe problems develop instead of redemptive improvements? Parents are constantly required to balance and weigh all of the options available; they have to recognize the benefits of each treatment and what is to be gained or lost by doing certain and specific procedures. Parents are always concerned about how to affect meaningful progress without harm to the child.

A major responsibility rests with staff members for assisting parents as survival agents by giving appropriate, realistic information so that when critical, apprehension-provoking junctures are reached, parents will know what's being risked or lost. When parents have this information, they may make different choices, which may be to continue treatment or stop treatment at some point.

When parents, as survival agents, decide to allow no further treatment, their focus shifts from active survival work to basic comfort/emotional work, thus moving toward closure with the infant. Their focus shifts from making investments in child's long-term future; they live one day at a time existence, making realistic preparation for child's death. When everything humanly possible has been done for the child, then the quality of that life from that point on takes special meaning. Minimizing pain and suffering, withdrawing "heroic efforts", allowing death to come as swiftly as possible. They give up the life that could not be and focus on assisting that life in its transition.

For those parents who opt to continue with treatment they do it ideally with full knowledge of the consequences: that nothing clinical will be gained and all efforts are experimental and that the infant's death is the ultimate outcome. Even though there may be some parents who may commit the child to science in order to further the acquisition of information relevant to the care and treatment of other infants who most certainly will follow, they must receive support in learning this new survival agent tasks.

The question arises concerning how much can you put these families through? When clinical uncertainty is replaced with definite assurance that an infant cannot be saved by any of the advanced and available medical technology, parents must be assisted in learning how to relearn and shift their work. Parents recognize that there is more to survival than the obvious, day-to-day existence of the infant; they are future-oriented and their concerns include considerations of the quality of life that the infant and its family will experience. Their biographical considerations are all inclusive and constantly shifting as the illness trajectory emerges and infants' life takes on new dimensions.

Therefore, it is quite possible that, when parents are given adequate and complete information that tells them their infant's chances for living do not exist, they are better equipeed to make active decisions commensuate with own biographical expectations and projections of their infant. When they weigh all of the factors inherent in the announcements of their infant's terminal conditions, some parents may opt not to invest in additional or continuous procedures that do not enhance survival, but will exhaust financial resources that are already stretched. For most parents, this is a major decision with which they've had no previous experience, and support in this area should be available from the attendant staff.

Parents begin to recognize the futility of putting a child through continual treatments, spending great sums of money, with no redemptive outcome of that financial investment. Some make decisions not to treat at all or treat up to a point and then stop before the child begins to experience both emotional and physical harm.

On a broader social level, medicine has goals of its own that may sometimes conflict with the needs or wishes of the parents of critically ill newborns. In spite of the aforementioned advancements in medicine, there are many questions that medicine needs answered, even at the risk of inflicting injury or pain to an already compromised infant who cannot speak or act in its own behalf. Some conditions cannot be treated for cure or even relief of symptoms, yet human experimentation-type activities under the disguise of treatment may exist. Parents as survival agents have an awesome task, one which they cannot share with anyone else, especially when they consent to procedures or treatments without complete and informed knowledge of expected outcomes.

The major ethicl dilemma for the staff under these circumstances is concerned with how much information should the parents receive and how much should the staff hold back. You do not want to deny hope, yet you want to be truthful and not make promises that cannot be kept. Although no one wishes for the family to suffer any unnecessary anguish, they must be told the truth and they must be supported in their efforts to continue in their role as their infant's primary survival agent.

B. Shifting Gears (perspective): From Burial to Resurrection

When infants survive the neonatal experience after having spent several weeks or months suspended between life and death, parents are somewhat reluctant if able to relinquish their required state of anxiety and foreboding demeanor. From the very beginning of their careers as the parents of a critically ill newborn, great uncertainty about these infants' survival was uppermost in everyone's awareness. The unstable nature of critically ill newborns encouraged this shifting of survival perspective.

Once survival is no longer an issue, parents continue to live with concerns about the uncertainty of their infant's future. They are never quite sure if all of the previously disturbing and life-threatening symptoms are really behind them as realities of the past, or if, from a physical sense, these symptoms will reappear. Parents acknowledge that they are constantly "on guard", looking for signs and cues that symptoms are present. As survival agents, through socialized into this role, parents are always looking, watching, wondering and waiting for something to happen that would change their present situation. There is usually a constant state of high tension, where they are never fully relaxed or completely free from worry and fear that the bad times will reappear.

Parents, as survival agents, must be taught by the staff how to shift their focus and learn what constitutes important versus unimportant symptoms; parents have to be taught what is normal, and what is not. First-time, new parents, have no gauge against which to measure what constitutes normal behavior from behavior that is not normal. They have to be taught, through anticipatory guidance, what their tasks are as parents of infants who survived neonatal nursery experience. These parents are not accustomed to treating these infants life "normal" children and the staff has a major responsibility for assisting with making a smooth transition from fearing that their infants will die to preparing for their living.

As the illness trajectory emerges over a period of time, and the issue of survival is no longer primary, all survival agents begin to anticipate and appreciate the necessity of making major shifts in their respective survival agents' responsibilities and tasks. The nursing staff and all other health care providers begin to prepare parents for the major responsibilities being shifted to them, in preparation for going home. The child's chronic condition will require continuing medical care and treatment, but it can be managed at home, with parents then having primary responsibility for assessing and monitoring all aspects of the child's development, physical and emotional.

In order for this to be accomplished smoothly and successfully, it is necessary for the staff to anticipate when that shift is emerging, guided primarily by the illness trajectory manifestation of the child's level of responses to treatment, as well as their awareness of the parent's abilities to take on the responsibilities at home, independent of staff's physical support.

Staff must begin to teach parents those activities and skills that will be necessary for successful home management. As these role changes begin to shift, parents are coached in how to begin to transfer some of their survival agent's tasks to the child. Parents are reminded of the chronic nature of the cardiovascular condition, i.e., that it is long-term, incurable but it can be lived with and managed within a framework that may change as the course of the illness is stretched out over a long, protracted period of time. The uncertain and unpredictable prognosis can often cause considerable stress for the child, the family and the medical workers. Parents may be required to walk a very thin line between relinguishing or transferring responsibilities for management of symptoms to the child, and maintaining some level of awareness regarding its ability to comply with the established regimen for survival.

This transerence of responsibility must begin very early in the form of anticipated gradual relinguishment that commences when child reaches age of reasoning. One cannot wait much longer, otherwise child takes on a negative definition of self that's defined more so by the social environment that by the chronic illness itself. One way to prevent the development of a "cardia cripple" is never to treat the child as a cripple. Parents' long-range goal is to enhance their child's emotional integrity by treating them as normal as possible; to recognize that something is wrong with the heart and not them as the ultimate proof that the person survives with the chronic illness. This is no simple task but it can be enhanced by an attitude grounded in a realistic appraisal and appreciation of the sanctity of the human spirit and integrity. Parents and medical workers joining forces early in the life of the child heightens the possibilities of such an outcome.

C. Saved for the Moment

As a continuation of the survival theme, the prognosis for those children who survive that initial intensive period as the illness and biographical trajectories emerge, remains uncertain and unpredictable. What parents do know is that the infant has survived, for the moment and that is all they know. They have only the reality of the child's physical presence, with no predictive estimates of what is going to happen and when. The child "appears" fine, for the moment — but how long will this last? The infant's "appear" and "act" as though they have not experienced any emotional scaring as a result of the intensive and extensive use of life saving/life supporting machines and instruments necessary for their survival.

As survival agents, what does this mean to parents? How long will this appearance last? One year, two years — how long? Parents most often worry about the possibility of more surgery or any other invasive procedures, that are sometimes painful and potentially life-threatening. Parents may relive those early moments of anguish and frustration surrounding the initial announcement of the serious and chronic nature of their infant's condition, and fear that there may be a reoccurrence of that traumatic experience.

Parents may also raise questions about the cost of continuing care and how they will pay for the care required. Strauss (1984) acknowledges that the long-term, repetitive, and complex character of chronic illness care implies proportionately greater overhead and administration costs for patients, health organizations and funding agencies. Many families have insurance that have generous benefits and coverage for major medical care in hospital; however, the coverage provided for long-term, chronic, out-patient care is less comprehensive, therefore more costly to the individual families. Medical staff should be cognizant of available community resources to which families may be referred for financial help and all other sources of ancillary support that families will need to call upon as they manage the demands of their child's chronic condition.

It is a major feat for parents to frame their childs's existence within the limiting reality of the here and now. In the past, most of their survival tasks had as an underpinning, their ability to project their present behaviors around future goals. However, the unpredictability factors about what can be anticipated in the near and distant future dues present problems for parents as they take on the multiple problems created by the chronic nature of their child's condition. The heart will never be perfect and all efforts are marshalled around making it function as best it can within a medical regimen that treats emerging symptoms of a less than perfect heart. The illness can be managed but it requires the construction of a major network of resources committed to the creation of a quality of life that sustains and supports a high level of personal and social functioning. Staff can and should help in that regard.

D. Development Future for the Chronically Ill Child

The conjoint survival work of parents and medical staff has been the primary focus of my study and the findings indicate that merely saving the child's physical life is only one important part of the child's total life perspective. As the illness trajectory emerges and the work plan for each survival agent shifts according to the crisis at that juncture of the experience, the ultimate physical survival of the child becomes manifested. Up to that point, management of the medical regimen sought to safeguard the child's physical survival by accurate and astute monitoring of life-support machines, gauging accurate dosages of medicines, observing and anticipating all reactions and responses to all forms of treatment, and determining where child's condition, improved or otherwise, justified reassessment and different level of care, and/or treatment.

Along with the medical staff's managing the illness trajectory safely and soundly, parents were busy in their efforts to ensure their biographical investment in the child, by marshalling an aggressive management scheme designed to enhance the child's normal emotional development while undergoing life-saving, life-sustaining, and life-threatening treatments that could create indelible emotional scars. A conscious, constructive use of themselves motivated by a future-oriented investment in their child's total survival, emotional as well as physical.

My study pointed out the significance of this conjoint relationship between these life-enhancing workers, and that the ultimate goal was to develop dynamic syncronity between their efforts at medical-biographical management. As this relationship developed around their mutual survival activities, they could trade-off each other's tasks, with parents doing some medical-type physical activities, and medical staff doing biographical-emotional things with the infants. These interactants eventually learned that specific tasks usually performed by one, could be performed to some lesser degree by the other, but under particular conditions when the primary person was unavailable.

At some point, usually several weeks or months postnatal, uncertainties about the infant's physical survival are abated, and its physical survival is assured. The once rocky and stormy experience takes on renewed hoep and focus. The infant is ready to be discharged home; the saved child has physically survived all of the original obstacles that made its survival so questionable. The illness trajectory has been successfully managed by the staff, with adjunct support provided by parents. But is this all or is this the beginning of something else? Are there new challenges to be faced by whom?

Physical survival, as such, is not everything. Focus must now shift to the home environment and the staff must now shift total responsibility for the child to the parents and parents must be taught a new set of survival tasks which now focus on the biographical integrity of the child and the family. The staff must now anticipate management tasks that lie ahead for parents, and though there will be some medical-management follow-up activities via outpatient clinic visits and on-going pediatric assessment, the primary management activities will center around the parents and their daily activities with the child at home.

From a developmental perspective, what is this child's future? It has been saved from physical death, but are there some residual problems that may compromise its future? Can the staff state absolutely to the parents that there are no other problems? Parents will now have to focus on the developmental future of the child, now living with the consequence of an earlier decision to save the child at all costs.

Many cardiovascular conditions can produce physical limitations and restrictions on growth and development. Consequently, many children with these conditions will grow more slowly than their peers, remain quite thin and "sick" looking in appearance. Some may have other obvious signs of difference, i.e., very dark-blue lips and fingernails; thin, course hair, etc. Some children may remain quite ill, requiring continuous medical treatments, and occasional or regular hospitalizations and one or several surgeries and still remain unwell and chronically incapacitated. Some children may be unable to attend school therefore requiring home tutors; some may also function with orthopedic-type problems and require special schools and/or equipment for mobility. Some children may have experienced some central nervous system damage, the results of which will not express itself until later on when specific developmental milestones are limited or are otherwise unattainable.

The question of the availability of community resources to assist parents in their management tasks should be raised and explored before children are released from the hospital. Appropriate referrals should be anticipated and explained in advance regardless of the uncertainties in each child's situation. Seldom can families manage these contingent issues alone and the medical staff should feel responsible for linking families with those agencies that focus on delivering multiple social and health services.

The continuing care needed by chronically ill children is expensive. How will families manage these costs? Even with so-called "adequate" medical insurance, there are some costs that remain the primary responsibility of the family. Where do they get the money to provide total care? Medicines and home appliances, such as special beds, walkers, antibiotics, oxygen tanks, apnea monitors, etc., become integral parts of the day-to-day reality of many chronically ill children. Where will parents find the money to purchase such equipment? Some might find it possible to manage for a brief period of time; but what happens when it is needed for long, protracted lengths of time?

Parents are also forced to acknowledge concern about the effectiveness of their previous efforts to protect their child's emotional state while they were undergoing those life-saving but traumatic treatment procedures. So the child was saved, but if it has become an emotional cripple, was the life really saved and for what purpose? Families need on-going supportive care provided in their own homes or in special programs that will assist parents in developing their skills as parents of a chronically ill child. Parents will need help in developing healthy adjustment-coping styles that will facilitate their ability to establish meaningful relationships with their infants that would offset the creation of emotional maladaptive behavior in the infants/children. Developing good ego strengths are prerequisites for all individuals, but may be especially necessary for children who will be required to live with a chronic illness that may improve but will never be cured. Chronically ill children may require a social world that individualizes their specific human worth, without attaching great worth to their physical limitations or incapacities. A healthy definition of self-worth is augmented by a variety of social worlds that supports healthy ego development. Parents, as the primary survival agents who are constantly responsible for its care, must obtain social supports that enhances their worth, from which each child develops its own sense of value and worth. The staff through its interactions with the child can also assist in this regard.

Parents of chronically ill children must discover when and how to assist each child in assuming responsibility for its own care and survival. Parents may need to begin to relinguish some portions of this to the child when it is developmentally able to reason and understand the meaning and ilications of its condition and how it can be managed. Realistic and truthful explanations by parents, augmented by realistic information and support by medical care staff members, should begin early in each child's life so that discussions and explanations can facilitate and identify in facts and not misconceptions and/or half truths.

Parents of all children recognize as a parental function the development of independence and self-reliance in each child in their care. Most parents experience mixed feelings about this natural fact, yet they recognize the reality of their own mortality and eventual death; therefore, each child, as it matures is encouraged toward independence away from parents, by a variety of actions, behaviors, and expectations.

Social pressures are no less demanding upon parents of chronically ill children, who suffer from a variety of dependency-promoting conditions that are built into their roles as sick children. Parents may experience some difficulty disciplining or punishing a chronically ill child for certain behaviors from which a well-sibling would not escape. Yet, in order to live with others, these children also require rules and responsibilities that govern and shape their behavior and responses to the social structure. Parents of chronically ill children need support in confronting those feelings that they possess which may interfere with their ability to provide effective parenting that would enhance their child's overall growth and development towards independence and self-reliance, responsible behavior. Ideally, this action would augment the development of a healthy individual able to live with a chronic illness and all aspects of its existence.

Physicians and other professionals caring for children are constantly confronted with these and other ethical situations and moral problems. The contributions of a variety of disciplines focused on serious ethical dilemmas in intensive care nurseries will hopefull ensure a balanced view of alternative consequences and contribute to an enriched, informed experience for all concerned.

XIV. Summary and Recommendations

In this study of conjoint parent and staff survival work in neonatal intensive care nurseries, the two major findings call for (1) a natural, purposeful extension of the staff's primary and tietiary functioning, and (2) a radical shift in the interlocking of hospital care and the patient's home and social agency-assisted care.

The major innovations in medical technology, more specifically, in the area of neonatology, with its life-support machinery and it s ability to rescue little lives previously unsavable, have created problems for which there are no easy solutions. Our reactions to these scientific advancements are mixed; on the one hand, infants are able to receive treatments that literally snatch them from death's door, yet their "survival" and the myriad of problems it creates impacts greatly on the social, economic, and political underpinnings of the health care system. Though we rejoice when these individual lives are saved, on a more broader level, complex issues emerge which pose problems for families in general, and the health care system in particular. In other words, there are larger structural conditions that must be recognized with systematic reference to their implications for policy and programmatic formulations.

Infants who survive the neonatal intensive care experience seldom survive without complications, some anticipated, while others are unanticipated. While most professionals focus extensively on the immediate and specific survival of these infants, most parents focus beyond and into the future, yet without a clear view of all the possible contingent factors that will only escalate rather than abate their survival agent's tasks. The chronic nature of the problems that develop raises issues regarding the quality of life of these technically salvaged infants as well as the quality of life experienced by the families who have the on-going, life-long responsibility for these infants after they are discharged home. The total "costs" involved in their care places major burdens on the families as well as the social agencies who have major responsibilities for continuing the survival care initiated by the sophisticated medical care advanced by the technically-astute hospital.

As these infants' survival trajectory is "stretched" out, the staff will necessarily have to extend their tactics in the direction of relinquishing into the hands of parents those survival tasks that will enhance their continuing success as survival agents at home. The 24-hour nursing care pattern momentarily relieves parents of the major responsibility of these infants' care and survival, however, when they are discharged home, this unit of care is reduced drastically to possibly two parents and/or several significant other potential caregivers, such as siblings and/or grandparents, and/or relatives and friends. In other instances, the major responsibilities at home are primarily on the shoulders of a single parent without a major support network.

The staff must be cognizant of these realities and situations must be structured so that parents recognize that their successful management of their infants' initially accute medical condition has emerged into a long-term illness that will make on-going demands on their time, energy, and resources.

As in all industrialized nations, increasing proportions of our population will suffer from chronic diseases such as cardiovascular, chronic renal and respiratory diseases. In this study, sophisticated medical technology, combined with astute nursing care and parent care, is saving the lives of infants previously doomed to early death. As a result, when these infants survive and are eventually discharged home, they then become members of society's rapidly growing population of chronically ill persons, with long-term incurable illnesses. In this present study of saving the lives of previously doomed infants, this is all paralled by the life-death dilemma of keeping doomed adults alive, as the result of advanced medical technology.

There are larger structural conditions and consequences that interplay one with the other, when we look at the impact of advances in medical technology and medical specialization on the trajectory work of neonatal intensive care nurseries. Families' lives are severely impacted upon when the illness trajectory is forcibly stretched out over several months, requiring major modifications in family arrangements, occupational adjustments, as well as encroaching on emotional adjustments of family members. Yet, once all of everyone's survival work has achieved its goal of keeping the infants alive, the product that emerges is not a healthy or totally intact child, but a child who must now live as partly disabled and completely incurable, with all of the health and social problems that will ultimately develop.

The impact of the influence of advanced technology on the larger health care picture suggests major concerns emerge regarding moral-ethical issues, quality of life, and the cost of continuing care required. How can the multiple impacts of this chronic condition best be managed and by whom?

The staff must have this larger view of the world, and even as they work so aggressively toward saving these infants' lives, families need their support in coming to grips with some painful facts about the future for their child and for themselves. Parents are usually resilient and resourceful people and they can be helped to face truth on a creative level in order to marshall their energies and resources accordingly. The fact remains that once they have been successful as survival agents in the nursery, they do have those potential resources within themselves to continue the extension of those survival tasks at home in their local community. When they become the primary survival agents at home, they will discover their real work has just begun. Therefore, as previously indicated, the medical care delivery system in highly industrialized countries including the USA, the emphasis is on acute medical care rather than on an integrated home/community care and medical facility care model. Infants who survive the neonatal intensive care nursery experience require the negotiated interplay of medical facilities and community services agencies in furthering the on-going survival work of parents.

Where are these community agencies and how do families and patients get to them? Infants are especially dependent upon others to establish the necessary linkage that provide continuity of care and the maintenance of quality care interventions. This responsibility can be shared between <u>discharge planners</u> and <u>clinical social workers</u> who activate this division of labor between medical facilities and community agencies. Liason nurses, resource nurses, and others join forces in their attempts to match patients' needs with community agencies, sometimes successfully, most times not.

Most infants are discharged home from neonatal intensive care nurseries on complicated drug regimens that should be monitored in some degree by someone medically responsible. Some infants are sent home after months of intensive care, around-the-clock management by numerous nurses and other functionaries on rotation and relief schedules, to parents who are expected and required to maintain, in varying degrees, a similar regimen. How do they manage to do this? How do they achieve relief and respite and from whom?

Some parents are quite resourceful, others tend to struggle relentlessly, achieving little support but experiencing continuing frustration and misery. Where are the resources? Why are families strapped with such responsibilities for maintaining the lives of infants who continue to require so much in order to survive, yet receive so little in accordance with the needs?

Self-help groups develop are basically on their own. Public health nurses are able to visit homes and give information and education-type advice and suggestions; visiting nurses/home health aides/community homemakers are available for certain types of concrete services at an hourly cost that may not be covered by medical insurances, and if they are, most often just for a period of time not to exceed a certain amount over a certain period of time.

As a result, some parents form their self-help groups, provide each other with emotional support, practical advance about management of their children; and as they become more sophisticated about their needs, they begin to make demands of and put pressure on appropriate agencies and authorities. Some self-help groups may include professional advisors (nurses and/or social workers) who may assist them in programmatic areas, as well as providing them with support in strategizing their efforts in acquiring resources commensurate with their needs.

The current emphasis on cost and cost containment raises concerns about quality care and how it can be simultaneously maintained. The demands for cutting costs have become increasingly more persistent. The way the current health care system is set up with the patient out of the medical facility as rapidly as possible may in most instances place patients in jeopardy of not receiving maximum quality care. The rush to get patients out "before their time", may create problems that esculate costs, when patients have to be rehospitalized because of complications developed, unchecked or unmonitored by family members unfamiliar with either the medical problems or the treatment regimens prescribed.

Mechanic (1978), and Enthoven (1978) believe that lower cost does not need to mean lower quality of care; quality and economy can work together, without discernible loss in benefits to patients. Enthoven is especially critical of our financing systems which, while they recognize that things could be done in a less costly but equally effective way, are biased against making greater use of home care programs. Vickery and Fries (1976) state that if incentives for physicians and patients were appropriate, we could make more use of self-care.

The medical care constituency includes an ever increasing population of elderly individuals 75 years and older, who also need long-term care for chronic and mental illness, support services and special care for the terminally ill. In addition to infants who survive intensive care nurseries and become chronically ill patients who require long-term care and long-range planning for use of community resources, there is also that less widely recognized group of patients who require high-technology services: organ repair and replacement (heart, heart-lung transplants, liver and kidney transplants) and irradiation and chemotherapy for neoplasms. The growth in expenditures for such care and treatment increases yearly, and the cost problems do not diminish, but will increase in the future.

In summary, presently the health care systems' current emphasis is on cost factors and reduced length of stay in hospitals for cost containment purposes. Structurally, this is how the health care system is set up. There are many consequences to this stance and there are pressures afoot to reverse them. When critically ill infants were allowed to stay in neonatal intensive care nurseries the prescribed period of time, very meaningful things occured that had significant impact on the survival work performed by nurses and parents and the ultimate survival of these infants. If these things are cut short in any way, there may be significant consequences. Therefore, any blue print that does not have infants' survival as a major emphasis must be turned back. The present structure must be changed, shifted or added to in ways beneficial to patient care activites.

There are no agencies, as such, that specialize primarily in the total care of children with cardiovascular problems. Therefore, it is imperitive that some structure emerges that coordinate the hospital, the home, and community agencies and their activities respective of the multiple on-going needs generated by advanced technology. Resources that exist must be strengthened and supported and encouraged to fulfill their obligations to the maximum. Yet, these programs should not be exhorted to voluntarily provide these services unless there is some shift away from the present social structure that will put costs primary to quality of life issues. Quality health care continues to remain a right of all citizens, and the responsibility cannot be forfeited in any way. The larger chronic illness issues must be made known to all involved, especially the general, at-risk community of mankind. We each share the same risks, the same vulnerabilities, and our quick grasp of the overall significance of these issues should insure the reconstruction of a health care system that truly meets the needs of the entire population. The challenge remains hopefully achievable within the near future.

This discourse has so far focussed primarily on the hospital's role in shifting its focus more toward forming network relationships with community services health agencies. The other side of the coin implies that community agencies, who bear the major responsibility for the on-going care and management of patients after they have been discharged home, will necessarily need to reevaluate their objectives and responsibilities to provide meaningful home care activities. These agencies will be expected to pick up more and more patients requiring community-based follow-up medical care.

Most agencies are not structurally prepared to absorb these additional demands made upon their services. It is possible that most were never really expected to completely meet these needs, yet the community continues to expect the delivery of services to continue. When agencies are more closely scrutinized and evaluated on the basis of what they actually do as compared to what they were proportedly established to do, there are some actual gaps and deficits there.

Many community agencies are actually developed to deliver a temporary, stop-gap type program; meant to exist until something more permanent can be established, or until the families of these patients are able to take over total and complete responsibility. Many programs were never ever intended to be a toal and specific alternative to hospital care, yet the hospital and consumers view them as being prepared to carry out a long-term care program.

The funding of these agencies are almost always dependent upon "soft-money", designated as "demonstration" or "research" projects, which have a specific goal to be obtained within a certain demonstrated time frame. These programs are expected to work themselves out of business, and "they" will ultimately take over the primary, continuing responsibility. This amorphous "they" never appears, yet the project is terminated, but the community need for high level community home care remains unmet.

In order for community agencies to take on these long-term institutional programmatic needs, monies will have to be designated and maintained at levels commensurate with the long-term, multiple realities of chronic illnesses and their pervasive impacts on patients, families and society in general.

The present structure of most community-based home care programs offers primarily episodic, fragmented care, which is only intended to meet immediate, presenting problems on a temporary, piecemeal basis. Structural changes are basically necessary and vital to the survival of patients presently coping with life-threatening illnesses.

In order for this structural change to be effective, negotiations must take place at all governmental levels, as well as within the health care delivery system itself. The division of labor required for this change has to occur along lines mutually designated by all parties involved. Social science practitioners, including medical sociologists, should play an important role in facilitating the communications necessary for these changes to occur.

The overall consequence of not doing this will be the continuing over-use of inadequate resources in meeting needs that require major changes on a scale larger than the level of local communities. In the long run, families will be required to carry the total responsibility for patients who require numerous levels of professional interventions, yet provided at a non-professional level. Families will be strapped into situations requiring skills they do not have, yet feelings of obligation and responsibility will force them to provide resources too demanding for them to carry. The consequences may be quite overwhelming for all concerned.

If adequate linkages do not occur between hospitals and community health care agencies, families will be required to take on the major responsibilities for the on-going survival of family members with long-term chronic illnesses. As this study has implied, there are social norms that encourage mothers to take on a major role in facilitating the overall survival of their critically ill children, and if costs of care are indeed escalating, major cut backs in resources will continue the utilization of women, as mothers and wives, as a dynamic source of unpaid labor in the health care field. The already documented evidence of inequities in pay scales between male and female workers in comparable areas of employment suggests that efforts must be made to not allow budget cut backs in health care to further devalue the worth of women as participants in the fields of labor and employment. This unsubsidized source of labor in health care can only extend the improper as well as unethical misuse of women committed to quality health care of their families. There must be numerous other ways to cut costs and a new blue print must be established as well as supported by legislature if necessary.

In summary, the data in this study calls for a natural extension of the medical staff's functioning and a radical shift in the interlocking of hospital care and community agency-assisted care. A summary of recommendations includes the following:

1. A major responsibility rests with staff members for assisting parents as survival agents by giving appropriate, realistic information at critical junctures in each infant's situation.
2. Staff members must provide parents with support in learning new survival tasks as the needs emerge.
3. Parents must be assisted by staff in learning how to re-learn and shift their survival tasks from one level to another.
4. Staff members must be truthful with parents about all aspects of their infant's condition and staff must be supportive of parents in their efforts to continue in their role as their infant's primary survival agents.
5. Parents, as survival agents, must be taught by the staff how to shift their focus and how to learn what constitutes important versus unimportant symptoms, and what is normal versus what is not normal behaviors or reactions.
6. It is necessary for the staff to anticipate when discharge home is an iminent fact and begin to prepare parents to take on responsibilities at home independent of staff's presence or physical support.
7. Staff must begin to teach parents those activities and skills that will be necessary for successful home management.
8. Staff must also coach parents in how to begin to transfer some of their survival agent's tasks to the child who is the actual patient with the illness.
9. Parents and staff members joining forces early in the life of the child heightens the possibilities of successful long-term outcome.
10. Medical staff should be cognizant of all available community resources to which families may be referred for financial help and all other sources of ancillary support.
11. Staff can and should be supportive in helping families construct a major network of resources that support a high level of personal and social functioning.

12. The question of the availability of community resources to assist parents in their management tasks should be raised and explored before infants are released from the hospital. Appropriate referrals should be anticipated and explained in advance.

13. Medical staff should feel responsible for linking families with those agencies that focus on delivering multiple social and health services.

14. Realistic and truthful explanations by parents, augmented by realistic information and support by medical care staff members, should begin early in each infant's life.

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