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ABSTRACT:

Social Interactions in Growing Up with Hemophilia: Developmental Milestones and Associated Risks

Evelyn K. Oremland

School aged boys with hemophilia, their parents, and siblings were interviewed and observed over a 5-year period, the field work taking place in their homes, schools, and during hospitalization, clinic visits, and summer camp periods. Qualitative issues were identified for study: How each informant and respondent perceives the hemophilia condition, how each participates in its management, how the interactions change over time, and how these are integrated into life experiences and development, particularly at this stage of childhood. Participant-observation techniques were utilized, with socio-analytic development of emerging themes pursued with additional data-gathering.

Self-development through the corresponding work of learning about the hemophilia disorder and beginning its management is highlighted, particularly relative to the boys' peer relationships, in that peer group interaction becomes salient for children of these ages. The family members' work is examined, with special focus on the processes of trading and shifting of tasks as the boys grow toward self-sufficiency with their home treatment. Philosophies and styles of management are delineated as relevant contexts for understanding the associated

variations.

A sociological perception of interaction emerging from the study is termed "taking a role for another" or intermediating work, indicating that one with intimate knowledge about another, essentially represents the latter's perspective in a group or institution in which the former does not regularly participate. Such work, most often performed, in this research, by a mother in her son's behalf, was seen as consequential relative to "normal" participation in groups outside the family. This work, though taking place from early childhood, becomes particularly prominent for developmental reasons, as parents problematically continue in such roles during their children's school ages, even as these children take on many other aspects of their personal and technical care.

Tempered childhoods are seen as resulting from, not only the disorders of chronic illnesses, but from the consequences of trying to maintain what are perceived as developmentally appropriate relationships with peers which, at the same time, risk damage to physical functioning and potentially affect future relationships.

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Social Interactions in Growing Up with Hemophilia: Developmental Milestones and Associated Risks

INTRODUCTION

Although children who experience chronic physical problems or illnesses of an ongoing nature have been foci for sociological inquiry, as in the works of Jeanne Quint Benoliel[1], Myra Bluebond-Langner[2], Peter Conrad and Joseph Schneider[3], Fred Davis[4], and John Gliedman and William Roth[5], the social dimensions researched having varied, the study presented herewith emphasizes particular child development perspectives. Social interactions of children pursuing life during their school ages while growing up with a disease are highlighted, with data reflecting processes specifically related to this level of children's development. Child development here refers to that trajectory over time through which a person grows from birth until young adulthood, gradually achieving independence of those caregivers who initially enabled the child's survival and care. Essentially, the examination is of a cross-section of biography and the related illness career of the school ages.

To be sure, in her study of diabetic children who begin to incorporate their disorders as integral with their self-identities, Jeanne Quint Benoliel demonstrated the process from the impact of the diabetes diagnosis into the adolescent years. Similarly, Myra Bluebond-Langner

followed the changing meanings of life-threatening illnesses to children during the time span of their "dying". Fred Davis' study of children who contracted polio, with its multiple research dimensions, also concentrated on trajectory-related interactions and the changes in these as they occurred from the impact of sudden illness, the evolving handicapped lives, eventually to a re-emergence of social order for these children and their families. Conrad and Schneider and Gliedman and Roth, focused primarily on perceptions the adult world has of children with disorders, from general social views to those of medical personnel and other service providers. Gliedman and Roth, in fact, conclude that general perceptions of child development do not "fit" handicapped children, thereby emphasizing their "deviance" relative to others. Over-lap in all of these studies reinforces findings regarding work processes for illness management, related family interactions, deviance issues, and meaning and identity development over time.

Whereas the current study covers these same grounds as basic to the experiences of the chronically ill subjects in their worlds, particular interest in that segment or phase of growing up that extends from being cared for by others to emerging self-care, influenced the research direction toward school ages as these are affected by illness and treatment. Institutionalized changes with entry into school underlines the move from early childhood care-taking inclusive of the children's work[6] to emerging self-

caring,[7 8] that is the development from the totally dependent aspects of babyhood, eventually to the industry and initiative characteristics of the school ages as elaborated upon by Erikson in his classic Childhood and Society.[9] Early conscious participation and interactions on the parts of these young social actors demonstrate their developing abilities to "take roles of others", as described by Mead.[10]

Living with chronic illness, whether in adulthood or childhood, as illuminated by Strauss,[11 12] forms the context within which to examine and understand the related social interactions. A particular dimension in this study, however, the genetic factor of such illness, while following Strauss' paradigm, extends consideration of having a physical disorder from birth (although the diagnosis may come somewhat but not long afterwards). It potentially enlarges the historical time-frame relative to experiencing, on some level, life with earlier generations living with the disorder, and envisioning possibilities for continuing similar experiences in the generation to follow. Sometimes the immediate prior generation may have had similar experiences (though not "same experiences" due to self-other properties, and because of social and technological changes and meanings of the particular times). The "looking back" for those who might have recalled earlier family experiences, or for those who sought ties to such information, and the "looking ahead" to

personal and family implications for the future, provide opportunities for studying dimensions specifically different from those examined heretofore. Even though Quint-Benoliel's work included some genetic considerations, the medical, historical, and social meanings of diabetes and hemophilia indicate differential consequences some of which the current study pursues.

Perhaps this study's fulcrum, the major issue on which its outcomes balance, relate to Mead's delineations of the self into the "I" and the "me" and the theoretical work which indicates that school-age children become keenly aware of their "me" as it incorporates the values of peers.[13] This underlines aspects of the study, especially issues of child development and the problematics of these children's speaking up in their own behalves, particularly relative to their physical differences. As a pivotal issue in the study, this emerged as a dimension unique to this research.

Additionally, throughout the data are suggestions that children's participation with their peers, when at levels of normalcy as set by values relative to socio-cultural meanings of childhood, supports development. Contingencies in the peer interactions qualify the children's development.

METHOD

This study evolved, initially, from a general interest in children growing up with a chronic disease. A research exercise inquiring into related questions enabled pursuit of details involved in the lives of six chronically ill children. Two of the six, managing with hemophilia, provided particular data relative to their peer relationships in that they regularly attended a hemophilia summer camp. Opportunities to compare their interactions in heterogeneous and homogeneous groups (related to their participation with non-hemophiliacs and hemophiliacs) enabled study of a broader population of children with hemophilia, their medical caregivers, and their families. Comparative potentials within the data became evident and enticed further delving into information specifically about the childhoods of the hemophilia group.

Referrals were sought from three hematology clinics in the general geographic area where the study centered. Additionally, the local chapter of the Hemophilia Foundation lent support in the search for subject families. Eight families volunteered to participate in the study, through which a series of home-based interviews were planned and pursued, the two initial cases from the research exercise having been followed with these visits annually for five years. The others have been followed, accordingly, for one to two years. The home visits included interviews with the hemophiliac boys, with their mothers, and with several of the fathers and siblings.

Additionally, selected school observations focused on the hemophiliac child were conducted on both the playground and in the classroom, and discussions held with teachers. One child was visited during his hospitalization, and others were observed during clinic visits, enlarging upon related dimensions pursued with the other children in interviews.

Participant/observation methods were utilized at the hemophilia summer camp, a one-day visit made one summer, and a full-week's stay (the extent of the camp period) during another summer. For the latter period the researcher joined the camp staff to help with aspects of the general camp activities, but especially directed the activity leading to the children's writing and producing their first camp newspaper.

Attendance at hemophilia symposia, presented by the Hemophilia Foundation, and the Foundation's business meetings enhanced the data, providing opportunities for interactions with adult hemophiliacs and more family members of hemophiliacs. Less formal data gathering opportunities emerged through interactions with an acquaintance who is a mother of a hemophiliac, as well as a friend who is a friend of a woman with hemophilia.

Contact was also made with clinic coordinators aside from those of the three clinics who referred subjects. One is from another part of the state and one from a near-by state who coordinates the treatment of all of the

hemophiliacs in that state. Perceptions about patients and information about their work filled data gaps in these regards.

Still further data came forth in response to a presentation of preliminary findings at an annual meeting of the Association for the Care of Children's Health.[14] On this occasion others discussed their philosophic approaches to hemophilia treatment, different from the perspectives the somewhat homogeneous styles represented in the study's early findings.

A particular data source, aside from the general literature of the field, proved to be a published account by parents of a hemophiliac boy.[15] It was possible to include these people, Robert and Suzanne Massie and their family, as if they were interviewees, in that their book encompasses details of their perspectives and work in the care of their son with hemophilia, much the way subject-parents were telling about their lives and work. The Massies, in fact, thus provided data relative to a somewhat earlier time (about twenty plus years earlier), reflecting a different socio-historical moment. Even though, from a general historical point of view, this is but a few years ago, the development of the anti-hemophilia factor having then occurred, made that span of time particularly significant for comparative reasons. Since the new technology marked a salient development in enabling self-care and treatment, lives of these children and their families were potentially affected to a significant degree.

Additionally, the perceptions then held about the hemophiliac child provided social and cultural dimensions on which to base further comparisons.

Still further data was provided by recent writings of the now-adult hemophiliac son of the Massies.[16] [17] His reviews of his self-perceptions and those of his family enhanced similar data collected from the subjects and informants in this current work.

These publications suggested another particular direction for study--that of finding texts written by parents about their family experiences with diseases to be compared with hemophilia. Several were studied, accordingly, most noteworthy for the comparabilities they offered are Deford's Alex, The Life of a Child[18] (on cystic fibrosis), Ducat and Cohen's Diabetes--A New and Complete Guide to Healthier Living,[19] and Featherstone's A Difference in the Family[20] (on multiple handicaps).

A historical "contingency" occurring within the period of this study, the identification of AIDS disease (auto-immune deficiency syndrome) and its linkage to transfusions, including the infusion of blood products in hemophilia treatment, had direct consequences for work in the families of the hemophiliac children in the subject population. Thus, further data gathering included attendance at medical meetings to hear the technical details involved and to consider the social implications, but also to learn medical people's perceptions of the

phenomena of what was being termed a "crisis."

All interview and observational sessions were recorded, initially by detailed notes recalled following each session. The last two years of interviews, however, were tape-recorded and transcribed in order to include all that memory might have otherwise missed.

Denzin's study method, reflected in his Childhood Socialization,[21] provided a model appropriate for emulation. His naturalistic inquiry techniques, grounded in the behaviors he studied, focused on "joint acts" as the unit for analysis. He made thoughtful selections of settings and moments for study, distinguishing for careful analysis representative, illustrative, and negative cases. His use of multirole observational approaches were included in his efforts to incorporate various research strategies that might reflect the problems of his study. These approaches find some replication in the research at hand.

The study was conducted, basically, according to the participant/observation techniques and data analysis methods posed by Strauss, Glaser, Schatzman[22 23 24 25] and others.[26 27] Theoretical sampling as explicated by Glaser and Strauss[28 29] was indicated in several instances, with study directions then increased to include, especially, camp observations, interviews with adult hemophiliacs, and the observations and interviews with clinic coordinators and AIDS specialists.

Data was coded according to "central" issues, with re-coding taking place when emerging data pointed toward

pivotal events or experiences that demonstrated linkages within the data. Again, coding and re-sorting based on newer analytic ideas were instituted for a final time, just prior to the dissertation writing.

Although particular interests initiated the study and were maintained throughout the research process, directions taken in the research followed data themes and sociological concepts that became evident in the process.

PART I: CONTEXTS FOR UNDERSTANDING

Chapter 1

HEMOPHILIA--IT'S HISTORY AND "REALITY"

Medical Issues

Hemophilia is the most important of the inherited bleeding disorders, classically a deficiency of Factor VIII, but with other deficiencies also yielding a similar diagnosis. The disease is genetically linked to the X chromosome, thus carried through the line of the mother, potentially affecting the son. Daughters and sisters of hemophiliacs may be carriers, with the potential to have children with hemophilia. However, genetic mutations may also occur, thereby rendering an individual without such genetic history, a hemophiliac. The disease is rare in women.

Varying degrees of severity characterize the disease, with designations "severe", "moderate", or "mild" referring to the degree of the clotting deficiency, and thus yielding properties to consider in this study. Hemophiliacs with moderate or mild clotting deficiencies may bleed primarily as a result of major trauma or surgery, the diagnosis perhaps not being definitive until such times. Those with severe clotting disorders may spontaneously bleed into their muscles or joints, or, of course, bleed pursuant to injuries. These individuals are more likely to be diagnosed as hemophiliacs relatively early. Even with mild

disease, though, hemorrhages can be profuse and life-threatening, as bleeding from the mucous membranes of the nose and mouth are usually long-lasting.[30]

A guide for the "non-expert" house officer or practitioner indicates that the medical history gives the important clues for the diagnosis, which can then be confirmed with tests. It is recommended that detailed descriptions of all past operations and traumas be collected, such as circumcision, dental extractions, tonsillectomy, and fractures, with duration of bleeding being a key issue if it extended beyond 24 hours.

It is interesting that there is generally no bleeding with the birth process, and that hemophilia may not be detected with circumcision that is within 10 days of birth, even for those severely affected. Generally, the first year is uneventful with the exception of bruising easily. A physician may falsely reassure a family if the only symptom is bruising.

The subsequent year or after age 2 or 3, however, the hemorrhages into the large joints appear with increasing frequency. Most of the hemophiliacs experience the onset of these bleeds by age 3 1/2, but the range of onset is from 13 months to 10 years of age.

Bleeds generally occur with less frequency after adolescence, but treatment is life-long. Early treatment is now frequently recommended for each episode to modify or check joint deformities, contractures, and muscle atrophy,

all of which result from prolonged bleeding into the muscles and joints. Advice calls for "when in doubt, infuse", with up to two home infusions 12-24 hours apart suggested prior to calling the hemophilia center.[31]

Early treatment is, however, relatively new as an approach, as subjects in the current study testify. In fact, it is with the initiation of home care that patients are infused more frequently, and use more product, this associated with the greater convenience of treatment than was possible with the earlier hospital trips.[32] Additionally, school absences have been reduced, yet there are still many absent remarkably many days.[33 34] It must be noted that joint bleeds result in swelling and pain, aside from being potentially crippling. Still, home transfusions do minimize the "pain of disruption on life".[35]

The treatment currently entails an adequate replacement of the deficient factor, transfusions for excessive blood loss being a possibility. The newer technology makes possible such treatment outside the hospital, the first home transfusion program being initiated in 1961.[36] These treatments may be administered by non-medical personnel, generally family members or the patient himself.

Orthopedic surgery, to correct joint deformities, and rehabilitation are now possible because of the capacity for infusing the missing factor to achieve normal coagulation. This extraordinary advance developed over the last 20

years.[37]

Earlier, since 1840, the treatment was blood transfusion, with frequent hospitalizations. Then, beginning in 1923, fresh plasma was used, followed by the development, in the 1960's, of cryoprecipitate, which is now used world wide. The highly purified concentrated product was developed in the mid-60's, and made possible the supervised self or home treatment. Prophylactic treatment is now an option, too, selected by those prescribing treatment, often to "cover" for particular exercise or activities.

Until the recent years, bleeding to death or the fear of it dominated the lives of hemophiliacs. (In fact, the earliest record of hemophilia in America is thought to be from 1791, with an account of the deaths of five brothers.[38]) Statistics from around 1877, reflect that almost all hemophiliacs died by age 20,[39] and by the end of World War II, the records were similar. The accelerated progress in medicine in general during the early part of the century was clearly not matched with such progress in treating hemophilia. Another half century saw the monumental advances in hemophilia care.

The greatest medical emergency for hemophiliacs, still, is intracranial bleeding, especially for a severely affected hemophiliac. However, with general control over bleeding to death, the major therapeutic task is to avoid crippling.

Genetic studies vary in terms of definitive identification of carriers, both in pregnant and non-pregnant women. Repetition of studies and tests are a frequent recommendation. However, positive indications during pregnancy of those with family histories of severe hemophilia have been most specifically recorded.

Social Meanings

In the medical literature there is frequent reference to enabling "optimum" lifestyle for hemophiliacs. Some emphasize allowing satisfactory pursuit of education and occupation.[40] Concomitantly, there is frequent discussion and debate over the prevention of injuries, most particularly how to accomplish this in light of young children's "normal" active behaviors. The dilemma posed is reiterated as a constant theme, both in the literature, but particularly elaborated in the data collected herewith: that the efforts to prevent damage are constantly balanced against those normal behaviors of childhood which potentially threaten damage; yet these latter behaviors and their related social relationships are perceived as consequential to ongoing development.

Long series of suggestions fill the literature, advising interactions which are cognizant of both issues. Some recommended "padding" the environment for toddlers. Similar action is recorded in relation to the royal family of Spain, who put their hemophiliac sons in padded suits, and even padded the trees in the park where they would

play.[41]

Psychiatric and other psychological studies have noted the family conflict over allowing or discouraging particular physical activities. There are "ceaseless efforts" to come to such decisions relative to preventing injury. Some researchers related these considerations to the guilt mothers feel for "passing on" this disease.[42]

Limitations in "normalcy" are ever present, and are detailed throughout the hemophilia-related literature. As an example, Queen Victoria wrote of her son Leopold, who was Alexandra's uncle,

> for Leopold there was such a restless longing for what he could not have./43

Also, a New York physician, in 1905, said,

> Hemophiliac boys should be supervised while playing and they should not be subjected to corporal punishment./44

The author Massie comments,

> To maintain the balance which provides adequate protection as well as a degree of normalcy is a cruel strain for a mother. Except when the child is asleep, there are no hours of relaxation./45

These nearly ceaseless efforts encompass perceptions equating normalcy with support for development in the future.

The recording of responses to hemophilia have been noted from biblical times.[46] The Babylonian Talmud of the 5th century A.D., as well as records from the 2nd century discuss hemophilia, the latter decreeing that if two sons of a woman died following circumcision, then a third son

should not be circumcised.[47] Modern rabbinic authorities extend this to state that any child with hemophilia shall not be circumcised, following Maimonides' injunction in the 12th century, that any threat to life overrides every other consideration.[48] Additionally it was indicated, in that era, that there was understanding of the particular genetic components of the disorder, with references to sons of sisters and sons of the same woman by different husbands.

One of the experiences with this disease that doesn't relate to the activity allowed or the management protocols is that of spontaneous bleeds. These occur for unexplained reasons, and are sometimes related to "anticipated events", especially in prepubertal boys.[49] One of this current study's informants noted that her son has bleeds just before school begins each Fall.

The January 13, 1983 issue of the New England Journal of Medicine reported the new awareness of the high cost for the factor treatment which had enabled a degree of "normalcy", namely the threat of AIDS (Acquired Immune Deficiency Syndrome) disease, possibly inherent in the use of blood products.[50] The daily presses carried the story, and for a period subsequently followed it with almost weekly reports.[51] The risk of AIDS was implicated, for within each vial of concentrate is commercially manufactured product from the pooled plasma of from 2,000 to 5,000 donors. Cryoprecipitate, more widely used before the concentrate was introduced, is prepared in blood banks from individual donors, and is made in relatively small

volume, thus with a lesser degree of such risk. The exposure to the large number of donors involved in the factor production was the crucial issue, as the New England Journal had reported. AIDS had then been diagnosed in homosexuals, heroin addicts, Haitians, and hemophiliacs. At the time of this particular journal article, 3 hemophiliacs had already been affected, with next news reports listing 9 hemophiliacs with AIDS.[52] Ongoing statistics were recorded and reported in popular media.

AIDS is eventually fatal, and in no uncertain terms, the New England Journal of Medicine report of early 1983 carried the distinct warning that

> preventing the complications of present treatment may have to take precedence over preventing the complications of hemophilia . . . . Current modes of treatment must be scrutinized./53

It was felt that it may be necessary to give up current programs even with insufficient evidence relative to AIDS, the reports continued. The implications were many for the 12,000-15,000 hemophiliacs in the nation, most of whom use the implicated blood product.[54] A return to more prevalent use of cryoprecipitate for this number would stress the capacity of blood banks, is more cumbersome, and is also more difficult for home infusion as the material must be stored in the frozen state, and then slowly thawed for use.[55]

Nonetheless, there were immediate responses from the Scientific Advisory Council of the National Hemophilia Foundation, noting the "unknown cause" of AIDS, the

resulting high mortality, and its being the second (to bleeding) most common cause of death for hemophiliacs. The demand was that blood donations be banned from likely carriers of AIDS.[56] Those whose blood would be excluded would be homosexual men.[57] The dilemma posed was that until causes of AIDS were known, "screening" would not necessarily be effective, and, as would be anticipated, members of the homosexual communities responded with "outrage" regarding the "shocking invasion of privacy".[58] Given the knowledge of that moment, the other known risk, hepatitis, was all that could be screened against.

Reports following the initial news of AIDS, which had not been found in hemophiliacs until mid-1982, indicated that some hemophilia projects took patients off the questionable blood products even though they said evidence was still incomplete.[59] The debate extended when others advocated continued use of the products in that insufficient research justified no change. This was argued even though it was acknowledged that in a single year, a hemophiliac on the factor concentrate, would be at great risk in that he'd use blood from hundreds of thousands of donors. The Hemophilia Foundation modified their advice by strongly suggesting that elective surgeries be delayed.[60] Thus the crisis of AIDS disease affected both the potential treatment for injuries, as well as the normal developmental interactions that had initially been enabled by the use of factor concentrates.

Members of Congress, further defining AIDS as a "major health crisis",[61] called for new research programs, indicating that the lack of such action was discriminatory against gays. Yet, the hemophiliacs were also a part of the victim-constituency.

Concomitant with the controversies over this particularly "critical" topic, a new treatment form, DDAVP, was introduced. Claims suggestive of its being a safe and effective alternative to the use of blood products, however, are conditional in that only those with mild or moderate disease would benefit.[62] Further medical research notes continue to be reported by the press. The cloning of a blood clotting gene, evidently to be available for trial use in 1986, as well as possible discovery of an AIDS virus made major headlines in the Spring, 1984.[63] Meanwhile other reports reviewed claims by blood banks that they are protected against AIDS,[64] this amidst news (the same week) of yet another AIDS death, although not a hemophiliac, due to transfusion contamination.

Economics of medical care for hemophiliacs are frequently discussed, and vary with different organizational stipulations. Debates relative to government Medicare funds indicate that costs for treating hemophiliacs in hospitals far exceed such costs for home care, yet Medicare pays up to $300 per day in New York hospitals, almost $50,000 per year for one hemophiliac, but does not cover the approximately $36,000 costs when the

care is at home.[65] State programs generally support the cost of the factor, however, with union contracts frequently covering home care.

Actually, in 1975, the federal government provided funds for the development of comprehensive diagnostic and treatment centers, which now treat approximately 30% of the hemophiliacs in the country.[66] These centers may have one or more physicians committed to hemophilia care, with mechanisms to ensure payment through state, federal, or other third party benefits where these are possible. A coordinator, identifying with patient needs, is frequently in a liaison position to help with management of the care required.[67] [68]

It is estimated that there are 400,000 hemophiliacs in the world, and that their numbers are increasing.[69] The costs for treatment vary, but in the United States it is reported that the average annual costs for blood products alone, for each hemophiliac is $6,000. For a severely involved hemophiliac, the average cost of the products is $8,000 per year. The current study indicates these figures as minimal, with costs considerably higher when hospitalization takes place. However, the recent world conference on hemophilia also considered the social and economic costs of the lack of treatment.[70]

Chapter 2

COMPARABILITIES IN OTHER DISEASES

Genetic and "Homework" Issues in Cystic Fibrosis and Diabetes

Genetic links in hemophilia, diabetes, and cystic fibrosis comprise the most obvious of the comparabilities among these diseases. Whereas hemophilia is a sex-linked disorder, heredity of diabetes and cystic fibrosis, while familial, is based on other genetic explanations and, with diabetes, may be based on still other causality issues as well.

All of these chronic illnesses require technical and related work at home to maintain control of the physical problems. Daily attention and care by family members or by the person afflicted with the disease are integrally related with the care by the medical personnel.

Socio-historic meanings of these diseases vary and change over time. Technological advances responsible for treatment changes may be associated with the variations in meaning. An example here relates to records indicating that early in this century, hemophiliacs couldn't be expected to survive into their twenties. Whereas this is no longer a limitation for hemophiliacs, it continues to be an aspect of the trajectory in cystic fibrosis.[71] Similarly, hemophiliacs long for advances such that now make diabetes a disease that can, to a marked degree, be controlled.[72] Conversely, the longevity of diabetics belonging to an earlier period, prior to the initiation of

insulin technology, was severely affected.

For diabetes, maintaining good control requires attention to diet, urine or blood testing, and careful adjustment and measurement of insulin dosage. Much of this care is frequently managed for the young diabetic child by his parents, with the child taking increasing responsibility for his own control.[73] With age, growth, and development, the "locus" of control becomes more "internal", thereby implicating self-care.[74] Problematics in the diabetic child's circumstances influence the timing for his or her initiation of self-care in terms of treatment.

Although with medical direction, parents become the "key" educators for the young diabetics.[75] Krausner and Madden, in fact, advise a schedule for teaching children to begin the work of their diabetic care:

> Urine recording, beginning ages 4-5
> Urine testing, beginning ages 6-7
> Insulin administration, beginning age 8
> Insulin measurement, beginning ages 9-10
> Participation in diet selection, ages 10-12
> Participation in alterations in insulin dosage, beginning age 12./76

Inferred, of course, is the family "team" interaction, as these tasks are transferred, approximately one at a time.

Historically, diabetes, as hemophilia, has been known since ancient times.[77] Whereas those afflicted with either potentially faced early death according to the prospects of 50 years ago, the discovery of long-acting insulin in 1935 and the development of cryoprecipitate and the isolation of

blood clotting factors in the 1960's radically changed the treatment and the outlook for diabetics and hemophiliacs, respectively. Since almost a generation separated these major discoveries in each of these fields, the historic "timing" may be the condition responsible for the remaining perception that hemophiliacs continue to be especially vulnerable. Literature in both fields, though, encourages their constituencies toward living "like normal".

Other basic differences, particularly with regard to social meaning, become evident, however, with closer examination of the particular conditions posed by these diseases. Jeanne Quint's Becoming Diabetic: A Study of Emerging Identity, indicates that many children at the diabetic camp didn't realize the severity of the condition.[78] Whereas the level of cognitive development may be associated with the child's understanding of the disease (no matter which disease), data in this current study of hemophiliacs supports the notion that it is non-family members in the child's world, including adults, who may not understand the disorder's severeness.[79] An unevenness characterizes the understanding experienced in both groups, relative to age levels and other variables, yet the locus of misunderstanding centers on different aspects of the self-other interactions.

Advice relative to group-related education for 8 to 10 year olds[80] can be viewed in conjunction with developmental interests in peers, as well as those intermediatory efforts which enable the peer interactions. "Open dialogue" at

school is proposed, encouraging parent participation to enable compensating for illness-difference problems in school.[81]

This work of diabetes care is further analyzed by Wexler as she notes that the tasks are

> individual and interactional, immediate and recurrent./82

She delineated cognitive-practical tasks and social-psychological tasks. Rationale for the peer and school advice is presented by Frankel[83] who notes far greater numbers of absences from school for children with diabetes than for other children. Popularity problems, indicated in non-selection by peers, and other school difficulties demonstrate inadequate teacher-knowledge of diabetes.[84]

Reports from both disease groups indicate that a close watchfulness on the parts of mothers follows diagnoses, with daily management on some level required from the start. The young children's responses to injections or infusions are viewed as "upsetting" in both groups. Since the hemophiliac does not have daily infusions, it is more likely that a medical person will continue with such treatments until such time as a family member can manage infusions. In the case of diabetes, families are more likely to be on their own, abruptly from the time of discharge following a first hospitalization.[85] The diabetics are "precipitously on their own" after the short hospital stay where the instruction takes place.[86] This, perhaps, is a pragmatic matter because of the frequency and

timing of insulin injections. Pragmatic considerations, of course, would have to include that insulin injections may be regarded as relatively easy by medical personnel, being intramuscular, even though it is not so for the lay person for whom these are not yet routine.[87]

Hemophilia infusions, being intravenous, require particular skill, time for proficiency in the task varying from 1 or 2 learning sessions, to 10 or 12, often from 1 to 1 1/2 hours each.[88] Elsewhere, hemophilia guides specifically state,

> We do not think that the early months of home therapy can be practiced in isolation . . . . The shift in responsibility is too great./89

Conditions regarding age of onset (or of diagnosis) have a wide variation, in that, as in Quint's diabetes study, the range was from 18 months to 12 years.[90] In the hemophilia group, especially those with the "severe" disorder, diagnosis may occur well before 18 months. Hence, for developmental reasons alone, the families' and children's responses may differ considerably.

In that meal-taking is frequently associated with family gathering, the dietary restrictions set for diabetics may problematically affect perceptions of and by a diabetic child-family member in terms of family belonging. The diabetic is an "outsider" in his eating habits.[91] It is of interest to examine psychological theories relative to children's envisioning withholding of food as being likened to a withholding of nurturance,[92] and

compare this with evidence from 19th century England where food withholding was indeed a punishment of a child.[93] Although differences between the hemophiliac child and his family may be clear, these differences may not be in the context of a most "traditional" family interaction. Clearly, the family-work and order-organization of diabetic care involves "fitting" it into family eating patterns.

Diabetic and hemophiliac children are taught self-control and self-maintenance, but their diseases dictate different lessons to learn. Diet rules are to be followed by one group, whereas physical exercise and other body behaviors comprise the guidelines for the others. The self-maintenance for both, however, include self-invasion procedures utilizing medical-technical needles and other equipment. Complicating perceptions of these procedures are the drug-related behaviors of certain young people in this era. The particular psychosocial conditions under which children learn to achieve certain skills to manage what is required of treatment for their disorders shall be referred to again with the data presentation.

Mathematical calculations characterize home care of diabetics, inclusive of menu calculations and urine and insulin measurements. Although care for hemophilia involves measurement of factor, the degree of the work differs, including the decisions about the treatment that follows. However, there is potential for problematic episodes consequent to mistakes or near mistakes in both situations.

For both disorders discussed here, a distinct juncture recalled by all of the parents is the moment of diagnosis and the realizations of its permanency. Consequences include restrictions on normal life, yet efforts surrounding both are toward "normal" living, supporting child development.

Parents as treatment agents are likely to follow patterns or styles of management. Quint delineated manipulative, protective, adaptive, and abdicative styles.[94] She cautioned that these are not self-contained, but dynamic categories. Findings in the current study on hemophilia will be compared with these. Children's styles are also to be considered, accordingly. Children who experience either disease may disguise the "stigma" of their diagnosis by masking its identifiability,[95] and children in both groups may hesitate to tell others about the disorder because of embarrassment if the others "over-react" in some way.[96]

Quint's conclusions reflect what can be said of other studies of chronic illness--that the chronicity is a process, reflecting a multiplicity of conditions, with sequentialities and shifts in terms of the illness phases.[97] Disruptions to family order may be repetitive according to crises which occur. Perhaps unique to the diabetic, though, is that he can never forget what time it is, as the clock is a regulator in his or her life.

The questions about how children and families

experiencing chronic disease manage with the particular health problems impinging on their lives--the objects of this and the other studies here referred to--grow more complex in a consideration of cystic fibrosis, still another genetically connected disorder. Historical differences as well as philosophic approaches to them provide salient social issues in a three-way comparison among hemophilia, diabetes, and cystic fibrosis. The medical treatment for cystic fibrosis is included within a trajectory influenced by pervasive awarenesses and perceptions of life threat. This persists, albeit that technological advancements during this last generation have enabled capacities to maintain life at least somewhat beyond childhood in some instances. In a study at the Cleveland Cystic Fibrosis Clinic in the mid-70's, 100% of these children lived up to age 12, while only 60% survived beyond age 15.[98] Frank Deford in Alex, The Life of a Child referred to the presentation of the diagnosis as a "death notice".[99]

Whereas diabetes, hemophilia, arthritic disorders, and some other diseases have been known throughout most of history, cystic fibrosis was relatively recently identified.[100] Until the advent of antibiotic usage, little was available to treat it. Currently, with early detection and the available medical approaches, crippling physical damage can be averted, though life beyond childhood is still a new frontier.

Caused through recessive inheritance, with equal

genetic responsibility for the disorder on both mother and father, this disease results in thickening mucous, which contributes to blockages and lung difficulty. This can lead to series of infections, with lung damage a possibility. Pancreas problems result, as well, from poor absorption of foods, especially fats. Wheezing, choking, coughing, and related symptoms keep the child so affected from "keeping up" with peers. These children soon "fall back in play".[101]

All normally given at home, the treatments include daily replacement of enzymes (with every meal), antibiotics, and physical therapy twice or thrice daily, with the potential need for sleeping aids (i.e. a mist tent). Thus the child's awareness of difference is constantly presented to him. Children interviewed felt these limited their freedom and interrupted their play.[102] One day these children may seem in relatively good health, and the next day they may need hospitalization for lung infections or bowel blockages. A range of disabilities is in evidence, as not all with cystic fibrosis are severely affected.

Although the actual home-based care and considerable work load are factors in common with the other diseases, the specifics, of course, differ. Families in a Northern Ireland study reviewed spent from one to 21 extra hours per week on the c. f. care,[103] this generally performed by the mother.

Emergencies, as with hemophilia and diabetes, occur, with further distress over disease-inheritance and other issues also in the situation.

> The sadnesses implicit in rearing a chronically sick child are undoubtedly compounded when parents have to sacrifice their own comforts and those of their well children to provide medicines, equipment, and hospital care./104

This statement refers to financial stresses, generally always in the picture on some level, with differing properties related to insurance availabilities. The North Ireland study refers to American and Australian literature which emphasizes the financial drain.

In Burton's study, already referenced, groups of parents and children with cystic fibrosis and other handicaps were visited, interviewed, and tested.[105] They reported initial extensive and lengthy efforts in search of the diagnosis, with early symptoms often being confusing. The diagnosis was made significantly earlier when there was prior knowledge that cystic fibrosis was "in the family". For the others, the diagnosis was approximately a year-and-a-half in coming,[106] the timing being more closely like that of the hemophiliac experience rather than the diabetic one.

Some parents found that doctors initially didn't take them seriously with the symptom descriptions. One mother, keeping a diary of her child's symptoms from two weeks of age, was reminiscent of the mother of a hemophiliac, whose efforts were to "educate" the doctors.[107] In that general practitioners aren't likely to see these diseases

frequently, parents recognize,

> I now know they don't know everything.[108]

With previous knowledge of the disease, mothers expressed twice as many fears as did those who were meeting the disease for the first time.[109] Parents without previous knowledge of their genetic potential for the disorder, in looking back, felt they would not have had children had they known they were carriers. Mothers with greater treatment experience eventually felt more secure.[110] This is to be compared with similar data in the current study.

The study referred to here also examined feelings of siblings of the sick children, discovering that the physically well sibling extended care and protection to the c.f. child, attempting to protect the vulnerable child from others.[111] This is also comparable to findings in the current study.

Whereas continuing maintenance is problematically complicated by other health functions, (i.e. vision as it is eventually affected by diabetes, arthritic joint problems resulting from long-term joint bleeding, etc), cystic fibrosis may be similarly affected, thereby rendering the child much more sick, at times progressively so, at earlier ages. Disease trajectories thus vary.

Deford elaborated,

> When a child has cystic fibrosis, she never simply lives. She must be kept alive. It's a lot of work . . . . (There are) lengthy, set routines every day, just to help her live . . . . Cystic

fibrosis is a tyrant that rules everyone in the family./112

While Suzanne Massie's reflections on her son's hemophilia frequently conveyed a sense of the "tyranny" of that disease, historically (for her) even prior to the introduction of the current, improved capacity for treatment, fright over potential death in the midst of the overwhelming tasks seldom had the meaning that Mr. Deford explained regarding cystic fibrosis. Yet, "manuals" recommend that these families, amidst varying threats, try to achieve "as normal a life as is possible within the constraints of medical treatment". At least one manual acknowledged that "mothers may become extremely tired".[113]

Inhalation treatment for the cystic fibrotic may last several minutes, whereas postural drainage (while the child reclines, practically upside down, to be pounded upon to loosen chest mucous) takes about one-half hour or more, utilizing eleven different positions, each corresponding to a section of the lung. Postural drainage is repeated during the day. Deford estimates that in his daughter's eight years, he did this treatment 2,000 times; the child's mother's like care was exercised perhaps 3,000 times. (This work by the father was made possible because as a writer, his time was flexible and he could often do his writing at home.)

Additionally, an enzyme is taken by the child before each meal. With this and all of the above, the family notes a lapse in routine during hospitalization, when the

treatment becomes hospital-based.[114] Other work evolves, though, in spite of hospitalization. A family who sensitively worked to enable their child's continuing peer relationships reported that, on each hospital visit, they'd walk with the child "down the hall" to the pay phone so she could call a friend.[115]

The physical symptoms and resulting problems characteristic of cystic fibrosis challenge "normalcy" to considerable degrees. Chronic cough with sputum production, offensive stools and flatulence, smaller-than-normal stature, delayed appearance of secondary sexual characteristics, and missed schooling are characteristic of the disease. Clubbed fingers develop, socially visible, as is the public coughing and "skinny legs".[116] It is not a disease that patients can readily ignore.[117]

Deford notes that as his daughter grew older she became self-conscious with new children. Earlier, about age 6, she had been at ease in such circumstances. Recess began to separate the child more from the others[118] as did teasing by peers for her "funny" fingers. In fact, she began to "ball up" her fists so she wouldn't have to look at her own fingers.[119]

Although written in relation to cystic fibrosis, a statement appropriate to all of these disorders is in a paper by Denning, Gluckson, and Mohr:

> The chronically ill will injure themselves, in physical reality, in an effort to achieve the anxiety reducing social reality of being normal. People in this position strive to be normal to enable themselves to escape both the wrath of the

disease and of society . . . ./[120]

Genetic linkage, chronicity, and "extraordinary" work at home, with more responsibilities placed on the child as the child grows older, continue to be bases for comparing the diseases noted here. For cystic fibrosis, however, some care tasks, (like aspects of postural drainage) are more likely to be accomplished only with the help of another, partially dependent on the stamina of the cystic fibrotic. All of the tasks may not readily be transferred, thus rendering the child always dependent on another.

As to how each family member "fits in" all of the work, it was noted that the child with the disease doesn't necessarily "fit" it in, as the disease

interfered with the rest of her life,[121]

as observed by a 3rd grade teacher.

With heredity as a dimension, procreation questions are appropriate. Deford recognized that the diagnosis of cystic fibrosis doesn't stop families from procreation, and, in fact, may be looked upon as a means of attempting a re-achievement of a social order.[122] Carrier status issues and problems are in the medical literature with great frequency, as well as studies, like that reported by Mangos and Talamo, indicating that more contraception is used following a cystic fibrosis finding in a family.[123] Related data appears in the current study, with problematics suggested.

Still other chronic diseases affecting children, like juvenile rheumatoid arthritis, actually similar in some

ways to the joint problems of the hemophiliac, suggest other dimensions to consider in studying associated interactions. Certainly the experience of pain, aside from the pain of treatment, is a factor in understanding the situations of the arthritics and hemophiliacs.

Disease Uniqueness

Strauss's paradigm referred to above demonstrates a range of variations, indeed a variety of dimensions to consider for studying chronic illness.[124] [125] Although variation within particular disease entities is characteristic, unique aspects of a disease influence interactions relative to a single medical entity.

With the proliferation of specializations in the health care field, particular diseases or physical conditions have not only become prime foci for study, but study has included children's responses to them. In that development is here a criteria for study, it is useful to examine, comparatively, various diseases as they affect developing children's social interactions.

An exemplary work was Selma Fraiberg's on the influence of blindness (from birth) on child development.[126] Considering the visual aspects of an eye-to-eye relationship in interaction and development it is immediately noted that such can't take place when the infant is blind. There is also the child's inability to visually track objects, including persons, and to reach for them. Assuming that the sighted child's motivation for

moving and crawling are objects, human and inanimate, to pursue, Fraiberg discovered a relative immobility of blind infants. Fraiberg's model for developmental guidance, accordingly, was that the parents speak to the infants more actively to enable their interaction, and to learn to interpret the children's hand expressions and gestures.

Less extensive observations at this point, but nonetheless instructive, are in process at the Lexington School for the Deaf in New York, where the staff has noted that by age 6 months, normal babbling of infants "drops out" when the babies cannot hear verbalizations or other sounds to which hearing infants respond.[127] Early interactions are affected, accordingly.

George Engel, in his extensive studies of a child born with esophageal atresia[128] and Scott Dowling, with his research on more such children,[129] compared these children with those normally developing, realizing the major difference in the human interaction over feeding. With esophageal atresia, the esophagus is not fully formed and therefore cannot function. Until a surgical correction can be made, these infants are fed through a tube inserted in the stomach; an opening from the upper esophagus to the side of the neck provides an exit for saliva or anything swallowed. The unique physical factor has an influence on the social interactions with significant caregivers. Engel and Dowling, in fact, demonstrate a series of the children's responses and developmental consequences so

influenced, including these children's "passive" quality and a lack of enjoyment in play.

Elisabeth Wann, an Australian physician who examined uniqueness characteristics of spina bifida, wrote,

> The 'toddler stage' is a difficult one for the spina bifida child as most will never 'toddle' but will, at 3 or 4 years of age or even later, move clumsily, supported by all kinds of calipers and crutches. Thus he does not have the joyful experience of independent mobility until a much later stage; he cannot relieve his anxiety about his mother's departure by going to seek her, nor can he leave her spontaneously to test out voluntarily for himself his toleration of her absence. Furthermore, he is unable to respond to his urges to explore his world since what he wants is often out of reach. In contrast to normal children, he is seldom reprimanded for sins of commission; rather, he tends to be blamed for continual infantile demands./130

Epilepsy and the factor of unpredictability of seizures, coupled with incontinence, has particular meaning for school age and adolescent youngsters, as their social lives with peers are affected by this lack of control and resulting embarrassment.[131]

There is, then, variation in responses to particular diseases. Study of these conditions and others, such as cystic fibrosis, juvenile diabetes, chronic nephropathies, and congenital heart disease have attended to specific and general issues with which families and children, at different developmental levels, must deal, and the consequences therefrom. In a comparative vein, the unique, though various meanings of blood, blood loss, as well as bleeding associated with developmental events and experiences such as circumcision, teething, and childhood

play and games delineate considerations relative to social interactions regarding hemophilia. Nonetheless, given the technology and the socio-historical dimensions of the current times, hemophiliacs follow a relatively stable trajectory characterized by the experiences of their disease, albeit with the critical events requiring reorganization of efforts to manage injuries; stabilizing periods follow, enhancing views toward future development.

Chapter 3

NORMALCY OR DEVIANCE--CONFLICTING PHILOSOPHIES

Normalcy as Ideology--Its Range of Meanings

For these campers were different than the
you's and the me's
You see they all had the bleeder's disease.
Some had bad elbows, some's ankles were sore
But you know, it didn't phase them much more
Than their healthier friends who all too well knew
What the ones with the bumps and the bruises went through.
But each of them came to have fun and to play
And if they got hurt, they'd be back the next day.
They'd swim cross the pool,
'Round the ball field they'd dance
For at childhood, everyone has but one chance./132

The "push" toward being like other children, being as "normal" as possible even though with a chronic physical problem, as already presented, is generally pervasive in medical literature and in counseling practices.[133] [134] [135] [136]

So ingrained is the normalcy ideology, that "preventive" behaviors, as opposed to those characteristic of the normal children, are only occasionally mentioned in the literature, but with carefully circumscribed conditions.[137]

Sociologists have demonstrated that ideology makes a difference in the organization of treatment, and indirectly, then in related social interactions.[138] [139] Ideology, as such, refers to "a body of systematically related beliefs held by a group"[140] that is basic to the group's way of life. Being "as normal as possible" refers to the collectively held ideas relative to chronic illness which influence action, shape negotiation for interaction,

and affect ongoing development.

Strauss, Schatzman, et al additionally indicate that ideologies tend to change in practice, which cautions toward attention to problematics in practice over time.[141] The newer AIDS information has the potential to affect the "normalcy" ideology which has had a major degree of currency, as will be described. Redefinitions and restructuring are conditional, possibly yielding a modified order.

The normalcy ideology is related to risk-taking in that being "like normal" or like the norm of others in the peer group, does pose the risk of injury for the hemophiliac. Yet, medical and psychological (development-oriented) advice toward normalcy provides impetus toward taking such risks. Thus, full preventive efforts are set aside to make possible those interactions and relationships which are akin to normal developmental practice. Conrad and Schneider reviewed the "medicalization" of child care practices[142] which is exemplified by the pediatrician who structured or limited children's access to their parents at a hemophilia camp, in order to remove conditions viewed as "over-protective".[143] The latter's report spoke of "treating" what were perceived as "abnormal" problems in the degree of attachment in the family. These authors discussed "tremendous parental anxiety and over-protection" (over the hemophilia condition and treatment), elaborating with details of a child who was "long due for some discipline", and with questions relative to parental

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tolerance of the "mischievous" behaviors.

Complications or shifts in organization in terms of a division of labor, are the consequences of these directions, which propose dominant ideas for normal interaction. Whereas families alone, or somewhat in conjunction with efforts in schools, have focused on the children's development, medical agents are also so involved, although peripherally, or at least only periodically.

The hemophilia camp operates under medical direction, with the precise philosophy that hemophiliac children need to have normal camp experiences. They explicate a rationale that, should an injury occur, (resulting from these "normal" experiences), "we can treat it in moments". The camp developed out of the recognition that these children were not going to any camp, and, the "any camp" was reluctant to accept responsibility for hemophiliacs. One mother (of a near-adult hemophiliac), however, felt that the general philosophy of "pushing" normalcy was not appropriate, costs of medication to treat resulting injuries being one issue, along with others. Nonetheless, the normalcy position persists, along with "appropriate" treatment to enable it, and, perhaps, the moral idea that it is good to be normal. The medicalization of these issues, incidentally, is action illustrative of Strauss' idea of policy relative to considering social issues

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inextricably a part of chronic disease care.

Fred Davis, in his Passage through Crisis, spoke of alienation from the normal experience.[146] Visibility and invisibility are frequently at issue with regard to participating fully within normal experiences.[147] Strategies involve disguising visible signs so that others won't know, making "light" of disabilities, or disassociating, which involves insulating from events and involvements, accepting exclusion from the world of normals, and reformulating values and activities. The choice of strategy, Davis explains, emerges from social experiences. Some strategies break down, and some persons practice a variety of strategies--all toward assuming some degree of being normal.[148]

Stigma, the "spoiled identity", and its management are interrelated with these ideas, as avoiding or minimizing stigma enhances normality.[149] Goffman's Stigma as well as his Presentation of Self in Everyday Life[150] take into account both ideas of normalcy and presenting oneself accordingly in public. "Normal" essentially refers to those who do not depart negatively from particular expectations.[151] Normalization may encompass the efforts of the "stigmatized" individual to present himself as an ordinary person while not making a secret of the stigma. There might well be a cooperation of stigmatized and normal people in acting as if known differences were irrelevant, thus emphasizing normality.

Some conditions allow for normalcy whereby others do not. The hemophiliac boy may participate "normally" in the

academic classroom, but is marginal relative to his peer group in physical education classes or on the playing field. He may participate "normally" in his music group, but does so wearing his medic-alert bracelet, verifying the abnormal aspect of himself and the "non-normal" treatment that he'll require under certain conditions.

There are commonalities between normal and non-normal issues, as opposed to conformity and deviance issues. Whether illness is deviance and not normal or deviance is illness, is highly dependent on the related definitions and the conditions for defining and controlling the related order.[152] Definitions are from many frames of reference. Strauss points out that in defining norms and standards, there is an assumption of homogeneity in the group.[153] Actually, defining deviancy is a challenging process in that there is more than one public and more than a single normative standard. As this current paper examines, school-age "publics" tend toward requiring what may be considered a single normative range of behaviors, upheld by more general "publics" relative to children's normal development.

Offer and Sabshin point out that normality and health are used interchangeably.[154] They elaborate that a rigid pattern of normality is inconceivable as there is a limit to the dichotomy between health and illness. Normality is, in fact, an adaptation within a context. This, it appears, is a strikingly valid assumption, worthy of comparison with

the related issues emerging in the data collected. Elaboration of the meanings of "adaptation" and "context", are included in the presentation.

The title The Normally Sick Child[155] epitomizes much that is otherwise implied. The normalcy definition here relates to a different population than "all" children; it is here defined in terms of the norm for the sick child, given the reality of his illness, an adaptation within a context. Adaptation entails normalizing the environment, achieving the "optimal", and managing crisis.

Recognizing the variety of ways to approach normality, including normality as health, as an unattainable ideal, as an average, and as a process, one notes the latter approach as especially in keeping with the symbolic interactionist perspective. The varying definitions are congruent with the variations of meaning placed on non-deviancy, with negotiation a part of the process of defining, which can be analytically linked with structural reordering.[156] Negotiations may be based on agreed-upon notions of acceptable behavior. Tactics, strategies, and sub-processes characterize these.

Illness as Deviance or Deviance as Illness

The "hemophiliac is marked out as an exception in a society which regards aggressiveness as a desirable male characteristic".[157] While the sociology of deviance focuses chiefly on rule-breaking as deviance, most certainly "differences" pose deviations from norms, and are

responded to by the deviant and the normative social actors according to problematic protocols within social organizations.

Considerations of deviance in terms of its significance in and to society have shifted over time, depending on the predominant historical and philosophic contexts of particular eras, and the interrelated societal definitions of the phenomenon itself. What constitutes deviance and what sanctions are brought to bear in response to behaviors considered deviant have complex implications for social organization. Illness and deviance as social paradigms present complex and interrelated issues.

In that every culture and its society, even in the most primitive and simple of encirclements, denotes conditions of illness and its management; and in that persons so affected have, from time to time, been ostracized or at least treated as being apart from inclusion in normative social interactions, it is appropriate to question whether illness is deviance or whether deviant behavior is symptomatic of illness. Questions of health and order, or those of ill health and disorder may indeed be naive in this regard.

Records of early or isolated communities indicating states of illness, explain that the afflicted persons may be possessed by the devil, and that the devil must be exorcised or that the community or the person must be cleansed of the disease. Mary Douglas cites the factor of cleanliness as being a concern of all societies.[158] It is

interesting to note, here, the text of The Law Code of Hammurabi which states:

> If a citizen has taken a wife, and intermittent fever attacks her, and if he plans to take another wife, he may do so. He may not forsake his wife who is attacked by the intermittent fever, but she shall dwell in a house which he has prepared, and he shall support her for life./159

The inference of the sanctions in the exorcism or the incarceration in a separate dwelling indicate a means of approaching these illness problems within the societal context. As definitions of health conditions and as treatment for these illnesses, these mechanisms for separating the sick from the well, the sick from the general order, constitute an essence of deviance labeling and its management in sociological terms.

Among early theories of deviance, there have been references to physiological conditions, such as the head bumps noted by phrenologists. Within the framework of sociological theories, Durkheim focused on suicide, delineating types or conditions for such action in terms of its relationship to society, solidarity, or the social order.

> When a society is strongly integrated, it holds individuals under its control. People who are well integrated into a group are cushioned to a significant extent from the impact of frustration and tragedies that afflict the human lot; hence, they are less likely to resort to extreme behavior such as suicide./160

He intertwined issues of morality with the "conscience collective". His essential explanation was functional, elaborating on anomie, a normlessness in a social

structure, a societal breakdown, which leaves persons without moral guidance. Degree of anomie, or its development or existence in groups within society, yield individuals susceptible to deviance, he further explained. In terms now "medicalizing" deviance, suicide would be considered an act of "sickness".[161]

Talcott Parsons' seminal description of the sick role in The Social System[162] described illness as being dysfunctional in a functional system in that the person's physical incapacity yields him unable to perform in his social role. It is in the interests of society, the logic dictates, that illness be minimized. Physicians are those aspects of social organization to define and control disease to fulfill society's interests.

Criticized on a series of counts, Parsons' theory doesn't take into account chronic illness and redefinitions of roles accordingly. Deviance relative to social roles, then, in Parsons' frame of reference, could conceivably include illness. Parsons actually elaborated that,

> If being sick is to be regarded as 'deviant' as certainly in important respects it must, (italics are mine), it is as we have noted distinguished from other deviant roles precisely by the fact that the sick person is not regarded as 'responsible' for his condition./163

Yet, given chronic physical problems, questions regarding "deviance" may still remain. Inquiry must include definitions of deviant roles, as opposed to deviant acts. Indeed, can "adjusted" roles necessarily be equated with deviant acts? The rule-abiding aspect of efforts

toward getting well (or maintaining control) may be the qualifying property.

Parsons described illness as a form of deviant behavior.[164] As the complexities of the physician's and patient's roles are discussed by him, a major integrating factor is the motivational balance[165] of the social system in the evolving relationship between the two. Deviance is implied for either if the appropriate motivation is absent. We may well wonder if the deviation from normalcy would constitute deviance. The obvious questions to ask focus on whose definition is followed, and who is (or are) the agents for social control. Problematic participation is accorded each aspect of the patient-doctor dyad to define or follow the path of the "definer" relative to what is normal as opposed to not-normal or deviant.

In another work, Parsons specifically examined the case of mental illness and its place in terms of a value system within the social structure.[166] He made the distinction that in mental illness, there is an incapacity for role performance, whereas in physical illness, the incapacity is with regard to task performance. This would appear to be a modification in terms of the earlier conceptualization regarding somatic illness as it affects role, and in a sense, may have implications for the idea of illness, chronic or otherwise, as deviance. Parsons' differentiations were furthered in another respect:

> The first of these . . . differentiates the types of deviance involved in illness and disturbance of

> commitments to collectivities on the one hand from those involved in disturbance of commitments to norms and values on the other . . . ./167

In this functional approach, and in the particular focus on illness in the context of treatment via the agent of modern medical care, there arises a range of sociology of knowledge questions. The prominent idea of at least a moderate degree of stability in the American social system during the time of Parsons' major writings must have been a clear influence on his ideas about deviance. His notion of the status quo condition for society might well have grown from the moral ideal posed by Durkheim. Without doubt, the Industrial Revolution influenced the idea of the interrelationships of roles in society, but early, the technological emphasis and successes in modern medicine contributed toward the power of medical people's becoming agents of social control. The shift from the religious realm as socially controlling moral issues had taken place much in advance of these current periods, and the state supported self-regulating aspects of the modern medical system contributed to this latter power's being a current social control agent of society.

Almost as if a fad, but reflecting the growing dominance of the medical world, varieties of deviance formerly considered criminal behavior, are now labeled as illness.[168] Continuing the optimism of the Enlightenment, the newer emphases on science and technology are considered as means to achieve good and avoid evil. Social constructions of what constitutes social problems, of

course, constitute that which is so labeled. Equally important to recognize is that these constructions do not solve the problems.[169] Morality becomes an issue in these definitions as one reality substitutes for another. Making these medical problems minimizes the power of management by others, such as parents or family.

Transformation to this current medicalization of deviance has been gradual. Defining and sanctioning mechanisms in society involve the agents who hold power to do these.

In focusing on how medicine achieved this power and authority, this monopoly, one can point to significant advances in disease treatment and the growing dependency on technology. Most definitely, these have contributed toward not only an expanding jurisdiction for medicine, but also the general metaphoric usage of illness terms, such as suggested by Susan Sontag in her Illness as Metaphor text.[170]

Whether illness or badness, these are both still considered negative and undesirable. In moral terms, however, a distinction is still made between such behaviors which are willful and those which are unwillful. Parsons' earlier discussions point to the responsibility of the actor to get well as being crucial. With illness, the approach is non-judgemental; the behavior reflects the unwillfulness of the actor in what has occurred. As medicine becomes central in the treatment of these

disorders, it is looked to as the restitutive agent.[171] Philip Rieff's book elaborates this domination.

The competing explanations of deviance as illness include concepts of normalcy. Goffman's idea of stigma, indicating society's belief that persons with a stigma are not quite human or normal, can be applied here.[172] Lemert's discussions are in basic agreement.[173] Differences to which stigma is attached include some of the same mechanisms as with deviance, such as social distance; however, there are essential differences between the concepts.

Alcoholism may be a "difference" to which stigma is attached, and it may be illness, or conceivably deviance as well. Alcoholics Anonymous imputes normalcy to the actor if he is "at large", but he, the alcoholic must admit or label himself as not normal, to be treated (again a medical-type term). Garfinkel describes "degradation ceremonies" which make persons the subject of treatment or rehabilitation.[174]

It is also noted in the literature that the sick or the deviant are without social power, and that they cannot define for themselves what their behavior means.[175] Distinctions are made, however, between such deviants who become part of collectivities and those who do not, the former making efforts toward their own definition.[176] Deviance avowal and deviance disavowal are concepts, for example, referring to handicapped persons' particular actions which problematically lead to organizing together

or not.

If one were to speculate on a trend for the not-too-distant future, it might be in the direction of less power for the medical profession, essentially based on seemingly growing criticism of and skepticism regarding physicians. The "you have to trust them" stance as once purported by Hughes is more nearly the "you can't trust them" of Friedson. Data in the ensuing work enlighten issues of who defines what kinds of situations as problems, and acts accordingly. Central to debates are those interactions relative to normal development, with both families and physicians occasionally contending for basic decision-making, the medical personnel sometimes being the questioned "authority".

If we might borrow parts of theories that demonstrate a compatibility on certain levels, illness, generally speaking, may be deviance, and deviance, on particular levels, may be illness. The data will refer to these as possibilities.

Recognizing that hemophiliac and other chronically ill children have special educational needs, including that they may require education for sedentary-type vocations, schooling apart from those institutions where physically well children study was pursued for a series of years up to nearly the present time. British medical authors had recommended special boarding school for severely affected hemophiliac children, this to be run in the context of a

medical treatment program in that early treatment without loss of schooling is difficult to achieve without special boarding school plans. They discovered that the mildly affected hemophiliacs did well in "normal" classrooms, whereas most of the severely involved hemophiliac children missed at least a fourth of their schooling if they were educated in such settings. When schools were organized for only handicapping conditions, it was felt that academics were generally minimized or ignored. Hemophiliacs in these schools didn't feel that staff understood their particular problems, having no idea how painful and serious bleeding can be.

In a particular study by the researchers referred to above, a major finding was that most of the severely involved hemophiliacs would have preferred the boarding arrangement that was proposed. Nearly 20 years have passed since this study, and one might speculate that given the same research now, the authors would have different conclusions, based on current ideological stances on normalcy that more subjects would probably take. For example, one hemophiliac boy wrote,

> I would not recommend the institution of special schools, unless as a last resort, as I feel the day-to-day contact with normal children of very great importance . . . ./178

The authors of the mid-sixties concluded that this minority opinion (then) reflected a misunderstanding of the possible medical benefits of their proposal. England and France had also developed the special boarding schools in that

particular era.

Public law 94-142, written into law for the United States in 1972, required that schools make possible education in the "least restrictive environment" for all children, regardless of handicap or illness. This instituted "mainstreaming" efforts to minimize differences in education by including children with special needs together with those "regularly" educated, and thus "normalizing" this aspect of their lives. That they still require special attention for their special needs points to their deviations from the group norms.

Chapter 4

CHILDHOOD AND CHRONIC ILLNESS AS CONTIGUOUS PARADIGMS

Childhood Socialization--From Dependence to Self-Care

Childhood is a sociological conception. One need only compare the ways children are depicted in the art of the early medieval centuries[179] and even later, such as in Bruegel paintings showing adults and children pursuing like activities[180] with such phenomena of more recent times to discover that the former portrayed children as small-sized adults; the latter demonstrate perceptions of children (and childhood) with multiple qualities unique to young human beings. Whereas Lloyd deMause, editor of The History of Childhood,[181] debates such issues raised in Phillipe Aries' Centuries of Childhood,[182] it is clear that variations of these themes reflect the range of perceptions of childhood, based on social-historical conditions.

In fact, multiple perceptions are coexistent, as in the relatively current examples of views of children's play, from judgements regarding its valuelessness to those extolling it as the "work" of childhood. In discussing these issues, Norman Denzin emphasized that children are social products and cultural products, culture defined in broadest terms.[183]

At any rate, Rousseau's focus on children and childhood as objects worthy of study, was noted to be the first such attention to children in history.[184] He spoke of children's needs[185] in the process of their growing up.

Rousseau's urging that mothers nurse their own babies was followed by texts recommending this as a practice--perhaps a foreshadowing of role development for parents relative to directly nurturing their children.[186]

Enlightenment philosophies made possible conceptions of humanity and thus childhood as basically positive entities, with Hobbes expressing the view that young children were not responsible for their actions--they had to be taught.[187] This further defined adult roles relative to children. Regardless of the historical or contemporary times, ideological considerations regarding children obviously influence the social organizations of which they are a part.

High mortality rates in childhood, as in the 17th century, are tied to "aloofness, religiosity or putting the emotional burden on childhood." Illick reflects that such ideas produced a "heightened sense of self", augmenting rationality which would alter conditions responsible for the high mortality and, therefore, the conditions of childhood.[188]

In order to juxtapose social-theoretical perceptions of children with those of chronic disease, clarifications of the period of time as well as the technico-cultural influences are required. Sociology of knowledge analysis explicates both aspects of the problems presented here.

History, development, and social experience shape perceptions of and by the individual and his or her experiences. Language and symbolic expression are the

links, the "dialogue" created between the child and his primary group(s) within the context of the broader picture. Piaget, Mead, and Erikson, the theorists who probably most significantly nurtured the theoretical conceptions in these processes, overlapped in time to certain degrees, but, interestingly, perhaps influenced each other little, if at all.[189] Ideas relative to a "ripeness" of the times to build accordingly on earlier theories may well be partial explanations for their relatively concomitant work.

Especially salient in Piaget's extensive theoretical work on the thinking of children are his constructs termed assimilation-accommodation-equilibrium, "assimilation" referring to the processes by which the child absorbs symbols or other ideas from the outside world, and "accommodation" explaining the adapting of the "information", eventually to achieve a balance or "equilibrium" between the individual's knowledge and the outside realities.[190] This specifically underlines the active process on the part of the child in his learning. Piaget described a series of sequential stages through which this learning takes place, these theories being highly compatible with Mead's on thought as the internalization of social processes.

Both Piaget and Mead extensively studied children's language development and games, whereby the focus on rule development and rule following demonstrated childhood socialization.[191] Erikson extended these conceptions by

elaborating on socio-cultural influences on children's responses to events, as evidenced in their play and other interactions. The psycho-social implications, understood in the context of personality and child development, are complex, requiring thoughtful study on both longitudinal and cross-sectional bases.

Erik Erikson's Childhood and Society demonstrated the interweaving of developing human beings and their social environments. He noted how historians ignored the "fateful function" of childhood in the fabric of society, and elaborating on a corrective, he framed stages of development, each with its social components.

In a juxtaposition of the aforementioned theorists' work (Mead, Piaget, and Erikson), it is easily recognized that their socialization and learning vocabularies integrate, but include: process, order, internalization, assimilation, accommodation, imitation, symbolic expression, equilibration, balance, and language development. Some of the terms overlap in meaning, some are seemingly identical in concept, and others are highly compatible in understanding. It is a process in itself to sift and sort the concepts to select appropriate emphases for study of a particular substantive area. Nonetheless, the works of the three are considered as frameworks for understanding childhood socialization influenced by hemophilia.

Denzin's specific work on the topic of children's socialization encompasses an aspect of these perspectives

and extends them somewhat. With limited interest in development *per se*,[193] he described childhood and even children, as social, historical, cultural, and political productions, with meanings attributed to children as socially constructed. He discussed how a child comes to enter into the processes that shape his or her self-consciousness and awareness of others. He demonstrated, through his studies, the emergence of self-awareness. In the process the child shapes, defines, and negotiates relationships with the external world, including others and social situations. Denzin emphasized that children are not passive participants in the social processes.

Current definitions of children, as per Denzin, disparage them at the expense of maintaining a "status quo", reminiscent of newer titles that connote their vulnerability, *The Hurried Child*,[194] *The Disappearance of Childhood*,[195] and *Our Endangered Children*.[196] Essentially, however, children render problematic a routine social order.

Denzin's important work on childhood socialization, were it to have included greater emphasis on child development (aside from the sociology of child development and histories of perceptions of childhood), would conceivably reach some different conclusions. In discussing theories of games and play, he noted a "divorce" from the interpersonal contexts that produce them.[197] Child development theories, particularly Erikson's,

however, cover this gap. Nonetheless, Denzin's contribution, particularly in terms of early socialization of children, deserves appropriate attention.

Denzin pointed to language acquisition and use of language as being critical for physical independence of caretakers and greater dependence on "social and linguistic guidance and experience".[198] Lines of action are signified through verbal and non-verbal language or the "language" of gestures.

Learning is integrally related with socialization--that phenomenon which influences behaviors on the basis of the socio-cultural system experienced. A particular socialization process, focused on the unique events and meanings of a specific physical condition, is involved in a hemophiliac's career. Given its genetic feature and its coming into awareness in early childhood (on some level for the children, on others for the adults), the particular disease and childhood itself must be studied as contexts within which to understand the specific socialization of these children.

Reflections on the social lives of children would not be complete without further examination, as Denzin has done, of play, games, rules in games, and responses to rule violation. Simmel considered this, too, in studying interactional forms of childhood socialization.

The play and games of hemophiliac children require special notation, to compare them with those of their physically well peers, particularly relative to "rule

violation" where this can be construed to mean social difference. Their longitudinal, processual histories, reflective of these and other interpersonal contexts, yields clarifying data. Inferences may well be made about the emergence of self-hood under such circumstances. Networks of social relationship, nonetheless, rear children and bind them together, as Denzin correctly noted.

It is of importance that one of Denzin's "negative" cases included a child who remained outside the school's friendship circles due to his being periodically ill and absent.[199] Denzin pointed out that significant sociological studies begin from an attempt to understand particular, even personal problems.[200] The hemophiliacs studied in this current work frequently fall in this category.

Each family is a distinct community within which the child interacts. The family creates its version of right and proper conduct, and its version of what society is and ought to be.[201] "Right and proper" behaviors taught to hemophiliacs, centered on family philosophies and values, are modified by the requirements of the disease.

Issues of self-care become progressively central in a child's development, i.e. feeding, dressing, etc. Self-care as an issue to be encouraged is frequently described in texts relative to child care, especially those on adolescent issues and the care of sick adolescents.[202] Although there are ideological bases within these contexts,

consideration must also include the learning of a complex technical process, as with hemophilia. The "realities" of self-care vary, accordingly. Interdependence of "team" members, including those in the family, is implicated relative to the division of labor entailed in these processes. The frequently explained rationale for encouraging this learning is that there will be freedom from care which is dependent on others, and virtually a more-nearly normal life. Medical journals focusing on this, nonetheless, qualify the self-care for hemophiliacs as "supervised" home care.[203]

Children, advancing into the school ages, are more and more in contact with their peers and peer groups, particularly as described by Urie Bronfenbrenner's studies of American childhoods.[204] Research focusing on 6th grade children noted that they spend an average of 2 to 3 hours a day with their parents. Slightly more time is spent with groups of friends, and an additional 2 to 3 hours are spent with a single friend. This amounted to twice the amount of time spent with peers as with parents, and was particularly true of more boys than girls. Bronfenbrenner continued with his recognition that the child's "dependence on the group and his desire to belong are motivating factors to behave like the others".[205] Among other conclusions, he pointed to the fact that within a formal educational context, as experienced by these children, the school is the social unit with which the child can most readily identify.[206]

School structure, now institutionally in place with its classes to which children belong, was not known before the end of the 15th century.[207] Peer groups then, perhaps, were more informal, with an age differentiation for groups of childhood being less structured, in fact melding with adults, as has already been discussed. Other differences (aside from age) may have taken on other meanings.

Some sociological writers have pointed to the systems prevalent in classrooms as providing fewer concessions for the child's "inadequacies" than are likely to have been the case within families.[208] These structural differences between institutions are enlightened by the study presented here. Yet, as Denzin pointed out, the child, like the adult, can shape, define, and negotiate relationships to the external world or objects, others, and social situations.[209] This is problematic, as the data will indicate.

Sarnoff's Latency includes the discussion that beginning around the eighth year of life, the move toward independence that occurs

> produces conflicts with parents and an enhancement of the influence of peer pressure./210

Body changes occurring at this age and the several years to follow tend to produce a distorted sense of self, Sarnoff continues,[211] which the child of these ages may think of in self-rejecting terms, actually attributing the rejection to peers. Withdrawing from social situations may occur. Given the fluidity of conditions experienced by chronically

ill children, such responses of "normal" children may seem exaggerated.

Relative to these phases and sub-phases of childhood, child-rearing modes for children in the school ages, still include child rearing tasks maintained by adults, even though the tasks and associated roles are shifting. Lloyd deMause's discussion of the evolution of these points to the current era as moving from "socializing" efforts to "helping" work.[212] From a past of "conquering" a child's will to a mode of guiding, teaching, and leading the child toward conformity (as in a sociological functionalist approach), the mid-twentieth century saw the introduction of helping the child fulfill his or her particular needs as he or she expresses them. This implies recognition of a child active in his own behalf, who is responded to by empathic adults.

Perceptions of childhood and the consequences of these in the 18th to 19th centuries of Russia provide a sharp contrast. During this period in that place, historical and cultural aspects of the attendant situations shaped Russians' considerations that children were unimportant; whereas children had to be cared for, the convenience of parents had priority over the well-being of the child.[213] It is believed that autocratic parenting eventually gave way to less parental restrictions with the expansions of school systems to educate children.[214] These socially constructed institutions being closer to the currently

known models of child rearing, the general organization moved from dependence on conditional parental care to "care" extended through schools. Personal values grew to be more salient than the older traditional ones through complex interactions over time.[215] It would be difficult, if not impossible, to envision the particular social interactions of chronically ill children and their caregivers to be presented here, in the context of the aforementioned Russian periods even aside from the technological innovations which contributed to the shaping of the worlds observed here.

Nonetheless, by the 17th century, a particular place for the child developed with his parents, as opposed to earlier entrusting of his care entirely to others.[216]

A Paradigm for Understanding Chronic Illness

The paradigm developed by Strauss and Glaser, together and separately, in various publications and other presentations[217] [218] essentially focuses on properties related to the illness itself, the symptoms, and the regimens. For example, the illness might be characterized as fatal or non-fatal, reversible or not reversible, with certain or uncertain qualities, or by special social meanings. Symptoms would include the whole range of physical signs, conceivably some being not as intrusive as prescribed regimens. The latter might be understood in terms of how time-consuming is the treatment, how often is the treatment, how expensive is it, where does treatment

take place, who is involved, and what are the consequences of treatment.

Each aspect of the illness, symptoms, and the regimen influences or impacts on life and its meaning in some way, and involves work, this work clarifying how the patient and/or family manages the details and their meanings. The scheme for understanding is the illness trajectory, the course of the disorder, the work entailed, how these are integrated, and how they impact on relationships and life organization. Variations are only suggested here, but must also include considerations of multiple trajectories, divisions of labor, varieties of perspectives, and changes over time, such as acute phases within the realm of the chronicity.

The problems of daily living require strategies for handling the disease and treatment in order to prevent crises, managing them if these occur, controlling symptoms, carrying out regimens, minimizing social isolation, adjusting to changes, attempting to "normalize" interactions with others, and managing the related economic issues. Cross-sectional (as face-to-face) and longitudinal (as historical, processual) views both enhance the understanding. Often the medical personnel have a role secondary to that of the patient and his or her family in terms of actual work and care; the medical professionals may focus only on certain cross-sectional aspects of what takes place, such as regimen prescribing and crisis

care.

Obvious is the complexity of issues, the variety of conditions under which these occur, their interrelationships, and the consequences therefrom, over time. Within this complexity which characterizes the paradigm are also those issues discussed in earlier sections. The simultaneity of factors includes awareness and learning issues, normality and risk definitions, and the processes of negotiation. In fact, the Strauss/Glaser model highlights the negotiated interactional aspects of experiencing illness and treatment for chronic problems. Structural aspects are also objects of negotiation, this perspective emphasizing the voluntaristic participatory capacity of the actors.

Perhaps it is the interactionist model's concept of work which is one of its most critical features. The patient and family are not only not passive in terms of the illness, (they may indeed have been active to some degree in its cause), but may be very active in those social responsibilities that entail management of a processual nature. The concept of work includes many dimensions, such as implicit versus explicit work, body work, comfort work, information-gathering (awareness work), psychological work on the self, rescheduling (time work), and self-care for greater independency.

The concept "career" can be encompassed within this paradigm, in that the "illness career" is that series of related stages or phases, within an illness trajectory and

its management, as experienced by a person or persons. There is a structuring of time within a biography that is implicated accordingly.

It is estimated that 10% of the children in the United States are "afflicted" with physical disorders lasting three months or longer.[220] Some sources list a similar percentage, i.e. 7-10% having some chronic disorder.[221] At least 5-10% of the population under 16 are chronically ill, according to Pless and Pinkerton.[222] Trajectories and intensities of illness need to be examined, of course, to understand the social interactions so implicated. Audrey McCollum, in presenting child developmental considerations for comparative and contrasting purposes, relative to chronically ill children, emphasized, as have theorists already mentioned, that in mid-childhood, an increasing proportion of a child's experiences is generally outside the home. Greater involvement and sense of belonging with peer groups, when this takes place, enhances values for peer group conformity, with increased independence from family.[223]

She elaborated on the child with the health problem whose situation is different from the norm, citing examples of differences, such as the child on a special diet who is conspicuous in the lunch room, where there may also be interruptions for pills. Her reports that the child worries about how his peers will react, are followed by actually suggesting to chronically ill children what they

might say in a group,[224] and demonstrating how parents, principals, and teachers can help the child function within his peer group. Her book thus "intermediates" between sick children and their well peers, and it suggests that adults in the child's environment become his or her advocate in intermediatory fashion.

McCollum also addressed and advocated teaching the child about his disorder with information in terms he or she can understand, particularly in terms of what the child directly experiences. As aids in managing the regimen, McCollum reported that by age 6 or 7, boys with hemophilia know that bumps or falls might cause internal bleeding, and should be able to report these to their mothers. It might not be until age 8 or 9 that they'd understand why this happens to them.[225]

McCollum continued by elaborating that the course toward independent management is rarely smooth, and that the 7 to 11-year olds are unlikely to take full responsibility for their care, even though some may take pride in their active cooperation with it. She supported the idea that parents "stand by" to assist.[226]

Kleinberg cited references indicating that at least one-fourth of chronically ill children are far below grade level, many missing at least 6 weeks of school per year.[227] She spelled out interventions to enable these children's continuing participation in school and with peers, highlighting the roles of the "professionals". Peer group membership, particularly at developmental levels where such

participation represents the "norm" toward increasing independence from parental care, is thus problematic in these instances.

Socialization theories are probably the most central of those to explain how chronically ill children proceed through childhood. The illness "provides" major "content" in the child's experiences, modifying most other aspects of development. A superimposition of the illness paradigms on those of childhood qualifies each, ideologies (as problematics regarding normalcy) compromising each, depending on the predominant values incorporated. How a child, particularly with chronic illness, functions in his various social groups, is here presented as a "key" to understanding the consequences of the interactions, i.e. his development.

PART II: THE SUBJECTS

Chapter 5

SOCIAL/CLINICAL DIMENSIONS AND DISEASE TRAJECTORIES

Social Structures

Particular social dimensions define the population and provide the contexts within which to understand social interactions and their meanings. Further, these contexts become the conditions as well as the range of conditions associated with interactive responses and processes.

The population of boys studied herewith range in age from 7 to 14. Two of the boys have been followed for five years each, and the others for one to two years. Thus, developmental aspects of social interactions have been a focus of study, both longitudinally and through examination of the social processes "of the moment".

The boys have been students in 2nd grade through 8th grade classes. Four attend public schools and four are in private parochial schools. However, five have changed schools since the beginnings of their education; one boy changed from public to parochial, then back to public; four others from public to private. Of these, three who made changes did so with institutionalized progression from elementary to junior high school, or from one elementary school to another when the grades in the former were completed. One of the latter had had his earlier education in a special school which served handicapped children, and

was then "mainstreamed" within that particular school so that part of his classroom experience was in association with handicapped children and part with physically well peers. In two instances, changes were made with rationale directly related to parental perceptions of school problems regarding hemophilia management.

Several of the boys attended pre-kindergarten programs, one was kept home in that he could play with the baby of a relative and also a child across the street,

> not a whole group . . . . He usually doesn't play with a whole group of children,

and one was rejected by the pre-school in which enrollment was sought because the latter didn't feel that hemophilia was manageable in its setting. These issues suggest problematics, as will be indicated, in terms of how the hemophiliac responds and is responded to in "new" settings, with the potential for new interactions. Characteristics of the school populations themselves become pivotal in this regard, one mother indicating the transiency in the child's peer environment at school:

> He has gone through . . . about 200 kids in three years.

None of the children are only children in his family. One is a twin, his twin being a sister, with a non-hemophiliac brother born just as this boy's hemophilia was diagnosed. Most of the others have sisters, one of whom is an adopted younger sister. Two are second hemophiliac sons for their mothers, the first in each case having died of hemophilia-related injuries or illnesses, both occurring

before the birth of the current child-subject. Other sibship patterns are present, too, but without direct association to responses to this genetic, sex-linked disorder.

Two of the boys live with only their mothers. Divorce took place relatively early in one instance, and within the time-span of this study in the other. The other families are intact, "nuclear-type" relationships, one representing a second marriage, with only the hemophiliac child born of this union (even though there are other older children, not living at home, products of the first marriages).

Three of the mothers are themselves sisters and/or nieces of hemophiliacs, each tracing hemophiliac experiences in their families for two to four generations. Another had relatives with bleeding problems, not then recognized as being hemophilia. Each of these mothers relayed vivid details of the experiences within their families, one having two sisters, each of whom has hemophiliac sons. Three others had no knowledge of hemophilia in their families, and still another claims that a genetic mutation occurred, causing her son's disease.

Family economics also span a range of conditions, from affording only a modest, scantily furnished and hardly groomed household in a "not old" neighborhood that "speaks" of limited incomes; to a flat in a crowded section of an ethnically-oriented, commercially active neighborhood; to a large, substantial Victorian house on a wide street in a

long-historied section of the city; to an attentively-kept, pool-accompanied ranch style home in an isolated, wooded area of a suburb. Neighborhood characteristics and interrelationships vary with the style of living and the child's school connection (becoming problematic related to accessibility of playmates).

Fathers' occupations range from bus driver to stock manager to accountant to physician; while mothers' occupations (for which there is economic gain) include computer record processor, small business owner managing the work from home, realtor, and health professional. One mother recently left a part-time position as staff member of a local disease-related organization, assuming her former role in a volunteer capacity, but taking on a full-time paid position elsewhere.

The economically costly aspect of treating hemophilia incorporates the resources of private medical insurance programs and government agencies. If a family earns more than approximately $40,000, individual, private insurance coverage is necessary for payment for the infusion materials and other aspects of the care. Even though private coverage may pay for a million or so dollars worth of treatment, given the very high cost of the complicated care, there is the potential that such resources can be depleted within a few-year's time. One family's insurance resources paid $70,000 in one year, including the regular home infusion materials and hospitalization costs.

For the families with lesser incomes and no other

coverage, California Children's Services enable payment, the costs to be managed by a government program for the genetically handicapped when the patients become adults.

A striking occurrence in the social realm has become particularly critical in terms of risk-taking and related responses to the illness and its treatment. The socially-implicated crisis of AIDS disease, directly linked to aspects of blood products that had enabled hemophiliacs literally to "revolutionize" their ways of living, has become a salient factor in regimen decision-making, thus affecting numerous facets of social interactions and their meanings.

Disease Information

The degree of clotting is measured as a percentage and categorized, accordingly. Most of the boys in this study are considered to have "severe" hemophilia, indicating no or minimal clotting capacity. One tests "moderate", but to date, bleeds have been "mild". Another tests "mild", but is increasingly having more bleeds. Additionally, one of 228
the boys, as 10% of all severely affected hemophiliacs, has a complicating aspect to the disease, actually an antibody-type reaction, which renders a body response preventing the clotting which would otherwise be enabled by the blood product. This is termed as having an "inhibitor", which other observers have noted to have negative influence on regular school attendance and other 229
aspects of "normal" living. Most of these boys are

missing Factor 8, and are subject to an infusion of missing factor as a part of their treatment; the boy with the "inhibitors", however, is treated with a Factor 9 product with problematic effectiveness. For all, signs of allergic responses or other negative reactions, though remote possibilities, require monitoring, with the manner of infusion to be adjusted, to alleviate these.

Diagnosis of the disorder was early in most instances. The mothers who were acutely aware of the fact that their genetics carried the potential for bearing a child who would have hemophilia, knew immediately or almost from the moment of birth that this particular child had this condition.

All of the children have had hospitalizations and emergency room trips for treatment of bleeds. These have lessened in recent times, with home infusion being incorporated with the family work. Nonetheless, all experience bruising and bleeds, with frequent accompanying swelling and pain, requiring treatment. Immobilization with crutches or wheelchairs occurs intermittently for almost all, depending on the severity of their injuries and the time necessary for recovery.

All have attended the hemophilia camp, some each year since age 6 or 7.

PART III

THE DATA AND FINDINGS: SOCIAL DIMENSIONS AND PROCESSES IN GROWING UP WITH HEMOPHILIA

Social processes inherent in child rearing and child development sequentially move from work involving total care of a child for the child's survival, to those efforts on the parts of both care-taker(s) and child which enable the child's development toward independence or self-care. Interim events or periods produce phases of shared care, then particular "milestones" which introduce the child to new (not previously customary for this child) experiences and interactions, all of these presenting challenges or potential risks on some level. Inherent in self-care achievements are issues of self-development and the meanings of such in social interactions, all of which occur within philosophic contexts and styles of management.

"Rites of Passage" have at times been listed to include birth, puberty, marriage, and death. Interim events might also be listed within the framework here developed (extending from total care by another to eventual self-care), to include, for instance, extension from the care of one person to participation (with obvious self-care aspects) in school. Meanings of the milestones to social actors vary, depending on a range of social considerations or conditions. Under particular conditions, events may be regarded as milestones which, within other contexts, are not regarded as such. The data in this current study

reveal attention to milestones, at times coincidental with those representing social norms of the culture, as well as those demonstrating various meanings in such moments problematically associated with hemophilia and the related social conditions. One mother, in describing such an experience of her son's, essentially presented that it was "a real milestone" for him; others, including parent-authors described similar meanings to particular times.[230]

Risking physical or social selves becomes problematic in the work of care-taking, achieving milestones and other aspects of self-caring when hemophilia is a "given". Often there is particular meaning relative to risk-taking when a milestone event is to occur--the person has not before experienced the event and is uncertain about its consequences. The range of physical risks and/or social risks becomes clear in the data, the implications for development to be discussed as the evidence is presented.

Chapter 6

THE MEANINGS OF HEMOPHILIA: DEFINITIONS, SELF-IMPLICATIONS, AND PROCESSES IN SELF-DEVELOPMENT

The socio-historical concepts biography and career imply temporal and experiential dimensions. Superimposing the diagnosis of hemophilia, essentially viewing what ensues as a career based on hemophilia's management, on parameters descriptive of ongoing life histories or biographies, must be considered with the problematics of who has the disease (self or another), and the relationship to the patient (oneself or another). The point in one's biography the hemophilia experience impacts and begins to evolve, particularly whether this is in childhood or adulthood, shapes perspectives influencing actions and consequences. Reciprocal relations between inner experiences and those of the bio-social environment provide clues to the internalization, socialization, and developmental processes.[231]

The Massies' book Journey specifically points to the centrality of hemophilia in their lives, and how it shaped their relationships and their perspectives.[232] Suzanne Massie wrote about their son and themselves,

> Everything that he is, everything that we are now, is because of hemophilia . . . . Our lives cannot be separated from it./233

In young adulthood, Robert Massie, Jr. commented on the dozens of letters his parents had received from families experiencing hemophilia, expressing that Journey

told their "story", as well. In fact, the mother of one of the subjects in this study spoke, too, of Journey as being her "Bible".

Massie, Jr. continued, in his essay which he entitled "The Constant Shadow", written at age 25,

> One's illness becomes melded into one's identity. (It is) a constant and sometimes overwhelming companion, a shadow both inseparable and eternal. There is a me distinct from hemophilia, but it is hard to say sometimes where the boundaries to that me are . . . ./235

A hemophiliac's mother, quoting another mother of children with hemophilia, generalized,

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> Our whole life was hemophilia.

One mother, particularly active in organizational work to benefit hemophiliacs, explained,

> I'm very involved with the Foundation.

Another, similarly involved as a volunteer, but having previously been on the staff of the organization, spoke in terms of "we", referring to the community of and for hemophiliacs. Thus, the individual hemophiliac's identity extends to his family, and, for some, the social relationships of families and individuals extend through the organization, with further common identifications. One mother noted that the young adult hemophiliacs "see" their mothers in her. She further underlined particular aspects of her identity by explaining that,

> The mother is more compassionate (than the father who may tend to minimize pain experienced by the hemophiliac).

George Herbert Mead elaborated on the development of

the self as arising,

> in the process of social experience . . . (evolving) as a result of (a given individual's) relations to that process as a whole and to other individuals within the process./237

Such is the basis for understanding responses to learning about hemophilia within oneself or relative to another in the family. The work of becoming self-aware, of knowing and eventually incorporating the knowledge within particular social realms may begin for children as their language develops,[238] [239] [240] and may begin for older children and adults who had no such direct experience in their early childhoods as they come to perceive the disease within meanings of their relationships to those so afflicted.

Self-delineations, particularly relative to Mead's elaborations of the "I" and the "me" within the self, have implications not only for personal identities as these evolve,[241] but for the work inextricably involved in growing up with hemophilia, either in oneself or as it affects a sibling, or managing as an adult with a hemophiliac child for which one is responsible. Learning about the disease and incorporating those aspects relative to social constructions about the disease, the person becomes an actor in learning and managing the phenomenon.

Adult Perspectives--With Prior Knowledge of Genetic Potential

Adults who had experiences with hemophilia within their families as they themselves were children, either as

siblings or nieces of hemophiliacs, have incorporated these phases of their lives, as this study's informants reveal. The childhoods of these persons bear consideration in terms of how they now perceive the meaning of the disorder.

Young women who have grown up with brothers who have hemophilia are thoughtful about their potentials for procreation. One of Robert Massie, Jr.'s sisters reported that she, as a growing child, had read an article about the carrier issue, and concluded that she still wanted to have children.[242] He (Robert Massie, Jr.) inferred that the concerns of his sisters continue as they experience a "silent genetic grip", particularly as the "protective shield of parents melts" after childhood.[243]

From those adults who were aware of the potential for the genetic disorder in the families they would be creating in that they grew up with brothers or uncles with hemophilia, come family histories detailed with events they reflect upon as salient in their lives.

In the three families in this study where there was distinct knowledge about this genetic connection, the mothers recount their growing-up experiences with vivid recollections.

> My (hemophiliac) brothers were (both) schooled in the house . . . (although) my elder brother went to school until he was in second . . . or third grade . . . . He wasn't walking . . . from around age 7, (but) started walking again when he was 13.
>
> They couldn't go to school every day because if they had a knee bleed they would bleed for months, and if they had a knee bleed then they would be in the hospital. They were home very little so our lives revolved around the hospital.

> We had a grandmother that owned a store and we spent a lot of time working the store with her and you know we were taken care of. It was all on the same block.
>
> We think two uncles died with it (my mother's generation) . . . . My uncle who always had bleeds in the knee and problems with the knee . . had (the) leg amputated (and died) six months later (when) they didn't control the bleeding. They didn't understand that he had hemophilia before they did the operation . . . . After . . . they knew it was hemophilia.

Still incorporating information, she continued,

> Three years ago I questioned my grandmother . . . and found out that she had another son that she never even told . . . about (before). It was her first son and he died at 2 years old . . . . The baby had fallen and two days later had died . . . It could have been anything . . . . An aunt had a child with hemophilia (too).

Another mother related,

> I had two brothers, one died post-operatively. He was four at the time they went in for routine, and you can choke on that, tonsillectomy . . . . They knew there was a bleeding problem, (but) they did not know he had hemophilia . . . . Bleeding had already been (identified in the) family history. My older brother is fine . . . . He self-infuses (and) goes to the hospital sometime . . . . My brother had more problems than (my son) has. Most of his started in the sixth grade.

These knowing carrier mothers compare the regimens of the early experiences with those of the current time, noting the improved living now possible for hemophiliacs, albeit with special problems. Emphasizing early experience and knowledge about hemophilia, a mother explained,

> We were there . . . . My mother and dad were of the few who started the Hemophilia Foundation. I think there (were) 18 families before my father and my mom and my uncle got into the Foundation (in the late '40's).

Poignantly presenting the further experience of tragic

loss due to hemophilia, the mother emphasized her personal perspective.

> I don't believe anyone could know (what it's like) losing (a) son. (It's different from a loss of a child with whom you are otherwise close).

She continued,

> I think hemophilia sons get over-loved and they over-love in (return). There is an odd bond there . . . . I guess it would be with any handicapped child . . . . There are controls that they need over you and you need over them.

Further impact of the experience is described:

> The first year (of school for the child) was really hard because any time my name was called, I went into tears 'cause I knew why I was being called--(_____ would be hurt). Then the second year I got a little better. I wouldn't cry, but then the . . . traffic (to the hospital for treatment) was killing me.

Another elaborated, simply,

> It's scarey in the beginning, (in spite of previous knowledge and experience).

In referring to her earlier perspectives, prior to having a child with hemophilia, a mother delineated identities,

> This is as a sister growing up, not as a mother.

A young adult sibling in the current study became pensive and said, relative to possibly having hemophiliac children,

> (I'm) . . . not . . . nervous about it . . . but I don't think I can deal with shots.

One non-hemophiliac brother in one of the families was a year older than his hemophiliac sibling who died, thus he's "always had it in his life". The mother felt it

made him accustomed to the situation of the next hemophiliac child to be born into the family.

Another aspect of personal family genealogy development is exemplified by the mother who talked of wanting to document, as with a book, the history of the disease in her family, continuing to pursue information she still does not have. She has ideas about verifying her earlier recollections to clarify personal meanings. In this process she maintains a sizeable series of clippings, some from the 1940's, from newspaper and other sources, describing early experiences with the disease, including photographs of blood drive activities relative to her own family in the East. Newspaper coverage of interviews with her son were also in the collection. With the batch, as well, were printed materials related to hemophilia treatment and research.

Another mother produced a similar collection, kept in a drawer, which included local newspaper interviews featuring herself and her son and announcements regarding medically-oriented programs from which to learn more about the disease.

Generational perceptions vary according to the historic times. Mothers of hemophiliacs, looking back on their own childhoods, setting their current situations in perspective, vary from potential mothers of hemophiliacs who are looking back and ahead.

Taking risks may well be a factor in any decision

relative to having children, but such a decision in the context of knowing that there exists the genetic potential for a physical disorder gives particular meaning to the chance-taking. Three of the mothers on this study panel took the risk and consequently succeeded in becoming mothers of boys with hemophilia. One, in contemplating an intensive interest she has in helping sisters of hemophiliac boys to consider the risk, explained,

> I think something should be said to the fact that you have a choice of children. You will either have a healthy boy or an unhealthy one, and the idea of having an unhealthy child is scarey; but an unhealthy child with hemophilia is not the same as an unhealthy child (with a disease) like muscular dystrophy . . . . I think a hemophiliac child gives you more love than any other child you have. At least my ratio is two to one.

A mother of a hemophiliac, not otherwise on the panel of informants, explained that had she known she could bear a child with hemophilia, she would not have had children. However, her two adult daughters, one of whom is a physician, plan to have children. The daughters' perspective is of "prior knowledge" from experience with the disorder, which they link to their decisions.

Comparing the groups from the point of view of knowledge and experience in previous generations, the condition of knowledge or awareness is associated with particular consequences. An interesting sociological study of a basic issue here is Nancy Chodorow's, The Reproduction of Mothering, which postulates that women act as mothers along patterns they experienced with their mothers.[244] Thus, particular social relationships affect later ones, a

now well-verified postulate in studies of individual human development, here demonstrated across generations, as well.

The current data is suggestive of aspects of the work beyond the initial decision-making, where there is interaction with further consequences within the context of genealogical history and genealogical futures. One knowing carrier mother thoughtfully considered the advice she'll give her children.

> I would have to say it would be pretty much the same as my philosophy was, that it really didn't stop me from having children because I figured it was a disability that I was accustomed to dealing with.

The beginning to know or the continuing to know, tempered with new knowledge according to the technological and social times, shapes social interactions to follow. Deford elaborated that procreation may not be stifled by knowledge of genetic disorders.[245]

A now young adult sibling (female) of a school-aged hemophiliac recalled,

> I was seven when he was born. I was jealous, a little bit. I can remember the day he was born. I was a little nervous because I already knew my uncle, (my mother's brother) who has hemophilia, and I knew my great uncle with hemophilia. I remember the pain that they had gone through. I can't remember up until what age, but all they could do for (the uncle) at the time was wrap his legs in bandages or put him in a cast for months. My grandmother thought it was so bad that there was nothing you could do for (him) . . . . Each generation handles it differently.

This latter informant elaborated on her experiences as she, as a small child, was always taken to the hospital whenever her brother had a bleed, as she was still too

young to be left alone then. She recalled that she, her grandmother, and her mother often all accompanied the bleeding child.

She estimated, though, that she probably was 10 or 11 when she developed a clear understanding of the meaning of hemophilia, as she remembers those ages as being when she could give her friends and neighbors an explanation of her brother's condition.

Adults Without Prior Knowledge of Genetic Potential

One mother with prior knowledge guessed that,

> Eighty percent of the people do not know that hemophilia was in their family . . . . They say it lies 9 generations.

Prior to the hemophilia experience, some had little or distorted knowledge about the disease. One now recalls that when she was an adolescent she saw a television program about a hemophiliac. She remembers her thought,

> That poor person!

When one of the fathers analyzed differences between understandings of hemophilia families and others, he said,

> Lots of people think if you cut yourself, you're going to bleed to death.

To which his wife responded,

> That's what I thought.

Early symptoms are vividly recalled, similarly to those described by the families with prior knowledge.

> _____ bled and bled when he was circumcised. (Then) at 3 months (he had a) lump on his hand (we) first thought was a bee-bite. (When he had a)

> blood test (there was) much bleeding (from the finger prick). Then he had bruises from bumps on the crib.

The search for the genetic links may be extensive as reported by the Massies who researched nine generations in Switzerland.[246] The work process of seeking family information varies, relative to having or not having prior knowledge of the disease. A mother without such prior experience searched for links of information from her parents and grandparents, remarking,

> If they knew, they weren't telling.

The mother who contemplated the possibility of the genetic linkage (and who has basic genetic knowledge) commented that the disease might not have become evident in the family in the generations of relatives she knows in that there were "many girls" (who are rarely affected) born into the family. In the quantitatively small sample of families in this study where the carrier issue is now affirmed and where there was no previous knowledge of a family connection, there are no subsequent children, aside from the child born coincidentally with the definitive hemophilia diagnosis in the older sibling, and an adopted child. Such circumstances require comparison with conditions in "no-previous-knowledge" families that have had children subsequent to the birth of the hemophiliac child.[247]

One of the mothers in this study claims not to have had the realization of her genetic potential to bear a hemophiliac, but she does recall some bleeding-type disease of an uncle, and has close connection with two sisters,

both of whom have hemophiliac children older than her own. It is her husband, rationalizing that the family's information was limited because of cultural and geographic conditions, who discussed how he finally realized that their son's disease is hereditary. This couple has a daughter three years younger than the hemophiliac child, but plan no further children "now".

Whereas the Massies had two children after their hemophiliac son was born,[248] one of the mothers in the current group is fairly certain that she wouldn't have had any children had she known of her genetic potential for having children with hemophilia; she has had no subsequent children.

> No one told me. I didn't have to make that decision because I didn't know. In a way I am blessed because I didn't know and then again maybe I'm not . . . . I feel that if I knew I wouldn't have any children, but then again, I don't know. Maybe I would have felt something different. I honestly feel that if I had known I wouldn't have had any children and then I would have been upset. So I am glad it turned out the way it did except that _____ at one point was very upset . . . . I was hurt because it happened because of me.

She repeated these themes in several interviews, and proclaimed that she wants her children to know the hereditary implications. For the next generation, they are individuals with "prior knowledge". She still compares herself, though, with "new" parents who come to hemophilia meetings with their many questions.

Conditions vary relative to plans for future children and processes in seeking information. Socio-economic level

and degree of intellectual interest, aside from the prior or no prior knowledge variable singled out here, are major differences in these families. However, these are suggestive of directions to pursue for further study of these complex issues.

Critical for consideration are the purposes of the various means of information seeking and how the consequences are perceived; from whom the information is sought and to whom it is transmitted; when or at what phase of the disease trajectory or career experience this information work takes place; and by what processes it is enabled or blocked. The complexity of these issues characterize processes inherent in self and identity definitions, these in turn shaping work to follow.

Overlapping with the above in some instances, but separate in others, representing, nonetheless a related category of work is self-oriented medical meaning searching. Whereas those without prior personal experience with the disease demonstrated search for understanding the disease and its implications for management, one with prior family experience felt that in a certain sense, the prior knowledge was more difficult because the recollections were of much more life-difficulty than the current technology encompasses. She felt that her initial relearning entailed the burden of knowing of more severe limitations than the current reality presents.

A mother without prior knowledge, yet with over a decade of experience at this point, continues to look for

help with ideas to manage.

> I think it would be nice . . . talking right from the hospital (with) people with hemophilia . . . a discussion on how they feel, how things work out for them, so they can share it with all of us. Some of the boys could tell all of us something I may know for next year or even later . . . . They help us . . . . Sometimes when I go to the clinic there (are) . . . other boys there . . . and I ask questions and they give me their answers and I learn from that.
>
> I . . . think it would be nice if they had an address book with the hemophilias' names (and) phone numbers . . . so they can call each other.

Others search for help through consultation with the medical or medically-related staff.

What evolved for the Massies was incorporating considerable knowledge of the disorder, to the point where Mrs. Massie wrote a story for Time-Life Books on genetic diseases, and reported that it's the story she's proudest of professionally.[249]

Children's Perceptions--Their Increasing Learning and Self-Awareness

The children's self-identities and self-related actions evolve as they develop and as they learn and are socialized according to the disease's requirements. They wear "Medic-Alert" bracelets with the detailed information required to manage emergencies should these occur

> when the patient is unconscious, (and cannot act for himself),

one of the boys carefully explained.

The Massie's book initially explained that their son's hemophilia dominated his childhood,[250] and later elaborated

that he hated the "domination of his life by the disease".[251] One of this study's subjects proclaimed,

> It wasn't my fault I was born.

Another told his mother,

> Sometimes I wonder why I am the one.

Still another, at about age 9, tearfully exclaimed to his mother,

> Mama, I hate that I have hemophilia. Why did this have to happen to me?

His pain and his failures to fill desired athletic roles with his peers due to his general avoidance, inexperience, and therefore lack of skills became themes as he contemplated his situation.

The children's perceptions of aspects of their regimens include exaggerations and distortions if these can be compared with their mothers' explanations of reality. One boy thought he had been hospitalized 17 times, yet his mother corrected him to say that this figure may be more like a dozen hospitalizations. Another espoused that,

> In the emergency room, when I came in to get my medicine, they (the staff would) wear ear muffs.

His mother argued,

> Not to hear the crying? That's not true.

Yet he maintained,

> They put them on.

We do know that this boy had great difficulty in maintaining composure and being cooperative with his treatments until about age 9. It might be inferred that his perception of others' perceptions of him includes that

his distress wasn't to be listened to.

Still another boy, in talking about his admissions for hospitalization, described his usual feelings about himself under these circumstances.

> I'm all scared like something's really going to happen . . . (like) I'm going to die or something like that.

A modified version of feeling threat to himself was indicated by the boy who wanted to ensure that he not be put in contact with anyone with AIDS disease because,

> I have enough trouble.

A sense of vulnerability may further be inferred from observations at a hemophilia conference when a surgeon was showing slides of joint surgeries, the pictures looking "bloody". One of the boys periodically left the room, telling his father he was bored, and that if he were bored again, he'd leave again. Whereas inference without complete objective verification may be insufficient, nonetheless, the observations remain.

Information work relative to the hemophiliac child's self-awareness includes learning what the disease is and what it means. A pediatric hematologist compared the timing of parent-learning with child-learning, the latter following by a number of years, implying co-existence of "open-awareness" and "closed awareness", not unlike the theory developed by Strauss and Glaser,[252] but within the dimension of cognitive capacity. Piaget's theories in this regard explain the inabilities of young children for such

understanding, particularly when the issues are invisible. Abstract thought becomes possible at about age 10 or 11.[253] The earlier experiences, however, become a part of children's thinking prior to these ages, but on a different level.[254]

Children date, though at times vaguely, when they first came to "know" that they had a particular physical problem. One boy claimed that he has "always" known. Another said,

> I probably started to realize (it) about (age) 3, I guess. Real, really early, real early on. Then I hurt myself and (they would) take me to the hospital (to) get . . . transfusions . . . . Just kind of gradually, you know, somebody explained it to me or something.

Then,

> Oh, somebody explained it all out to me, probably about 5. There were all these chemical . . . and things like that. But I knew that I had to be careful because if I hurt myself I had to go out and get stuck in the arm.

This boy's recollections are relative to hospital or clinic treatments, whereas another associates his early knowing with school and peer-related consequences:

> In second grade I knew it for sure . . . . I came to school a couple of times on crutches (when first being given crutches) . . . . My mom had told my teacher that I had hemophilia, (but) I wasn't going to school unless she told my teacher (about the crutches). I was sort of embarrassed. You go to school on crutches one day, and the next day you have a shot (and) you go to school without crutches and all the kids were going, "you fake" and all that.

These recollections were described by the oldest of the boys being studied. The youngest boys did not make such connections.

There are interesting considerations here relative to

Piaget's premises that cause-effect understanding, at least understanding of such a relationship in concrete (not abstract) terms, begins at about age 7.[255] The associations, here, are relative to social consequences; the children saw relationships to particular experiences and interactions.

Not recognizing children's cognitive incapabilities one set of parents tries to explain hemophilia to their 7-year old son.

> I talk to him, my husband talks to him. We try to talk to him to understand the bleeding in his knees, the (affect on) the bones.

The mother here gives a "no use" gesture. The father further described how he began to tell the boy, at about age 3, that there is the possibility he'll die as the result of injuries which cause particular bleeds. The boy now repeats this information when he responds to related questions asked by his peers. In contrast to what he says, he "plays rough".

Appropriate examples for comparison are those in the data, essentially demonstrating that the youngest boys respond with an "I don't know" when pressed to explain what goes on "inside" hemophiliacs. The closest they come to explanations is relative to the apparatus and medication visible to them.

The development of self and related identities is enhanced by the beginning to know and knowing about the disease being experienced. There is variation in the

timing for these processes as they are described; yet the variation is not extensive. Massie, Jr. related,

> I have never known a moment when I did not have hemophilia and that fact has pervaded my family life, my education, my experiences with medicine, and my spiritual growth./256

He, in his parents' book said,

> I always knew I was different.[257]

One of this study's subjects indicated a similar sentiment when he said he's known for "as long as I can remember".

Other responses demonstrate a range of perceptions about when they began to "know" about hemophilia.

> At about 4 or 5, maybe . . . .

> In the first grade . . . ya . . . no, sort of. In the second grade I knew it for sure.

Yet another,

> The best guess I could say was around 6 or 7.

From always knowing, to realizing the disease's meanings by ages 6 or 7, there is variation, yet a circumscribed biographical span of time is agreed upon. The former is perhaps more perceptive of feeling, while the latter may better encompass specific childhood memories relative to cause/effect relationships in events surrounding hemophilia.

One household has, at times, had notebooks and other printed materials on hemophilia readily accessible due to the mother's community organization activities. While a younger non-hemophiliac sibling used these to develop extra credit reports for school, his hemophiliac brother occasionally perused them for his own information, only.

Self-orientation and associated meanings are suggested as a reason for this differential.

The learning takes place over time, with the perceptions and understandings changing according to achievement of higher cognitive levels. One boy (age 7) who was told he'd have surgery, with some of its details explained to him, could point out, on a diagram of a knee, what was to occur. His mother noted, however, that,

> You say "operation" and he draws the pictures, but he really doesn't know (about) the pain.

Another boy, at 11, recalled lessons in which he had participated that explained "x and y chromosomes"; yet, he couldn't quite understand how these related to himself and his own future. Self-orientation and its associated meanings make the connection unclear for this boy.

The siblings of these hemophiliac boys report similarly in terms of beginning to know and understanding. Robert Massie, Jr.'s sister, 20 months younger, was quoted,

> It wasn't until I was 7 or 8 . . . that I began to get a real awareness that something was different about him.

It was related that she would overhear "things" at school.[258] A sibling of one of the subjects claimed he began to know when he was in the first grade. None of the siblings spoke of "always" knowing.

Relative to having tests to learn about carrier status, one girl was very upset to learn (at about age 9) that she may be a carrier. Although these tests are not conclusive and will be repeated in a few years, her

response prompted her mother to say,

> In a way I wish I hadn't had it done. Then she wouldn't know.

A sister of another hemophiliac, nearly 13, claimed that she just learned about the hereditary aspect of hemophilia.

They just told me that last week.

Her mother elaborated that this information was not withheld from the girl, but she is just now beginning to understand it. The girl began to ask questions when she recognized that two other hemophiliacs she knows are brothers. She persisted in getting answers relative to her noting this as opposed to her particular family's situation where only one of the boys has hemophilia. Degrees of awareness co-exist relative to cognitive capacities, self-awareness, and incorporation of social understandings.

The learning process is particularly evident in the questions of an 8-year old sister, which she asked of her mother during both of the home visits made for this study. (Mother talking):

> She came in and asked if she was like me or Daddy in blood ways. (To child:) Your blood type is your daddy's, but that is entirely different from a carrier. You may or may not be a carrier, and that would be from me. We don't know yet. Testing said probably not, but don't trust it.

The abstractions involved suggest that this child's understanding will match "realities" as understood by adults in a few years hence.

Gradual learning, including the learning of a style to

manage, is acknowledged by a mother who attributed the process to her teaching.

> He was hurt because he couldn't do a lot of things the other kids were doing . . . . He could go ahead (and) do them, but he knows he will get hurt, so I will keep him from doing these things. Then eventually he started not doing them.

Thus, self-perceptions of deviance from the norms develop amidst growing knowledge about adaptations or strategies to incorporate these. Further data indicate this as a crux of the developmental problem to do "things the other kids" are doing, which becomes a central issue with self-development and growing self-consciousness.

Self-considerations in Peer Interactions

As indicated earlier, peer group identity relates to self-development, as these issues are constructed through the socio-cultural norms of the times and through experiences over time relative to development. The data illuminate this aspect of the children's biographies and hemophilia careers.

> A lot of my friends knew what hemophilia was before (my speech). They knew that if I got hurt it was more serious than a lot of people.

Another child elaborated,

> Everybody knows. They believe me, but you know it is just weird to them.

Relative to a third grader whose peers push him in his wheel chair, a mother said of her son's peers,

> I don't think they really understand, but it's accepted.

Another of the younger boys tells his friends, as he shows

them his hemophilia bracelet,

> Don't be rough because I've got hemophilia.

An older school-aged boy explained,

> They don't know what I'm talking about so they leave me alone . . . . They just understand . . . they can't sock me or anything.

A mother told of a protective aspect in the relationship with peers.

> They have a real rough-tough image, but when it really comes down to it, they really do care. When they are playing sports and they are out to win the game, that's one thing. But playing or fooling around in the neighborhood . . . they do really watch out for him . . . . They care and are protective of him.

Peer group pressure is frequently cited as being different from individual interactions relative to "care" about differences.

A sibling reported that,

> friends understood, but they just can't comprehend it.

The learning processes for peers evolves similarly to those of hemophiliacs and their siblings. Greater variation appears, however, in actual participation with peers, with structural implications to be elaborated upon.

> I wasn't accepted (by) the pre-school,

reported one of the subjects. Now, almost a decade following the "non-acceptance", the boy's mother reported that he is with his classmates at school,

> and that's it . . . . Most of the boys play football and whatever, and _____ doesn't participate in that.

This boy occasionally attempts to join games, but is

rejected since his lack of skill makes for errors on a team, which are quickly responded to in negative fashion by the other players. The only "friendships" this boy claimed were with one classmate who suffers from seizures, (but the boy's sibling claimed this isn't a friendship at all), and another hemophiliac, slightly older, but with learning problems, who invited this boy to spend a couple of week-ends at his house a year or two ago. (The two knew each other from camp and from a hospitalization period they shared.) His mother indicated that the only boy that he plays with is the little boy next door.

> With the other boys, no, because he doesn't do the things that the other boys do.

Observations at this boy's school revealed a peripheral participation during free play periods out-doors where he sat and watched games from side lines or "just walked around", or played with a few girls during free play indoor periods while all the other boys grouped separately. Participation during academic times is most likely to be like the participation of all of the children in the group in that physical selves are not the primary aspect of the interactions.

Of another boy, frequently confined to a wheelchair for extended periods of time, his mother reported,

> when we let him walk around, he goes and plays with kids, which he wasn't doing for quite awhile there.

The boy clarified further,

> I don't really play with other people because sometimes I don't want to or like today, I wanted to be like a teacher . . . . I started to tell

the kids to not run.

The Massies included with their data that,

> fewer and fewer mothers permitted their children to play with Bobby . . . (and) as others grew more independent, Bobby's infirmities became more obvious./259.

> He had entered kindergarten, on crutches, two weeks late because of a bleed, knowing no one. At recess time he was sent to the principal's office to sit alone. Because of frequent and extended absences, he missed half of the first grade and at least a third of the early school years.

Mrs. Massie proclaimed that "the most precious gift" is friends, children of the boy's own age. The boy spent winters in "loneliness and ostracism" and experienced the pain of never being asked to birthday parties.[260] This theme continued as it was explained that friends came more and more rarely, finally stopping,[261] and that the Cub Scouts wouldn't accept him as a member.[262]

This limited participation with peers is not evident for all of the subjects, however, such consequences varying with a variety of conditions. One boy's participation with peers, although somewhat peripheral at school where he plays teasing games with a few others on the sidelines, far from the great majority of peers who are actively involved with ball games, is qualitatively different outside of school. He talks of much involvement with neighborhood peers, including birthday party planning. Although he had marked difficulty getting along with schoolmates by the 5th grade, and schools were changed twice because of this, he has now (in 7th grade) added participation with and seeming acceptance from a large music group where he is the

youngest member. Adaptations made or strategies followed for "success" in peer relationships are suggested here and in other data, pursuant to group situations or selections made by personal initiative, rather than those circumscribed by placement in school. The characteristics of the peer groups are thus conditional. Nonetheless, the school situations must be dealt with, relative to the intense amounts of time spent there.

Another boy is reported to be,

> quiet with a group of friends, likely to do what is asked of him, yet not likely to lead.

He had missed 15 or 17 school days last year, the longest period out being 5 days. Such school absence has implications relative to peer group relations in that it graphically separates the boy from the others. This boy said he would like to play tackle football, but can't. When asked if this bothers him, he responded,

> It kind of bothers me . . . all my friends are.

When these games are played, he goes to the playground to swing. Yet, he maintains some active peer involvement, particularly with swimming where, as his mother describes, he has

> a lot of freedom to be rough and jump in the water. When he's with his friends in this activity, he is comfortable without being rowdy.

However, every boy in this boy's classroom had signed up to be on a touch football team, and he didn't want to be the only child who could not play. Thus, he signed up, too, rationalizing later that he plays this game less

formally with his friends at recesses. An alarmed principal, consulting with the mother, prevented this participation. The mother reported,

> He was in tears when I suggested that maybe it wasn't a good idea.

She further explained,

> When you form into teams, I get the impression that there's a little more pressure on you to be good, to win the game.

The boy rejected the idea that he referee the game. He pursued other options, which were to play with the girls or with members of other classes. His mother sympathized that it is "rough to feel left out". She considered that if he could be more involved with sports, perhaps he would go to school more enthusiastically. She is concerned that, at times, he may extend absences from school, remaining at home for a full day following a painful bleed, when he could conceivably return to school by the afternoon.

Another of the boys, this one with only a moderate clotting problem, is very active in sports, although he's been told by his physician that he'll need to eliminate the various team participations when he gets to the next grade level of schooling (5th grade), in that these sports are likely to become "rougher". Unfortunately, as the boy puts it, he'll not be allowed to play football, his favorite. He has found, though, that some of his friends prefer basketball anyway. He proudly announced that he "scored most of the points", this showing the degree of his current participation. His friends usually don't play rough, he

reported,

> but the people that it gets rough with, I just don't play with . . . so I try to avoid them and play with those people that know that if I get hurt it is more serious . . . . I think they play just as hard, but they still watch out.

His mother said further that,

> No hard balls and wooden bats are allowed at school, so the baseball that is allowed is the kind he plays.

One of the siblings (of another boy) recalled that when her brother

> started going to school . . . and . . . started meeting . . . friends, they were always scared to play with him because they (thought) . . . he would get hurt.

This boy maintains very active participation in sports, particularly in comparison with the other subjects. He proudly announced in one of the interviews,

> We won . . . . I was wide receiver.

The youngest in the group of subjects also plays very actively with peers at school and in the neighborhood. He demonstrated another aspect of peer participation with his closeness to his cousins, five of whom have hemophilia.

Another of the boys, one who needed to change schools after 5th grade because that concluded the grades in the particular school, enrolled elsewhere where he knew no one. He did, over a period of time, develop close friends he feels will last into and through high school.

The peers with hemophilia become a formal group during the hemophilia camp period, and are less formal as groups with occasional "friendship" get-togethers at other times

in the year, involving only 2 or 3 of the boys at a time. One mother thinks these hemophiliac boys are more relaxed when they are with each other. One of the boys, however, makes the point that he doesn't really associate with other hemophiliacs.

Still, the hemophilia camp remains popular, especially for the early school ages. One of the boys selected to go to camp instead of participating with school festivities honoring a graduation. Another was enthusiastic earlier (age 9) then, (age 10) questioned,

Who wants to be with a bunch of hemophiliacs?

but went to the camp nonetheless, feeling (later) it was the best session ever. He, in earlier interviews, seemed to want to convey that he was very active and almost daring in participation with peers at camp, as he related incidents like a game of chase around a tree, two hemophiliacs bumping heads and going to the infirmary with bloody noses. The medical report didn't corroborate this, but observations confirmed at least very active, if not strenuous playing on the part of this boy.

Of the hemophilia camp, the usually socially and athletically active boy said,

> The counselors were playing half football and half basketball . . . . They were just wierd. I didn't like the way that they played. They can almost kill you playing like that . . . . Everybody would be running all over the place. Five guys would be going for the ball . . . . It was just unorganized.

He explained that with his organized after-school group,

the patterns for play are clear, and thus he feels more protected. Yet, he claimed he has "wonderful" times at both the hemophilia camp and with his neighborhood peers. His sibling made an interesting observation when, for the first time, this hemophiliac boy went to the camp associated with the neighborhood group. Instead of his usually active participation,

> He (didn't) talk as much . . . . He (didn't) go swimming as much . . . . He didn't have a smile on his face . . . . He was always just walking around.

The mother elaborated that,

> this was the first time he had ever been away, where there was no one who could help him if something happened . . . . This was the first time he was really on his own.

The sibling added that his brother's "best friend" this year at camp was a boy who doesn't attend the neighborhood group, whereas most of the others are "regulars" in that group. This selected friend was also known by the children to have serious social problems, (no parents, etc.). This speaks to conditions under which peer interactions change, and suggests an issue of self-perception relative to particular peers selected for interactions. Additionally, there is a structural component to the concept, as peer group pressure (especially in larger groups) is less tolerant of differences than are smaller group interactions.

The boy whose peer participation is the most minimal of the subjects noted that,

> if somebody else had hemophilia and went to the

same school, that'd make it a lot easier.

This was discussed in the context of explanations about hemophilia at school.

The peers' perceptions of the hemophilia, as perceived by the subjects and informants bear implications for interactions with peers. The information given or not given to them and the questions of peers are conditions within which responses are organized. Robert Massie, Jr. elaborated,

> I never had to tell the kids very much. The teachers had usually explained it. Then the kids were automatically disoriented and immediately prejudiced. They had heard about me before they met me. It would have been better if nobody explained./263

Relative to her son, one of the mothers in the study said that he

> does not like to make a point of his hemophilia at school . . . . (He) doesn't speak up . . . . (He) does not like to be in the limelight at all.

Along similar lines, a sibling asked his hemophiliac brother,

> If a new kid came to school with hemophilia, would you let everyone bug him about asking questions or would you want them to ask you?

To which the subject responded,

> I would let them ask the other kid.

Another boy explained that friends used to ask questions, and

> used to think I was faking it.

A mother talked of teasing her son would experience when he went to school on crutches. Her explanation was that it was natural for the children to question what is

wrong. They notice nothing on the legs (like casts), and further, the boy is walking normally the next day. One boy, in similar circumstances, explained to his peers that his wheel chair was necessary because

> I bummed up my knees.

The Massies wrote of the blunt questions sometimes asked of their son. They noted the boy's feeling of ostracism and humiliation resulting when a school principal told all the children no one was to touch him.[264]

One of the older boys in the group talked of how he selectively tells peers about his hemophilia, in order to avoid teasing.

> First of all, I have to get to know them, and then, more gradually . . . then tell them.

He recalled, however, that going into 2nd grade, and a new school,

> I don't think I told anybody.

His mother elaborated that due to an injury in the 2nd grade, resulting in a black eye when colliding with another child in a kick ball game, his whole eye closed. No one apparently needed to ask if the boy had a problem, but reminders for all of them were recorded when the school photographer took pictures of the group during this time.

Some peers have watched the infusion treatments of a few of the subjects. One set of parents felt their son initially wanted such an audience. Another father noted,

> some kids can't watch it,

this qualified by a sibling who continued,

because they don't like the sight of blood.

Name calling or labeling or further questions from peers are frequent in the data. The Massies noted that,

> Bobby was called "leather legs" because of braces./265

A sibling reported that one of his friends spoke of a suppressed urge to call the hemophiliac boy "Mr. Hemophilia", but corrected this to "Pink Crayon", which is a melding of the idea of the boy's physical appearance during play and his name. Another friend of this sibling cautioned,

> Your brother, he better get that infection taken care of,

referring to the black and blue induration on the back of his hand, the site of infusions. With explanation from the sibling, the friend responded, "sorry".

The non-hemophiliac children from non-hemophilia families are obviously keen observers relative to differences. Incorporating this sense of difference, one of the older hemophiliac boys in this study tries hard not to cry in front of peers when he is hurt.

The boy who participated with a traveling music group became concerned that the group members would become angry with him if he delayed their tour when he needed an infusion. His mother cautioned that this would be a minimal disruption for the group in comparison with what would happen if he didn't treat himself and then required hospitalization for complications.

Demonstrating a density in the data, related self and

peer interaction detail appears in the next chapter, as well, but in conjunction with data on "peer interaction work". These particular data could well be categorized under several socio-analytic themes since the work of presenting oneself in groups is integrally related to one's identity. They provide inference relative to development, the parodoxical situation posed by trying to avoid injury, yet participating with others in normally-prescribed ways which may cause injury.

Chapter 7

WORK INTERACTIONS IN TREATING HEMOPHILIA WITHIN THE FAMILY AND THE CHILDREN'S WORLDS

Work, the divisions of labor, the interactions and integrations inherent in the related and interrelated roles, and evolving identities in the corresponding continuities or careers have traditionally been foci for studies in sociology.[266 267 268 269] Qualities discovered in work interactions are obviously applicable to those involved in accomplishing tasks, whether or not there is economic remuneration. Meanings associated with the tasks, negotiations within the work processes, resistances, conflicts, and self-definitions yield various social consequences for children and families as they treat hemophilia and manage life in general, albeit with a chronic disease.

Strauss's paradigm for studying chronic illness, with its series of dimensions for consideration in examining illness trajectories and other characteristics of diseases, imposed upon work paradigms, presents potentials for enlightening this new data.[270 271]

The work of knowing and understanding, although continuing processually relative to self-realizations, extends to other categories of work associated with the regimen management of hemophilia. As will be demonstrated, these processes show overlapping, shifting, and changing courses, relative to special tasks, development over time, and the participants, themselves. The focus here is

primarily the social action apart from the medical and hospital work, highlighting the work of the family members, including the hemophiliac boys. The roles of the medical workers are, nonetheless, critical to the variety of responses described here.

Personnel and Work in their Milieus

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Mothers and Sons

The data on "divisions of labor" are divided and categorized, first by "Mothers and Sons", in that the most pivotal work interactions as evidenced in this study occur between mothers and sons, with salient trading and shifting over time, from the adult's work to the child's efforts. "Pivotal" in this context refers particularly to the technical treatment of bleeding, first learned and applied by mothers, and eventually managed by the sons once they have mastered the technique. Once learned by the boys so that they can treat themselves, they can participate with peers and others with a normalcy more akin to that of the others. They need not return to their mothers or wait for treatment agents to come to them before resuming other social interactions.

Obviously, the total "picture" includes the work of various members of the household, such as fathers and siblings, and those of other members of the children's worlds as they move toward and into participation with groups outside the family, as with peers and school

personnel. Traditional social roles may well be the major influence affecting mothers' care of their children. Nonetheless, the Massies indicate that the hemophiliac is

> subject not only to the limitations of his disease, but to a dependence on the kindness, generosity, and sheer physical presence of other people./273

The clear implication, as well as the evidence as culled from the data, points to the fact that the hemophiliac boy cannot "do it alone". The family also points to others on whom they rely. The Massies felt that much of their learning about life with hemophilia came from parents of other hemophiliacs[274] and, indeed, that they didn't learn everything at once.[275]

Learning/Teaching:

The work of learning and incorporating knowledge about hemophilia has already been presented in terms of becoming self-aware and interacting, accordingly. With learning and trying to learn, there is also teaching. The variations in teaching reflect considerations such as the object(s) of the work, who teaches, and the timing. With thought relative to who is being taught, is also the action of a complete sharing of knowledge versus an incomplete sharing, essentially a "sieving" of details. Whereas others have termed such work "selective disclosure",[276] "sieving" is here meant to include that which cannot be conveyed for reasons other than non-selection. The latter distinguishes the children's work, in particular, where it is evident that, for developmental reasons, there is limited cognitive

ability to understand the issues, and thus limited conveyance of them. Other "non-conveyance" is related to limited ability to relate information to oneself, even with cognitive ability to comprehend the disorder and the rationale of its management.

Learning and teaching the technical aspects of treatment (to be discussed in the next section) either follows learning and teaching about the disease *per se*, or is concomitant with it. The latter includes the data regarding educating sisters of hemophiliacs or other possible carriers, such as sisters of mothers who have produced hemophiliac children. The lessons taught in these instances are generally discussed in terms of the genetic potential to have hemophiliac children. Opposite this effort are indications, in a variety of situations, that there is variation in the interest on the part of these would-be-"students" to learn the information that another wishes to present.

> (My sister) . . . has never married . . . has lots of friends, and is a traveler and a career lady. Even if she would get married, she has more or less decided that children . . . would not be something to have . . . . Out of curiosity she said (she) should get the carrier test done, but she has not yet . . . . It hasn't been a priority (for her).

Another of the mothers talks of her sister and that sister's daughters, none of whom pursues testing to determine if they are carriers. The informant's opinion about the rationale here is that they are "just scared."

Of the whole "story" to tell, the Massies, with their

professions in writing, articulate,

I knew we would have to write.[277]

Their reading audience, though, would be far different, particularly social-distance-wise, from family members or even baby sitters, for example, when revealing "too much" in the latter instance might frighten them away.[278]

Also, it is clear that each of the parents does not see for himself the mission of doing this particular teaching. A social, structural feature also affecting this teaching, as well, is that persons responsible for program development in agencies which attempt education on hemophilia respond in various ways to presenting particular topics.

> She (the program planner) listens to our ideas, and then does what she wants.

Continuing pursuit of a particular idea, however, the mother (just quoted) encouraged a related clinic to present a program on the desired topic.

Relevant data presented in the prior section with considerations of self-other relations is, of course, indicative of learning-teaching work. Additionally, a great deal of teaching takes place in other contexts, and shall be elaborated upon in the section on "Work Across Institutional Boundaries".

Early explaining to peers, especially in school, varies in form, but is often in conjunction with mothers' work. One boy elaborated,

A couple of years in lower grades me and mom

> brought in all the equipment and showed it . . . . We explained this needle stuff and my arm . . . and the medicine goes in . . . and the tourniquet made my veins show.

Now a fourth grader, this boy began to refuse to partake in the "show and tell" his mother had initiated. When the mother of another boy presented the idea of having a person from the medical clinic do a hemophilia-explanation session for the class, the boy's response was,

> I'd be absent from school that day.

Changes occur in the boys' sharing of information about hemophilia, particularly with peers. One interview included a mother's saying,

> When he was younger anyone could ask and he would go into detail, but since he's gotten older, I guess he's tired of the same thing over and over, so he doesn't answer them any more. Like there (are) a couple of new students . . . and he won't tell them; the other students tell them . . . or he figures it's his business and not theirs . . . That could be it.

The boy claimed he never talked about hemophilia with peers, but then clarified this to acknowledge that it was "ages ago" in the first grade. The mother counter-claimed that he explained his condition at school up until the fourth grade. (This particular interview took place when the boy was a sixth grader.)

One of the oldest boys, when asked about his problem, said he responds with "shut-up". Still another of the older boys described that he begins a very technical, cognitively sophisticated discussion of missing clotting factors, following which his peers, with humor, stop his "lecture".

One of the younger boys, now that he no longer makes a
mal presentation" to his class, felt that his peers
to think he was "faking" it. When seeing the
ches, they would ask, "How did you do it", as if there
been an accident. He said he would answer, "A dinosaur
me". He continued,

They think I have a broken foot or something. I just leave it at that.

bove is reminiscent of comments devised by Mrs. Massie
er son's explanations to his peers, that the injury
aused by a dragon when the boy was fighting it in the
279
yard.

ne of the youngest, whose mother is still his "base"
aking explanations at school, said,

ost of the kids know to just don't fool around ith any of us hemophilia kids,

hen responding to a question on how to explain it to
ne new, said he could explain the kind of factor, but
the hemophilia itself, finally answered, "I don't
. Another of the youngest had the identical response,
ssentially added that he tells others, "Don't be
". He "told" his friends, but not his teachers. One
articularly as he reached about age 10,
es not talk about hemophilia . . . very much.
n contrast, a sixth grader, one having moderate (as
d to severe) clotting capacity with few bleeds, gave
l speech at school on hemophilia.

is was for the "I had a dream" contest. I d the dream of finding the cure for hemophilia

and I explained what hemophilia is.

litions differ for this boy. Although his bleeding
city is rated "moderate", clinically his problems have
mild. He has had few bleeds in contrast to the others
he study, and participates fully with friends,
eivably appearing less "different" to them. One might
er if his "difference" is sufficiently mild to make him
very acceptable to his peers in terms of all of the
he is like them.

Whereas some of the boys agree that one must let
ners know about the hemophilia, another, at age 12 and
riencing a whole set of new teachers, proclaimed,
didn't tell them nothing.

s his mother likely to convey such information.
The 13-year-old, entering a special interest group,
ll of the explaining to his peers (all older),
as, at earlier ages, his teachers conveyed hemophilia
mation to his classmates. He reviewed,

> ots of times the kids constantly bugged me about
> t, and I'd just tell them they're dumb or
> omething.

From no direct explaining to explaining those aspects
e disorder which entail visible experience, to
osing medical "realities" or veiling such information,
is an age differential. The sieving may be
ated with the child's cognitive level of development,
lective disclosure or veiling may be associated with
f taking social risks. The desire to be like the
roup, not to be different, is characteristic of this

as has already been presented, particularly with the
ing independence from family typical of the mid-school
. A newer self-consciousness evolves, developmentally
he middle of these school years.

One of the older boys who described annoyance with
stant" asking "every ten seconds", demonstrated that
of his explanations is relative to physical risk in
al contexts:

I just say, "Let's say you get punched or something; you'll bleed inside for a little bit, then you'll stop. I don't stop. I leave it at that.

er explained similarly:

go, "No, I'm not (a fake) because say you got urt and got hit by a baseball or something in the ead and you had a little bump. The next day after hat it would be all healed and better, but if it as me, I would have to have a shot and if I take he shot the first time, hopefully it will be etter".

ntinued,

ome people . . . I tell them they can't see (the roblem), but I say, "Look at my veins. This is here I get my shots because my veins are all lack and blue." Some people talk to me you know; hey make fun. They say, "Oh, you're a druggie" nd all this stuff. Some kids, like bigger high chool kids that are like juniors, seniors, and ophomores, they make fun and say, "You're a drug ddict" and all this stuff.

ocial risk of this information work is characterized
oignancy in this boy's explanation and his comments
followed, and suggests implications for others' not
such risk.

he telling or not telling is problematically also in
ntext of relationships with teachers. One of the

oys is in a school program that involves a special ducation teacher's visits to school to help him develop etter motor coordination skills to support social articipation.

> (Mother talking): They do things like basketball. Well he had this thing going on with his finger, and I wasn't sure if she was coming every week because it has been . . . sporadic . . . . _____ had this bleed that started in his finger and we treated him for it . . . . It seemed to be getting better the next day (when) . . . he went to school . . . . This lady came and I guess played basketball with him . . . and then the next day he needed another treatment for it. It was definitely worse . . . . I said, "Did you mention to her that this was a sore area and this might not be a good thing to do?" And he said, "No, I didn't say anything".

Following one of the mother's having told a teacher about the hemophilia condition, the teacher asked the boy a "bunch" of questions. The boy reported feeling stunned by the questions, and essentially didn't answer them. (The teacher had queried why it was that he selected certain games to play, but did not play others.)

Technical Work:

The search for and learning about what the diagnosis means pragmatically, evolves eventually or concurrently with work otherwise performed by medical specialists or technicians. Whereas it appears to be common knowledge that diabetics inject themselves with insulin, it is not "commonly" known that hemophiliacs eventually infuse themselves with the clotting factor they are missing or with another blood product.

Technically-speaking, the hemophilia infusion is more difficult to accomplish in that it involves injection into a vein, whereas the insulin treatments are intramuscular. Learning to do this work at home often becomes the work of mothers of hemophiliacs, pursued, generally, until the hemophiliac boys can infuse themselves.

One mother described her learning to infuse her son:

> I had done it once, trying it on myself, and I did it into my hand, and just as I was ready to pass out . . . I said, " I can't do this" . . . so I was ready to really forget the whole thing, and the next time we went to the hospital one of the nurses said, "Oh, come on . . . try it on me". And I had to dig and dig to find her vein and then the next time we went to the hospital . . . (one of the technicians) said (to my son), "When do you think Mom is going to be able to do it?" And he said, "She can do it now." And I said, "Okay". And I tried and I found it and I just started crying, and I couldn't even move because I was so nervous. And then since it was a week-end and we would have to get interns at the hospital with no doctor on call . . . I decided I would do it at home . . . . The doctor said . . . "Take it home, and if you can't do it, then come on in".

Another simply explained that the nurse had taught her to do the infusing, and another described that the physician had taught her the process. Still another learned, essentially, through her professional training.

Whereas most of the mothers in this study became the first in their families to learn to infuse their children, Mrs. Massie reported that her husband learned first, and gave the first transfusion in the doctor's presence. The boy himself, at age 13, then learned the process. Both parents eventually became proficient, with early "misses" as the veins are "slippery". Conditions then differed

those reflected in the current data, in that first,

home infusion idea was very new and still relatively

ied, and secondly, if not primarily, the hemophiliac

was, at that point, beyond the early school ages and

less fully dependent on his mother for most of his

.

"Errors" or "misses" occur in the learning, as they

in medical personnels' learning, as well. One boy, in

ng about his mother's learning, noted in comments

ted to his mother,

> ast year, around September or October, you
> ere trying to get in (the vein) . . . and finally
> the doctor) had to get into the vein. You did
> nce, but we had to go back the next day for
> nother treatment. You couldn't get in.

so reported a particular event:

> fortunately, my mom doesn't know that (reference
> de to treating injuries) because I took a roller
> ate in the forehead and got a big bump and we
> ver got it treated, and the doctor said that it
> ould have been treated.

ch the mother responded,

> blew it on that . . . (but) it turned out to be
> ne.

ne process of learning, then, leads to the on-going

infusing.

> takes about 45 minutes. It used to take a long
> e when I missed the vein and stuff, but I'm
> lly good at finding the vein now . . . a lot
> ter than I think I am. It (actually) is about
> hour procedure by the time I run it down and
> ff. But we could do it anywhere. At first we
> to go in the bedroom and have these lights,
> now . . . if he is watching TV or if he is
> cing on the phone all he has to do is lay down
> arm . . . . I still put the board on and
> l use the saline. He is waiting for me to
> up so I don't have to use the saline. I like

to know that I have it before pushing the needle in.

Learning is integrally related to eventually becoming oficient, with stages of learning extending over time d representing various interactional and experiential ctors.

A boy whose clinic treatments extended beyond the age en home treatment could have been initiated, was involved clinic care in that his mother couldn't manage his ghting" the infusion. The medical personnel, in fact, mented on the physical effort required to treat the boy. mother explained the eventual shift to her managing the tment.

All of a sudden _____ stopped himself because I told him that he was hurting himself . . . . He started asking me if I would do it and I said, "okay" . . . . They (didn't) mean to hurt him, but I'm his mother . . . . I'm gentle, you know, more gentle than the doctors . . . (so) I learned.

ontinued,

ou take it out of the refrigerator . . . . f he has 3000 units . . . that's three bottles, o that would take me about 7 minutes to mix that. ou know you have to wipe it off with alcohol and ransfer the liquid to the medication. Then it akes maybe 15 minutes for it to dissolve, which s really quick now. Before with the old edication it would take about a half an hour or re and it (was) a long drawn out process. So it kes maybe 15 minutes total, but I give it 5 nutes more because I want to make sure it is mpletely dissolved. While I'm mixing the dication, he's preparing everything else for me give him . . . . So he starts to pump his arm get his veins up and then about 20 minutes ter the medication is mixed, I start giving him e medication. He lets me know if there is too h pressure because you can't just give it to like you're turning on water because it is ng through the vein, and I listen to him when says, "Mama, stop" . . . . So every 5 cc's,

> I'll stop for a minute . . . . When the clock shows a minute has passed, I start it again. Sometimes it is only necessary for me to stop about half a minute.

Another mother, whose son's hemophilia is of a milder nature, explained,

> The only reason I insisted on home treatment was after we had those earthquakes a few years ago. I wanted to know that in a crisis we knew how to treat him . . . . They don't recommend it when you are only being treated once or twice a year, because you can't become accustomed to getting into the vein. We have known how to prepare it since day one . . . but you don't want to practice on the kid except for the real thing. So right after we learned we did it a couple of times and succeeded once, I think.

Her son interjected,

> They kept missing my vein.

He clarified, though that he is now learning to be proficient in the treatment.

Another mother reported that she has just been shown the treatment process, in that her 7-year old son now has many more bleeds than in previous times.

> They showed me how to fix the factor 8 at (the hospital), and how they shake. I learn a lot.

She had not yet performed a treatment.

Most of the mothers particularly recall very clearly the history of their sons' treatments, including the names of medications, forms of treatment, and the timing of these. Therefore, the one "negative" case where the mother was not clear on such delineations prompted further examination of conditions which might be associated with the difference. She is the one least likely to "interact" with others regarding hemophilia issues. Her general style

as she presents it is to listen, with little direct asking of questions. She then pursues problems on her own. Interestingly, she's been reprimanded by medical personnel for errors in her treatment decisions.

Other parents report pride in home maintenance of infusion treatments. One mother especially pointed to the fact that her son has no arthritic problems and no scar tissue.

The technical aspects of home infusions began with this group of respondents primarily when the children were around 4 or 5 years old, with the mother generally the infuser. A later beginning for two of the boys took place when they were 7 and 9, respectively, as already described.

The shifting of the focal point of care from the medical person to the parent varies in timing, but also includes a back and forth exchange of this management. One mother reported that her son may have been infused with an AIDS-contaminated blood product (from a batch of factor withdrawn by the drug company for precautionary measures) the one time she decided to have the hospital treat the boy instead of doing it herself.

The teaching of the technical work is most directly an aspect of the work of the medical professionals, with the mothers' efforts usually guiding the teaching of their children to times relative to the children's ages, such as when they are "old enough".

The technical teaching of giving the blood products

through infusion is further qualified, in that the mothers' work may be in a supportive or other-wise enabling role, as others, often the medical personnel, teach the hemophiliac children. The decision regarding the timing and method (regarding who does the teaching) is a part of the mothers' thinking (and encouraging), problematically related to resources, including participation at the hemophilia camp.

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> Hopefully he will (learn) in the next 6 months . . . . We have a friend that came and showed him how to get it in the arm and everything, and he did that fine . . . . I'm going to take (my son) to (the friend) and let (them) do whatever friend-type thing (once again).

This mother added that she is especially interested that her son learn the process in order that he might go camping with his father, who won't learn to do the infusion.

Respondents generally agreed that the teaching of the boys is done most easily if the one who teaches is outside the family. One mother clarified that she remembers how difficult it was to learn to drive when her mother was the teacher. Two of the mothers indicated interest in having help in teaching their children from a particular young technician who is also a hemophiliac. One indicated that it was her idea to enlist the aid of this person, and he has agreed to be available when the boys are "ready".

Another parent specified,

> (He'll learn to self-infuse) if not this year, no later than next year. I'll give him until next summer (at camp).

One of the boys explained he had appointments with the

clinic coordinator to learn to "stick myself better". He was to practice on

> a dummy or her hand or my arm.

The length of time the treatment takes changes with growing proficiency and with changes in the particular product or medication used. A newer treatment method using DDAVP, a product to enhance clotting capacity (but only for those mildly or moderately affected) without the risks of blood products, takes longer to infuse and is not yet used at home. One of the children, in fact, commented that,

> (The) boys don't want it . . . . You have to sit there (longer).

The parents' achieved proficiency makes the consideration of children infusing themselves problematic in that the treatment time would again take longer until they (the children) are proficient.

> It's unfortunate . . . that his treatments are always under the duress of time . . . . Yesterday morning . . . I (had just come home from work) in enough time to get the kids'. . . books together and get them off to school . . . and we had an hour . . . but he needed a treatment before he went to school . . . . It's a very quick kind of a rushed thing . . . . (The bleed may not have been) so evident the night before . . . and that's one reason . . . (he) hasn't been as involved. Because . . . he (would) need the time to get it set up.

As indicated, the boys' beginnings to learn vary according to their ages and other issues; the process is generally gradual and in conjunction with interaction with mothers and others who teach the techniques. One 7-year old explained,

> I got myself the needle and mixed in everything, but I didn't put it in . . . . I put it in his hand . . . . It's easy to do that.

The method of learning a little at a time is pursued, as one boy reported,

> (At camp) . . . they got the needle in for me and I pushed it in and took it out.
>
> (At home) Mama does it most of the time. I could put it in . . . . Mama was standing there and watches.

Overlap of the work of responsible persons with the boys' efforts prepares for an eventual end of the transition.

> Maybe just the mixing the medication up, and the sterile technique that's involved would be a help. (He has done it once or twice), but the times were so spread out.

There is thought, however, given to when the transition(s) can be made, one mother saying that

> I'm kind of waiting for him to express more of an interest in doing it himself.

Another mother reported,

> He hasn't been doing it totally by himself because sometime he doesn't want to do it, or it all depends on the time, and then I'll go ahead and do it.

Regarding one of the older school age boys, the mother commented,

> Now that he is older he can handle most of it himself. They (the school) called me a couple of times (and) when he came home . . . I (from work) talked him through his infusion over the phone. Before I was working (and he was younger), then they would call me and I'd go pick him up.

Even when a boy has learned to infuse himself, his mother may still do the work, given particular conditions. One mother, talking about her son's learning to treat

himself, said,

> He knows how to stick himself. He can do that but the problem is sometime he doesn't quite get the vein. He becomes very upset. If he does it the first time and misses . . . . He does it a second time . . . (and misses), after the second time, I take over.

One of the older boys, although he learned this technical work two years ago, explained,

> I don't really like giving them (injections), but I can. But I get nervous, and if my Mom's home, she will give it to me. But, if I really need it, sometimes if it is really hurting bad, I take it.

Another of the older boys could take his first trip away from home with his new ability to give himself the infusions.

A mother explained,

> He did it very well right away and then I guess the time he got sick; I did it, but then he started doing it again, and he has done it ever since.

She continued,

> He does it all himself. The only thing that I do is help him with the tape and he can even do that himself, but it's faster if I just do that in the morning . . . . It's just a matter of saving time . . . . If I weren't here, he could do the whole thing.

A boy's recently gained proficiency with independent treatment enabled his participation in activities for two weeks at two different camps, only one being the hemophilia camp. At one he infused himself after he pulled a muscle in his leg, and at the other he infused himself after hurting his shoulder in a game.

Sequential stages following mothers' learning are from

mother/infuser to mother/infuser with child practicing to mother/infuser with child infusing on occasion to child/infuser. Learning to give oneself the clotting factor via intravenous apparatus is the aspect of technical work which is pointed to as the most pivotal milestone in the self-care process, the most salient part of the move toward independence for hemophiliacs.

Frequency and conditions for treatment vary; for some the "every other day" prophylactic treatments were replaced with "when I get a bleed", this change directly related to the initial impact of information on AIDS. Modifications in frequency, then, took place following the development of still further information about AIDS, with considerations relative to non-treatment.

Technical Assistance Work:

Whereas there are relatively few properties in the technical work dimension as performed by mothers of hemophiliacs and the hemophiliacs, there are a considerable number of properties relegated to the technical assistance work performed by the family members and other non-medical persons in child-care roles. Each, of course, varies with particular conditions.

The children's being the object of the technical work points to <u>cooperating work</u>, entailing holding still. This is, essentially, <u>body work</u>, yet of a passive nature. (Active body work will be discussed also.) By the time these boys have reached the school ages, they have learned

to participate and in fact enable the technical work of infusions, regardless of who does them, by holding still. An exception was the behavior already described of the boy who "needed to be sat on" for his infusions. Descriptions of the "non-cooperating work" of the younger ages have been listed, as well, and particularly documented by Kassowitz[282] in a study citing cooperative behavior as essentially beginning with children at about age 5.

The cooperating work may mean that the child sits or rests while the factor goes into the vein. This may take about 45 minutes, and the child in the meanwhile may watch television or talk on the telephone, as these families have reported.

The Massies point out that most chronically ill children spend the bulk of their time <u>waiting</u>--for treatments to be complete, for tests, doctor appointments, physical therapy, and through innumerable intrusions as in the hospital, and, most especially they wait to get better.[283] This work fits into the time organization of those for whom they wait. Passive work of this nature might also be compared with the holding still required for treatments, both being technical assistance efforts. The holding still may be enabled by a parent, as Mrs. Massie described holding her son down for his early transfusions.[284] (A parent in the current interview series explained that she didn't want to hold her child for his treatments.)

Some of the boys give direct <u>advice</u> <u>or</u> <u>help</u> <u>with</u>

preparing the medication. A mother further elaborated, in explaining her work,

> Like when I'm mixing the medication . . . and the needles don't act right, I say, "_____, what should I do?" and he tells me and it works.

Monitoring symptoms is basic to work which leads to actual technical treatment or the decision not to so treat. This monitoring takes place, as well, when previous symptoms are watched to determine if a technical treatment has "worked", a special problem when the hemophiliac's physical condition involves inhibitors. One mother described such a situation:

> There (are) no definite clues; it's never a dramatic immediate response . . . . When he starts having a bleed . . . even if the treatment works, it's not necessarily (the) next day (that) everything is fine . . . . It's not something we can look at and say . . . "This looks so much better." . . . (We judge) how he is using (the limb) or not using it, if he's really guarding it from movement . . . . It's basically just . . . . looking at it or in some instances actually taking measurements of the swollen area to see if it's grown any larger the next day or it hasn't . . . We just wait and see . . . usually a day.

Another mother responded,

> At first I don't know, then I will suddenly see something that (tells me his pattern is different) . . . . I know by the way he walks. If he is not walking right something is wrong with his foot or his knee or his leg or maybe even his hip. So then I'll look at it. Sometimes I don't even see a bruise because he has these . . . muscle bleeds and you can't see it, and I still have to give him his medication.

Still another explained,

> If it's the same or a little better, we just wait and see . . . . If (blood) continues to accumulate, the pain gets worse . . . . The blood that has accumulated in the joint's face or in the

muscle area takes awhile to re-absorb.

This parent continued,

> (We) . . . wait and see a day or two, then re-treat him . . . . If it's getting worse, if this goes on and he needs a third and a fourth treatment, then we would seek advice from (the clinic).

Spontaneous bleeds, those not related to known injuries, may occur, as well, thought by some to be related to anxiety. Mrs. Massie is reported to have been able to detect when a bleed would occur, by monitoring her son's moods, as he'd become pale, cranky, and irritable.[285]

A mother who does not do infusions explains her monitoring,

> If _____ is hurt, I get ice on it . . . . If it starts to swell, we go to the doctor's. If it is really bad we have to transfuse it.

Related work for all subjects, then, is noting symptoms, measuring bruises, and applying ice, all of this assistance stemming from monitoring.

Pain is a symptom that may indicate bleeding in a joint. In these school ages, the boys can all report this symptom; but, in the earlier ages, they could not necessarily do so, thereby requiring that these mothers "monitor" the indications of pain as well. One mother put the age of this transition at around 4, and another indicated how much it helps now that the boys can report, with clarifying explanations, the sensation of pain.

> (Mother talking): We have to go by his evaluation of it . . . . (It) really helps (now that he's old enough to do this).

One of the mothers recalls that her son used to report such

bleeds just before bed time.

Whereas one mother said she didn't let her son out of her sight at the early ages, partially to protect him, but also to monitor problems, other mothers who worked outside the home weren't spatially present for some of the monitoring.

Getting to know vulnerabilities enhances monitoring.

> Now I can tell because it seems like my ankle is the worst spot to get hurt because that really hurts. It gets hurt bad and when it gets hurt there . . . when I bend my toes out, it hurts.

In discussing ending treatment (such as crutch-use) for a particular bleed, one boy expressed,

> I . . . just get off them when I can walk.

Reporting work, including reporting pain, is salient in the problematics of considering technical work.

> If it is a real bad bump, I go up to the office and call my Mom.

Another time, regarding the same boy, there is a conflicting report:

> (Mother talking): I've always mentioned that I'll be here near the phone and if he feels very uncomfortable during the day with a certain bleed that is going on . . . to call me, and I can come and pick him up, and he has never done that. It frustrates me that he doesn't speak up when it is necessary to do so.

At school, an older boy reported that when he is hurt, he goes to the school office and says,

> Just give me an ice pack and call my mom.

Robert Massie, Jr. reported on conditions under which reporting a bleed is very difficult.

> (The) decision to announce a bleeding was

hardest in the middle of the night.

He said that he sometimes delayed his decision to make the announcement, understanding the household disruption this would initiate.

Protecting is also a part of the general monitoring in that avoiding accidents also has implications for treatment. The Massies note that when young, parents protect the impaired.[286] Several of the mothers discussed having padded their children's clothing in the early childhood period in order to prevent accidents and bleeds. Mrs. Massie reported that she tried to sew pads in the small child's overalls and found that these didn't stay in place. She padded the edge of the coffee table to cushion bumps the child experienced, while another mother spoke of having padded her son's infant seat. One mother carried this theme further.

> When he (her son) was a baby, we made pockets in his crawlers (to fill with padding).

She's also the person who didn't let her son out of her sight. Constant watching in these early stages were part of the attempt to keep the child from doing what would hurt him. The world of the playground encompassed mothers' watching beyond the household itself.

Another mother protected her son from playing with potentially "rough" children. She had complained that the other children in the particular neighborhood really "reared themselves" (which is opposite of her philosophy); hence, the child care plans she devised kept her children

from interactions with these neighborhood children.

Protection work includes concepts about self-protection as the hemophiliac children are taught protective behaviors. Interventions, accordingly, for the children's protection at school, become potential efforts of parents and school personnel, as will be described.

Body work of a different nature, essentially protecting from injury, was described by the young boy who maneuvers his wheel chair in various ways to avoid balls coming in his direction. With gestures and animation, he related,

> Once it (the ball) was coming towards us, but it was up in the air and it could come up like this or come like this or come boom or wham on my knee. So I try to protect my knee.

Avoiding risk with body work brought to this boy's mind an "invention" which would enable his doing "wheelies" safely.[287] He thought of

> a design for my wheelchair . . . . I was thinking of putting a board back here so when I do wheelies I wouldn't go back on my head. If I go back too far, it would swing out by itself.

Further protecting work, through body work, was observed in the playground behaviors of several of the boys. One literally flinched when another child rushed by him on the way to recess. Another played with only one other boy, far from the kick-ball game that was taking place, which was involving most of the rest of the class. (The teacher said, in this instance, that she permits the children to "do their own thing".) Still another boy played quite peripherally with only a few others, in a

teasing-flirting game, while all of the rest of the youngsters were involved in a series of ball-related games during the lunch break.

Protection of an extensive nature was practiced by a family (in the 1940's) who built their house away from other children, so their hemophiliac child wouldn't be "tempted" to join friends.

Transporting work becomes technical assistance when this is done in conjunction with hospital and clinic treatments. Transporting work includes, as the Massie book indicates,

> All those transfusion trips.[288]

Transportation to clinics for treatment received heavy emphasis for those periods of time prior to initiating home treatment. One mother talked, wearily, of the era when she was frequently required to "drive up the freeway" for her son's infusions. Another mother described the process she would undertake:

> Before I learned, they would call me (at work) and I would (take a bus to) pick him up, and take him (by bus) to the clinic.

Although the degree of this work has changed with the children's reaching the school ages and with the initiation of home treatments, the transporting continues to take place under other conditions, some for, essentially, protecting purposes. One mother elaborated that she drives the boy to school if he is experiencing a bleed that prevents him from riding the bus. Two other mothers drive

their boys to and from school. One explained that the child can take the bus when he doesn't need to be in the wheelchair, whereas another transports her ambulatory son to and from school even though his sibling rides the bus.

Consultation-seeking work appears in the data under a variety of conditions. Consultation-seeking work, at times, is the work which is involved in getting a "second opinion". The consultation-seeking was clear for most of the families in the efforts to find, initially, a diagnosis for the problem. Others sought consultation in the process of making changes relative to physician or clinic plans.

Still others seek consultation when special problems or situations appear. In such an instance, one mother, while on a trip with her son to a distant city, took the opportunity to consult with someone who has been treating hemophilia "for over twenty years".

> I drove . . . into the city and _____ looked at it and . . . as soon as (the doctor) saw the brace . . . said, "That's barbaric". . . . I always (left) it up to the doctors to make all the decisions and I just can't any longer.

She further explained that she could have gotten the consultation closer to home, but took advantage of the trip's opportunity, particularly since the person consulted is one of the country's foremost hematologists and pioneers in hemophilia treatment.[289] The mother additionally explained that,

> if _____ didn't give me the opinion I wanted, I would have gone somewhere else.

Consulting work was inferred by a discussion with one

of the mothers regarding a plan to visit in another state. She consulted with knowledgeable persons relative to names of hospitals and other treatment sites of the particular area. The family's hemophilia connections made it possible for them to call upon hemophiliacs in the area, should this have been considered helpful.

Here, as in examples cited for moving medical responsibility to a new physician, consultation-seeking becomes problematic for course-changing work relative to the direction of the treatment itself. A mother continued her discussion,

> The thing that I always find is that the parent seems to know the child better than the medical field and just because you know it happened this way for Johnny Smith, it does not mean that it has to happen this way for Joe Somebody-other. Every person is an individual.

Two and one-half months had elapsed from the time of the first interview with a family until the second. At the time of the first, there was discussion about possible surgery for the boy, in order to treat a joint problem. At the time of the second, the mother indicated that she had decided upon a different course of treatment, embarking on an exercise program for her son, trying to avoid an operation. She had thus altered the advice she had originally sought.

A condition perhaps interrelated with this issue is, as she described it, a long-time experience with observing that hemophiliacs don't necessarily require surgery for such problems. (The mother referred to a 1940's report

by a family who described record-keeping to demonstrate and teach physicians from personal observations.)

The consultation-seeking takes place in the context of a particular health-care service, as well as in the context of "other" or outside medical resources. A mother described a clinic visit to discuss her son's particular symptoms and problems.

> The last time that I took him into the hospital the young doctor, you get the interns coming through . . . looked at him and . . . (said), "Well I don't know what to tell you", after I told what was going on . . . . "I'll try to find somebody that I can ask." So, as (he) was walking out the door, I said, "I hope God is out there because that is about the only person I can think of . . . ." So (he) comes back in with this young Dr. _____ who soon as he walked in says, "I'm not (God)". So we're all the way up to the head of hematology.

During an interview, a mother explained that she had just put in a call to the clinic to ask a question relative to a new observation she had made (monitoring) regarding the effect of an appliance, particularly due to its weight. She was anticipating a return call from the clinic.

Non-consultation seeking appears in the data, as well, particularly in relationship to the mother whose philosophy includes self-reliance (see chapter on Philosophies and Styles).

> There were even a couple of times where I didn't even call Dr. _____ . . . . They (later) said it was more involved than him having a bleed. It might have been something there that I wasn't aware of and by me not being a doctor which is true to a point . . . . I can understand the doctor's side, but with my side, my instincts tell me . . . . Now when (he) has a bleed, I take care of it . . . . Then I'll call (the doctor) the next day . . . . I have to let (the doctor) know

> because (he) got upset with me, which I can understand, because one time I didn't and it was really a bad bleed, but I didn't know it was a bad bleed . . . . That was a lesson for me, but it could have damaged (my son) for life.

Exercising and exercise-directing, as active body work, is further technical assistance. In a particular exercise program, the mother works with the child twice a day, approximately 15 minutes each time, directing his work (muscle tightening, leg raising, and weight lifting), counting, and negotiating with him over the number-count being required. This takes place after school and at bed-time.

For one of the older boys who has a "chronic thing with his knee",

> He's still in a program to strengthen his knee, (by) do(ing) his exercises.

The boy elaborated,

> I do them here (at home) . . . about 10 minutes per day. I bike sometimes.

Mrs. Massie's experience with her son's required exercising indicated particular aspects of her work in that he expressed resistance to this body work. There were intense efforts to keep the child occupied and stimulated so that the exercises at home might be pursued. She called it a "battle".[290] When traction was required for 3 hours per day, she tried to have visitors come, to distract the child from his unwillingness to be in this position.[291]

An observation of a mother directing her son's exercises revealed this child's resistance, as well. She pursued encouraging and counting for him as he would lift a

one pound bag of cereal on his foot. He meanwhile had some distraction in discussing the lock system on his brace.

> (There's) only one way this can be bent and I can control that.

The mother's understanding and planning for the exercises and movement are indicated in her explanations.

> So now he has to get all those muscles back before the leg will be sturdy enough to walk on, (and) I do want to start taking him out of the wheelchair a little bit more slowly.

An older boy discussed participating in one of the Japanese martial arts, partly for recreational purposes, but his mother wanted him to be sure the exercise and motions would fit his hemophilia regimen. The exercise-directing thus also takes the form of selecting "safe" forms of exercise and enjoyment for the child. One family encourages swimming and modifies special family outings in terms of water-skiing and snow-skiing so that the hemophiliac boy participates in forms of the activities somewhat different from what the others do.

Teaching the children about appropriate exercise may be considered indirect exercise directing. Non-directing (as illustrated by one family) takes place under certain other conditions, including philosophic ones. A physician's advice for one boy is that he not play soccer. The boy indicated that he has played soccer "hundreds" of times; the father then talked about the boy's then suffering the "consequences". The non-direction on the part of the parents reflects their philosophy that the

mother quotes,

> If a kid's going to fall, he's going to fall. We can't keep him in a vacuum.

For another child, the "exercise direction" came from the pediatric hematologist, whose instruction was repeated by the boy.

> I can play basketball through junior high and then that's it.

The physician's evaluation was based on his recognition that the game becomes rougher at the higher levels of school.

Other technical assistance work surrounds the requirements for attaining, maintaining and storing medical supplies, particularly the factor and materials for injections. These are critical for enabling treatment to take place at home.

Both the Massies and the families in this study who had experienced hemophilia in the generation before, though, knew well the processes then involved in getting blood for transfusions. Collecting blood through neighborhood and community blood drives were required activities for them.[292] The Massies said they needed to "beg for blood",[293] while the grandmother of one of this study's subjects had told a newspaper reporter,

> We owe blood and we need blood.

They reviewed the pervasive difficulties in obtaining this commodity.

The factor use has significantly altered the process and socio-economics of attaining and maintaining supplies,

since it is a blood product manufactured by drug companies. One mother said she

> call(s) the clinic and tells _____ what I need; (then I) go to the (pharmacy) window. It takes awhile . . . . Sometimes the wait is incredible.

The mothers and subjects speak of picking up supplies of varying quantities. One mother picks up materials for 6 infusions; one of the boys was to bring home 20 boxes of materials from the clinic. Another of the boys now takes his infusion materials to school to store in the refrigerator there.

The family using an especially imported product to counter the inhibitor problem realizes the particular costs involved in what they bring home to store. A power outage drew their major concerns over the $46,000-worth of factor they were storing which required that the refrigeration be maintained.

In discussing the utilization of refrigerator space, one of the mothers explained,

> There are ways that you can take it out of the box and you can even take it out of the small box, and put the factor in (the refrigerator) and keep the water out, so that there is more room. I did that actually. We kept the water upstairs.

For another family, a storage plan was developed for the infusion materials for the duration of an overseas flight.

> On the plane we . . . (had) a little bag of ice. We (had) packed (the) little bag . . . which happens to be a diaper bag, and I put blue ice in it.

Paying costs is obvious work. The costs, although

generally managed by insurance or other plans, are nonetheless noted by these families. The mothers generally keep track of requirements relative to the insurance and other coverages, recording the costs to these third-party payers of the care. One mother specifically mentioned that she and her now former husband had decided that they would share in the responsibility for the medical care, both involving themselves in employment-related coverages.

A job loss changed payment circumstances for one of the families. While working, yet without sufficient private insurance coverage, payment for the hemophilia treatments came from the state program designated with this responsibility. Remarking on an unemployment period, though, a parent said,

> We are now on Medi-Cal . . . . I guess they will have to (pay) . . . . I haven't received a bill yet.

Another mother talked about the complexities of payment. She said that the state program

> help(ed) to pay . . . . They pay all of the Factor 8.

She continued that she pays her insurance plan $36 per month, but that the total costs of the factor were about $7000 a year,

> sometimes even more, especially when he stays in the hospital . . . . Every bottle costs $25. It depends how much they put in.

Another family worries that the million dollar life-time coverage they have might cover only 4 to 5 years, as their son needs increasing amounts of the costly materials.

The Massies were heavily involved with major fund raising events in several places in the world, honoring premiere showings of "Nicholas and Alexandra", based on the book of that name by Robert Massie. The Hemophilia Foundation was a beneficiary of these.

On another level, aimed toward attracting various kinds of support, many of these families participate in publicity efforts about the disorder, consenting to newspaper interviews relative to personal matters connected with the disease, and to other forms of media coverage about hemophilia.

Efforts relative to meanings of particular relationships might be termed relationship work. Timing of these interventions includes moments when the child's emotions are considered vulnerable, such as in instances of fear or loneliness due to experiences with the disorder.

Robert Massie, Jr. claimed that his mother

> helped me fight off occasional bouts of depression . . . when confined to bed, with a combination of sympathy and challenge.

She brought books and games, helped the boy learn to cook, and straightened the pillow to support his swollen knee.[294] She would often sit up nights with him when he was in pain.[295]

Other personal relationship work is demonstrated by a mother who spoke of her spending all the time of her child's hospitalizations with him when he was small, but generally only evenings with him during the hospitalizations of the recent years.

With hospitalizations now infrequently experienced, she works in the context of particular relationships to postpone week-end plans involving others if the boy has a bleed.

Still another mother maintains very close relationships with her sisters, each of whom has sons with hemophilia, and drives them to the hospital when this is necessary.

The Massies' move to France for a period of time when their son was 12 was essentially relationship work of a different order, to

> take Bobby from circles which emphasized sports participation to emphasis on academic excellence./296

Organization work relative to the disease, an aspect of relationship work, fills many hours of several of the mothers, one stating,

> I have a lot of hemophilia work to do,

in reference to such tasks.

Peer-Interaction Work:

Social participation and interaction with peers, as processes, are, at times, characterized by what appears to be symbolic representations. How the boys present themselves with others is reflected in the way some of these children costumed themselves and appeared during Halloween celebrations.

> I was a Hurt Man. I was hurt at the time, too. I put fake blood all over and a stained scarf around my head and my leg, and took a crutch I

> didn't want to go around as a clown in a wheelchair, so I just decided to be a hurt man.

Another boy, while in a wheelchair, decided the wheelchair should be camouflaged by boxes, encompassing him, to make him look like a car. Both of these boys disguised, yet didn't disguise, the visible aspects of their hemophilia care.

Actually, it is the visible aspects, including those aspects visible to the boys themselves of how they are treated, which are discussed with peers when the hemophilia is discussed at all. (See earlier section on self-considerations in peer interactions.) Only the older boys use social examples or even sophisticated discussions in explaining the disorder.

It is appropriate to question how the information is "received" by physically well or non-hemophiliac peers. One mother commented that they all know about the hemophilia, but none of them understand it. Another pointed out, in discussing that the son demonstrated the infusion treatment to neighborhood children that

> It's real hard for most kids to be really impressed by this to the point where they wouldn't ever get into any desire to let it swing if they wanted to get into a tussle with each other.

A peer of another of the subjects watched an infusion treatment, and this friend, following the treatment "went home", apparently with no comment.

There has already been mention that peers indicate disbelief over aspects of what is explained to them. One boy's comment is reminiscent of several of the others.

> I've had to deal with the kids always calling me faker or something, and you know . . . kids in Junior High . . . pick on me.

This is in contrast with the peer interaction which takes place at the hemophilia camps.

Utilizing labels to describe themselves, at one particular hemophilia camp the children vote each year to name their camp. All of the names selected represent aspects of the hemophilia experience: "Romanoff's Revenge", "Nobody Can Do It Like Your Mama Can", "Take This Needle and Shove It", and "Camp Hemo-Ridge". Tee-shirts for the boys are annually decorated with the selected title and an appropriate emblem. Other hemophilia camps with "permanent" names are "Camp Blood Brothers", "Camp Blood, Sweat, and Tears", and "Camp Wounded Knee". The distinction to be made here is that there is a more "open" presentation of oneself in the homogeneous groupings, rather than the "closed" or disguised self as presented in heterogeneous groups. Likewise there is relative confidence that each understands the hemophilia experiences.

Peer interaction work in heterogeneous groups may include assigning a classroom friend to push the wheelchair and relying on an older peer for help with infusions, as per the data collected. Social participation problematically involves protecting work to some degree. One of the boys plays, practicing less protection, in most of the major sports of his peers, except tackle football.

His risk-taking is generally considered, though, as his many injuries must be followed with treatments. Balancing social participation with body-guarding work is practiced, with conditions varying. The balance tilts toward taking either social or body risks. From the data it appears that toward the mid-school ages, the boys become less willing to take the social risks of being separate from the group. This follows developmental considerations.

An often central process in enabling the peer-interaction work during these school ages is the role played by parents, as shall be discussed in the section on "Work Across Institutional Boundaries".

Fathers

Problematics characterize father and sibling participation, and, in a sense, condense the work of mothers; fathers and siblings may do many of the same tasks, but generally in lesser proportions. The particular perspectives qualify the differences, too, with the fathers' work being more closely aligned with mothers' efforts; siblings grow into work related to their hemophiliac brothers.

Particular work on the part of a father was singularly exemplified by Robert Massie who gave blood directly to his son when the hospital had no fresh-frozen plasma.[297] No comparable example emerges in the currently collected data; the condition most clearly making the difference is the technological advancement beyond use of whole blood or

plasma.

One father in the group participates fully in infusion work and related decisions, monitoring and caring for the boy, especially during his wife's work hours spent at her job. His professional training "matches" the requirements of these tasks. Other fathers participate in transporting work when clinic visits are required, either for ongoing monitoring or for infusion treatments following injuries. They receive and administer aspects of the medical advice. Clinic staff at one treatment center felt that, at times, one particular father understood regimen details more clearly than did his wife. This father often followed the progress of his son's exercise program, as per what he had learned from the clinic visits. Another father takes his son for treatments should these be required when he, the father, is available, as

> It depends on who is home at the time.

He further reported,

> When they need me, they call the school, the school calls my job, my job calls me, and I just take off. My boss already knows and he understands.

The wife of this man responded,

> He goes with me all the time . . . right away. Sometimes I want to go over myself (when our son needs to be treated for an injury) because (my husband) works, and my husband says, "I don't care. I'll go with you.

The range of possibilities in protection work was described by the father who spoke with his son's kindergarten teacher, as well as with the principal, about

the protection required for the boy on the play yard. The father was told,

> Well, if you'd like to come watch him . . . (the protection can be as you'd like to have it--We have no time).

He contrasted this with the work of the teachers in the school to which he had his son transferred, indicating that they are

> very interested in doing what they can to help.

Other fathers procure medications and supplies from the pharmacies and make hospital visits when their sons are in-patients. Several of these fathers attend hemophilia symposia, as well.

A remarkable negotiating effort with a drug company was accomplished by a father in order that his hemophiliac boy could receive the blood product from a lot from which the boy had already been transfused; hence it was known that no adverse effect could occur from the use of product from this batch. This was to avoid infusing factor which might be contaminated with AIDS disease.

> We stopped giving it (factor) to him until we could get a hold of some that were back lots. We can get a hold of quite a bit--a year's supply.

Then, later, the mother reported on progress with the father's further negotiation.

> And we did it again. We got another batch that he had already had. So we were lucky enough to be able to do that.

Monitoring on the part of a father was described. This parent explained how he knows that a trip to the hospital is indicated.

> If he (the boy) is experiencing a lot of pain, (and) if it is bleeding it will start to swell. It will be very . . . hot in the area of the swelling and once you see that and you feel it, you know right away that it is bleeding.

Another father checks on his son's progress with his leg. He also went to the boy's school when an injury there was reported to him. Although he had never given an infusion, he wanted to do it. The boy, a sixth grader at this point, however, treated himself, with the father being present.

Massie listed his work, aside from giving blood. The specifics included looking for specialists, tracking down new medicines and techniques, paying bills, trying to offer comfort, exchanging ideas with his son about infusions, writing about hemophilia to make people more aware, picking up bags of cryoprecipitate, lobbying, letter writing, and wanting to relieve pain.

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Several of the fathers in this study have shared in these tasks. In contrast, one mother qualified this with her impression.

> No way. Ninety percent of the fathers (don't infuse). That . . . should change, but we can't change it. I think the father should take just as much of a role in it, but most of them don't.

Another mother reported that she was responsible for the total care of the children since her son was 2, when the father left. When the boy was well into the school years (about age 9), the father called "out of the blue". He has since shown some interest, visited the boy during hospitalizations, carried medical information with him when

he took the boy on a trip, and attended hemophilia symposia.

Mothers' perceptions of fathers' work vary from cooperative perspectives, to appreciative acknowledgement of efforts, to annoyance with a husband's involvement that is far less than hers (although she recognizes a particular bond between a mother and her hemophiliac son), to negative evaluation.

It's not the way it should be.

Family contexts and the ways members fit in the hemophilia care with their ongoing lives vary, accordingly.

Siblings

Siblings' work is conceivably the most "hidden" of efforts, as per comments from a series of sources.[299 300] With the very amount of attention and work required in the care of the hemophiliac child, a consideration of "fitting it in" reasonably points to leaving out some attentions to "other children" relative to the issue of time alone. A comment by an adopted sibling was surprising to one set of parents. In an intimate moment that they shared, in that the hemophiliac child was away for the evening, the mother said,

> This will be the seventh Christmas that we've had you, that you've been our sweet little adopted girl.

The child reportedly thought about that and said,

> Yes, and I know why you adopted me . . . . Because if you had had another child with hemophilia, you don't have enough hands to give

treatments at the same time to two children. If nothing else, the sibling's work is related to standing back to allow the care the hemophiliac's treatment encompasses. This child is reported to be, at times "extra nice to (her brother)" and, at times teases, "quite normal(ly)".

Siblings report on going for supplies, bringing homework to their brothers when they are absent from school, calling for help when there is a bleed, and advising their brothers on activities and even on when to go for help.

The Massies again provide data about sibling interaction and participation in the care of hemophiliac brothers, while including direct comments from the Massie boy's sisters.

> When everyone was running around taking care of him, I stood looking on./301

One sibling's first going out as a baby was a trip to the hospital because her brother had a mouth bleed. Sometimes she was left with neighbors during emergencies.

Other siblings report they "almost always" go with their brothers for clinic visits or treatments. One described,

> Sometimes the whole family (would go to the hospital). Sometimes my mom and grandmother and me (would go). My grandmother was usually around. She was sort of wrapped up in it, sort of scared about it because of (her son) . . . . She was more cautious than my mom would be (in that her son's situation was different, without the experience, then, of newer treatment methods).
>
> When _____ had "cryo", every time he went to the

> hospital, basically I was at the hospital with him. (With the cryo), it was very traumatic. Every time he fell down (or hit his head), he had to go to the hospital . . . . (Later, I was) still watching him and participating.

One sister learned intimately about other hemophiliacs she would meet when they would be treated at the same time that her brother was treated. In fact, she asked this researcher if there was knowledge about the well-being of a particular hemophiliac she had come to know, who used to "skate-board under buses". She wondered if he were still alive.

Massie points out that the girls had to deal with the unwitting comments and inquisitive looks of their friends, relative to the chronic problem from which their brother suffered. A poignant comment of one of young Massie's sisters followed an accident from which the boy suffered a major bleed. She cried,

> I didn't mean it,

as if she had caused the problem.[302] When her brother had a cerebral hemorrhage at age 14, upon coming home, she could immediately tell that something was wrong.[303] She had become attuned to being a responsible monitor.

Further monitoring by a sibling in the current study was reported when the hemophiliac brother got hurt at school. The well sibling told his brother,

> Go home and get treated.

Although the injured boy didn't immediately follow his sibling's advice, he eventually did.

A sibling described how she watched her brother (1 1/2

years her junior) at recess time, and, at times, would apply ice to his swollen joints if injury should take place at school. At other times, when he was too young to go on the bus alone, she accompanied him on trips to the clinic for treatment. The mother of these children elaborated that

> _____ never was a baby. (She) helps me when it comes to (infusions) because sometimes the needle doesn't come out right, or the bottle is too big for my hand . . . . Sometimes I have a problem and then I will tell her to hold that while I pull the needle out. She knows . . . if I say, "Get everything ready" . . . she knows what to do and how to do it. She doesn't know how to stick him, of course; that's not her responsibility, that's mine. She's only his sister.
>
> She knows when he has a bleed. When I'm not here, he talks to her. (If he gets hurt at school), she tells him to go home. (If he detects a bleed when at home), she tells him to stay home (from school).

The latter event took place when the mother worked a night shift, and wasn't home when the children were getting ready for school. The basic decisions about management were handled, then, by the older sibling. When these children were much younger, and the hemophiliac boy needed to stay home from school, the sibling was kept home as well. The mother remembered,

> She brought it to my attention, why should she have to stay home because he couldn't go. She told me about that (when she was about 10). So finally I realized, I just thought about it and said, "okay". If he is bleeding, I let her go because I didn't want her to get to the point of hating him because of his problem.

A sibling spoke of "watching after" the hemophiliac

boy, to make sure he didn't get hurt, that he not hit the corner of the table or "something like that". Another older brother was frequently the evening baby sitter for his hemophiliac sibling when the parents went out for the evening.

An incident of sibling work was reported this way:

> Mom and Dad were at a dinner down at _____ and (my brother) was hurting and he was crying. I asked him what he wanted (and he said), "Run down to _____ to get Mom and Dad". So, I ran down there and my mom came up and she gave him a shot . . . and my mom was saying, "Watch . . . for him . . . ."

A sister reports of an incident following her brother's tonsillectomy, when he, a couple of weeks later, again started to bleed.

> Our parents weren't (home) . . . and we had to take him to the hospital. We tried calling, (but) we had to go to the hospital real quick. My friend's aunt drove us over . . . . Finally my parents came . . . . and (my brother) had to stay in the hospital because he lost so much blood.

To avoid problems, a younger non-hemophiliac brother advised the hemophiliac sibling not to go swimming with only one person since if the boy were to get hurt, the one companion would find it hard to carry him back without more help.

A refined focus on siblings of chronically ill children is a study in itself, but some data is already in place with the above and in the research of others.

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Teachers and Others

Mrs. Massie illuminated parental feelings about leaving the hemophiliac boy at school with others.

> The first day of school is a milestone . . . with Bobby out of my hands--entrusted to others./306

She pointed out that parents sense a risk as the child is more active and independent.

Aside from class work sent home by teachers for these children when they are absent, teachers' work is variously managed. One family reported that at one school the staff couldn't accept

> If he has a bleed, let us know.

At another school in which a child had been newly enrolled (in the 2nd grade), the mother reported,

> The first couple of weeks I got called quite a bit because of bumps. In the third or fourth week I was called because _____ had a big black eye.

Teachers' work in the care of hemophilia, beyond monitoring and reporting, is further noted. One teacher, observing that children were touching the wheel chair brakes on the hemophiliac's appliance, while all were at play on the playground, intermediated by setting a rule that the wheel chair can be touched only under the direction of the hemophiliac, himself. Protecting work is involved.

As may be inferred from some of the above, curriculum-planning to include particular programming for the hemophiliac is part of teachers' work, indicating how some of the work at school "fits together". Arranging for individual education plans (I.E.P.'s) for the hemophiliac is in this category of work. Including the mother with the special interest in watching her hemophiliac son as a

teacher's aid, can be attributed to school organization work, too.

The data describes teacher-work which becomes non-protective, even though this work is not so-planned. In one classroom, the teacher, in efforts to bring order to the large, noisy classroom, asked the whole class to write 500 lines relative to an infringement of order that occurred within the class.

And _____'s hand started to bleed.

Along a similar theme, a boy earned a "D" on a homework assignment which he actually had done, but for which he did not get credit because he was out of school for 11 days due to an ankle bleed. This "negative" work infers that some other aspect of the organization had not performed the intermediating work involved in teaching the teacher. (Implications for these issues evolve from the material in "Work Across Institutional Boundaries".)

Peers at school may be asked for assistance, as one boy spoke of selecting classmates (always selecting girls) to push his wheelchair (in the second grade). Other protective responses of peers have already been indicated.

The Massies provide data on others who are helpful. Friends organized to give blood, and a neighbor (at a vacation place where the Massies didn't have freezing facilities) provided storage for fresh-frozen plasma in their freezer compartment. A plan was made so they wouldn't be disturbed at night if the Massies needed it

then. (The Massies then used dry ice to keep the plasma frozen en route to the hospital some distance from the country home.[307])

Counselors and other adults fill in with a variety of tasks, not the least of which was the learning involved on the part of an athletic leader in order that he know how to infuse the hemophiliac, thus making it possible for the particular boy to attend an athletic camp away from home. (The person who taught the counselor is one of the medical persons responsible for the boy's treatment.)

At the hemophilia camp it was observed that counselors frequently detected bleeds, particularly with younger children who may not report their own, and carried the affected child to the infirmary.

Work Across Institutional Boundaries

The various kinds of work categorized above are generally centered in a specific arena, within the family milieu, the "locale" for almost all of the technical and technical assistance tasks listed. In fact, it is within the family milieu that most of the work described was initiated. There are a series of "jobs", however, which require interactions outside the family, some already referred to; yet these are frequently initiated by a family member. Such is, of course, the case demonstrated with aspects of learning and teaching work. Initial learning may be from the medical arena, and teaching about the

disorder may take place in school. Certain tasks, such as consultation-seeking and negotiating require an exchange of definitions with representatives of agencies or institutions outside the family, with new meanings problematically constructed and/or altered, for use in potentially reorganizing aspects of work and relationships. Links are thus drawn between milieus or arenas, demonstrating the interactions between institutions, with problematic consequences for social structures.

The latter is illustrated by social intermediating work, which emerged to a significant degree as the data was collected. The social intermediating work of parents of school-age boys with hemophilia, often "taking a role for another", describes those interactions, generally of the mother but not limited to her, related to aspects of hemophilia care which takes place beyond that of the parent-boy dyad. The intermediatory person, in these instances, is one who knows the boy intimately. The interaction is "off-stage", and is directed toward enabling the social interactions of the boys in the particular social or institutional groups in which the boys participate. A series of questions are essentially answered by the mothers of these boys, the major intermediators, in terms of the "why?" of their interventions, the "with whom?" the "where?" and the "how?". The interventions are particularly associated with parental styles that are negotiative or directive. (See chapter on "Philosophies and Styles".)

Lobbying and medical consulting already discussed as the work of parents, also has intermediating aspects, for these interactions entail taking a role in behalf of another. Mothers' information work in the form of lobbying is emphasized by several. It is appropriate to quote from an editorial in the September 1983 issue of Infusions, the newsletter of the Northern California Hemophilia Foundation.

> September is here and school bells are ringing once again. Most parents of school age hemophiliacs are well aware of the problems generated by frequent bleed-related absences from school. Not only are missed assignments and tests detrimental--more important, from an academic standpoint, are the missed lectures and discussions which are impossible to reproduce after they have taken place. Not least, is the disruptive effect of many absences on social relationships with peers and teachers. The result of all these factors sometimes lead to . . . poor grades and loss of interest in getting an education.
>
> No one program can be prescribed for hemophiliacs as there are many complex psychological issues at play and although public schools have the same basic obligations, differences in funding and even attitudes will affect the school system's ability to help.
>
> Communication: We, as parents, can help to ease the problems by initiating an open line of communication with our children, their teachers, guidance counselors and principals. A meeting at the beginning of the year is an opportunity to inform them about the hemophiliac's special educational needs. Mid-year meetings enable you to review progress in a face-to-face setting, stressing the need, if warranted, for mid-course corrections or extra help, and end of the year conferences can help guide the next year's course of study. Each meeting emphasizes that you are concerned about getting the best education the school system can provide for your child.
>
> Rights: It is important for all of us to become knowledgeable of our child's rights under law.

> Under federal law, any child with an emotional or physical handicap must be provided with equal educational opportunities. Specifically, if frequent absences can only be made up by periodic tutoring, the school must provide the tutoring. Other academic help which may be justified includes access to special assistance during school, special transportation to and from school in a van capable of transporting the student in a wheelchair, a special education staff member to act as liaison with teachers, and special consideration when giving tests, even giving tests away from school.
>
> Diplomacy: Our success in working with the schools will require a balance of courtesy, confidence, persistence and flexibility. The school districts' goal is to provide the maximum level of education for the largest number of pupils within budget limitations and our goal is to obtain the best education for our child at no extra cost beyond the taxes we already pay. These two goals are sometimes in conflict, but with the proper atmosphere and our persistence, there is a good chance of reaching a compromise acceptable to us and of real value to our children. A helpful booklet entitled, "The Student with Hemophilia: A Resource for the Educator", is available . . . .

The lobbying work here focuses upon potential intermediatory efforts of the "in-group", the hemophilia families, particularly of the parents, themselves. The qualitative aspects of the work being lobbied for is that there be continuous monitoring of the interactions and consequences of these in the educational setting, and that there be persistence in ensuring appropriate progress. A mother described her efforts, following pointers in the above model.

> Our son is 10 years old and, at times, has needed to attend school in a wheelchair. He seemed to feel quite comfortable with the idea of going to school on crutches (which has been necessary off and on since 1st grade), but being seen in a wheelchair was viewed quite differently and often there were tears and threats that he wouldn't leave our home when it was time for school. Recess (for play on the blacktop area after lunch) was

> particularly stressful and often I would bring him home for the lunch hour and return him for the final hour of school. I noticed that he became more and more dependent upon me to do this--not only for recess, but also requested that I come during a 15 minute break in the mornings. My concern was that our son was viewing himself as a non-participator at these times and, in fact, he was. Our solution was to remove him from the stressful situation. I was not comfortable with this solution, as I feel that the socialization skills which develop during the elementary school years are no less important than the acquisition of academic skills. I discussed alternatives with our school principal and teachers who supervise the playground area and, as a result, our son will be enrolled in I.E.P. (Individual Education Program) this year. Among other benefits, a special recreation teacher will be working with the staff to better educate them in how they can include children who have limited physical abilities in games and activities during recess. Hopefully, this will prove to be beneficial for our son, as well as the staff.

Whereas, technically, there is much more involved in these lobbying efforts than "information work", there is a series of processes entailed in the reorganization efforts implied. The functions of these are to intervene in behalf of the child, taking a role to enable his roles in school.

Researchers are lobbied, as well.

> I did take the time to find out . . . (the name of) the head of the research team, so I called and found out the address of his laboratory and I did write a note to him saying that we were very excited about the new information (about the possibility of making the missing factor synthetically), but (with our son's special complication), I hope that research would continue, (accordingly).

This mother's concern was that, with relatively few people having hemophilia, and even fewer, then, having this particular complication,

> I feel like maybe because we're not large in numbers, that . . . sometimes these things get

over-looked.

When there was the potential for California's initiating the "block-grant" system of funding health care, a major lobbying effort was launched by the Hemophilia Foundation, in which a number of these mothers participated, to urge the legislators to exclude hemophilia treatment costs from this plan. (Inclusion of hemophilia would have severely cut finances available for hemophilia care.) Additionally, there were such moves in conjunction with the United Way campaign, to ask for "specific donor cards" in order to designate the Hemophilia Foundation as the recipient of donations.

Still another example is the Massies' work in lobbying the Board of Education to try to acquire a tutor for their son, as his absences from school didn't fit the numbers of days required to be eligible, otherwise, for this service.

Parents who were the intermediating force in interactions with the drug company to set aside a particular lot of factor product for their son also acted in an advocating manner.

The Massies dramatically described their advocacy for their helpless child as they noted his

> enduring 5 to 6 failed venipunctures (by hematologists) before a pediatrician would be called.

They explained how they learned to insist on the pediatrician at the outset, to protect their son from the added pain.

A father pursued teacher requests for more information

on hemophilia so they could do a better job with his son. He called the hospital to ask for literature for the teachers, and mentioned that he'll have to check on why the materials were never sent.

An advocacy role appears basic to the lobbying described as well as to the work of the mother who perceived surgery as threatening or otherwise a risk. She consulted with others in the process of avoiding surgery. She consulted both within and outside the organization of the "home-base" medical agency. She acted in like manner in discussions with the general pediatrician. When she felt that the conversation the child hears will be a "risk", she changed the subject to avert her son's attention from matters which she perceived will frighten him.

Not all describe such a role for themselves. Confidence in the validity of such efforts characterize the most experienced (experienced with hemophilia) parents. Another influencing condition, for the persons who take on very active intermediating work, may additionally be associated with responses to their having lost sons because of the hemophilia.

Poignant expressions of a child regarding his hospitalizations belie his concerns for self-risk.

> It's wierd. It's pretty neat. It's, I mean when I get in there I'm all scared like something's really going to happen bad . . . like . . . I'm going to die or something like that.

He explained how his parents "encourage" him when he has

these experiences. Their intermediating is, essentially, for his "vulnerable" self.

The work of siblings to get help for emergencies, as described earlier, is intermediatory, too.

In another context, a member of a clinic staff taught a sports coach to do infusions so one of the boys could participate in group activities away from his home when he wasn't

> 100% (yet) on self-infusions and would miss sometimes.

These particular kinds of social intermediating generally take place when the parents perceive its importance, most likely as a means of protecting the son from some kind of risk, social or physical, in his interactions in social situations outside the family.

These kinds of work, as other kinds, could be compared with similar actions performed by or for patients who are adults to see if, indeed, the adults "require" an intermediating person in like instances or if they might be more likely to do the work themselves, in their own behalves. The ages of the adults and their physical conditions would need to be studied in terms of modifying or problematic issues.

All of the mothers and some fathers do intermediating work at schools, the extent of such work varying, with more such work evident when the boys are younger, but also when there are complications in the hemophilia disorder. A father acknowledged his wife's work, saying

basically she has done most of the work with the school.

Almost all of the mothers report going to school at the beginning of each academic year to discuss the hemophilia with the teachers. Two of the mothers described their making presentations to the classrooms of children, together with their hemophiliac sons, to explain the condition. This teaching generally, according to some of the subjects, takes place in the early grades, as by the mid-school ages (around the 4th grade), the hemophiliac son may refuse to partake in this "team-teaching".

One of these mothers became an aid in her son's school and became acquainted with all of the children in her son's school environment, "teaching" the children relative to cautionary measures to protect the hemophiliac, while she also did her teacher's aid tasks.

One mother described,

> I usually go to the first day of school and talk to the teachers.

Her son, now in the 7th grade, qualified,

> Next year she doesn't have to say anything 'cause in 7th and 8th grades . . . we have every teacher (we have now) . . . . When I was in the 5th grade, she (my mother) told my teachers, in the 7th grade she told my teachers, in the 8th grade (she won't have to tell the teacher) . . . because I've known her (the teacher) a long time.

Structural conditions indicating continuity in the same school are extended in this particular instance in that there is a further link with this teacher because

> My sister goes to the Girls' Club and she (the teacher) is always there.

Still another mother who claims that she talks with the school personnel, is seen by those school workers to be reluctant to disclose information about the hemophilia. (This is also the mother who wishes that others, the medical or medically-related staff, would be more active in teaching at the school about the hemophiliac's condition and needs.)

Intermediating work became negotiatory when one of the boys announced that he had joined an athletic team at school. The mother told her son,

> "Let me talk to the principal to find out a little more about how often they're going to be playing and what's involved". So I called her and she said it's a very rough game. She said they do get knocked and pushed and shoved down. (When I) asked if he could be involved without being in the game itself, (refereeing was proposed).

His mother's basic explanation to him about not being in the game itself was,

I just don't feel it's a good thing for you.

The intermediatory interventions, however, didn't speak entirely for the boy as he didn't want to be the referee. It is interesting to note that eventually, although not necessarily in conjunction with this incident, the boy remarked,

I don't think that would be good for me,

conceivably modifying an aspect of himself, accordingly.

Recreational or other such activities are also areas for the intermediating work of mothers. One described her work in negotiating with a social agency to see if she

could arrange a male adult relationship for her son, which would include bike-riding lessons. She then explained the hemophilia disorder to that person. This, in fact, was linked to the intermediation process of the hematology clinic staff, encouraging the mother to pursue this. Still another mother talked of intermediating work she plans with the local scouting organization, to enable her son's participation.

> My mom told the director about my hemophilia. He thinks I would get hurt (so) I don't play as much as I would want to.

There are many further references in the data to talking with teachers, principals, and intervening with school programs. A mother described how she had gone with her child's pre-school class to the playground whenever the group took this outing.

> I really got the feeling that they really didn't understand exactly what could happen to him, and at that time I did not have coverage (home coverage of the factor). It was still the time when we were going to get cryo so he could be injured severely without them even knowing how severe it was, without somebody there . . . . (I) trailed along with the class.
>
> I told the teacher that if any day . . . they were going to go to the playground, please tell me so I'll go with them . . . . I knew that . . . she knew . . . he had to be protected, but she didn't really know.

Another mother explained,

> When he was young, I would explain this (the hemophilia problem) to anyone that would ask.

A mother, elaborating on information work at schools, articulated,

> I would tell the teachers (in early grades) before

school started. The last couple of years I have told secretaries . . . and let the teachers have a day or two . . . and then I go and talk to them to make sure that they have gotten the message and that it's in the file and that somehow they know. I haven't determined who all we will tell next year as he goes on to junior high.

At this point, her son interjected,

Tell all my teachers.

A father explained,

I went and I talked to the principal and then the teacher. The first school wanted to put him in the retarded school, a handicapped school, (but I wouldn't let this happen).

His son added,

Mom and Daddy told the 2nd grade teacher. The second grade teacher told the 3rd grade teacher.

Another mother who goes to school each "first day"

still (in 7th grade) tells the teacher that I have it,

according to her son. In discussing this further, the mother realized that she didn't go to school this year because most of the teachers are familiar with the problem; then added,

He does have one new teacher . . . . I should go.

A boy explained how these explanations may not be sufficient.

My classmates knew that it was real because my teachers explained (it) to them, but like other classes when we would be outside at recess or something, and I was on crutches, they wouldn't (understand).

The Massies reported similar misunderstandings in the
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schools. Before entry in a new school, Mrs. Massie would examine the physical layout of the building and the

facilities. She then talked with the teacher, the principal, the librarian, and the p.e. teacher. She felt it was hard for them to understand a problem they couldn't see. They couldn't cope, she felt, with the variety of problems, for unpredictably, one day it would be an arm, then a leg. They found it hard to integrate the boy in the classwork.[309]

One time, though, the Massie son had a teacher who intermediated for him. She arranged that someone would carry Bobby's lunch tray (when he was on crutches), so that he could eat with the others. When he was immobilized at home and had an intercom connection to the school, classmates carried the intercom system from classroom to classroom.

A teacher of one of the current subjects intervened by making a rule that no other student can touch his wheel chair. Another teacher's intermediation was described by one of the youngest boys. She told the children

> Nobody hits _____ because he got the same as _____ (another hemophiliac in the school).

In another instance in the current study, it was reported that the boy's physician intermediated with letters he wrote to the school, to explain the needs of the hemophiliac. Letter-writing is also done by mothers vis-a-vis the schools, in the form of explanatory notes about absences.

Parent-substitutes and others are intermediators, as well. Neighbors, on occasion, intermediated for one of the

boys when he was too young to watch out for himself as he played. Chaperones for a particular trip handled a bleed problem for one of the boys. On that same trip, an older girl who would like to be a nurse, helped the hemophiliac attend to his treatment.

During a camp observation, the participant-observer became an intermediator for a boy, playing in a game to collect "treasures" for the boy when he couldn't use his hands at the same time that he needed to manipulate his crutches to get to places where the "treasures" could be found.

There are a series of references, too, to moments when there were no intermediatory persons available; implications are that such would have yielded different consequences.

> (The school had appointed) a lady to help _____ improve eye-hand coordination and work in areas where he is weak in motor coordination skills. They played basketball. _____ had had a bleed in his finger, which we treated, and seemed to be getting better. Then the next day (after the work with this woman) it was definitely worse. He needed another treatment. (I asked _____ if he said something), and he answered, "No, I didn't say anything".

Another boy's teacher asked him,

> why I can't play baseball if I roller skate and get killed in that.

About his answer, he said,

> Beats me. I didn't say anything.

An intermediating effort of a different nature was demonstrated by the younger sibling of one of the

hemophiliac boys, when he, at about age 9 or 10, gave talks before his classroom on hemophilia so that his friends would better understand his brother's situation.

Whereas like work may well be an aspect of child-rearing when hemophilia or another chronic illness is not a condition, work relative to developing or discouraging peer group interaction compatible with requirements for hemophilia care are evident in many aspects of this current data. The mother who wanted to develop an ongoing interaction for her son (and for herself) with hemophiliacs contrasts with the mother who continues to invite friendships for her son, aside from the hemophilia contacts. Each has a different purpose in mind for this work. The former, in fact, felt relieved when neighborhood children stopped coming to ask if her son could come out to play with them, indicating that "that's good", inferring that they had learned that her son had limitations in the playing he could do. She felt, on the other hand, that peer relations within the hemophilia group would enhance hemophilia management because of the common experiences each has. Philosophies relative to normalcy affect the organization of these social relationships, and the intermediation to enable them.

The mother who works at bringing peers home with her son from school or who offers to take her son to the homes of others who call, supports, and thus intermediates in these social relationships. Several are accordingly involved in the summer camp arrangements for the

hemophiliac boys.

Mrs. Massie wrote of a "most precious gift of all" as having friendships of one's own age. She reiterated this a number of times, first describing how she enrolled Bobby in nursery school in her search for companionship for him. She then wrote of trying to get friends to come to be with him,[310] and, in fact, "begging"[311] companions for Bobby. At other times, she'd help Bobby to find ways to tell peers about his injuries.

One of the families in the current study took friends for their son on small vacation trips. Another of the boys was, on occasion, called for by the mother of another hemophiliac, so that her son would have companionship.

One of a mother's strongest efforts is to withhold "critical" news from her son, refusing to allow the television to be on when discussions on AIDS take place. This intermediation, shielding the young boy, differs from the intermediation which permits another boy to go to meetings to hear discussions of like information. Once again, there is an age differential, in that it is a younger boy who is protected, and a somewhat older one who goes to informational meetings on topics the "protective" mother would regard as "critical".

In another instance a mother, whose first hemophiliac son died, said that the current hemophiliac son is aware that he had a brother, but is too young to have the details told to him. An older boy whose mother had a prior

hemophiliac who died, doesn't mention this at all--nor does his mother.

A mother who isn't aware that her son knows about the AIDS concerns, or even that he has listened to such news, was most aware of his excitement over hearing a broadcast about new research which may make possible the synthetic manufacture of the blood product. In relating the event, the mother included her explanation to the child

> in his way of understanding . . . . Even though it (didn't) relate directly to him, that I thought this was all connected and that it was good news, that research was going on. Hopefully our day would come.

Although this interaction isn't strictly intermediatory in the sense described here, the work was meant to help the boy deal with understanding other resources of information.

Weighing Risks, Balancing Work, and "Fitting" into the Context of Family Dynamics and Personal Development

Entering school, moves to new schools, encountering classmates new to the school, and playing in new situations have associated with them risk-related thinking, wondering how it's going to be relative to the hemophilia. Those events are entered into, or not, problematically moving to interactions different from the child's ordinary custom or "norm" of interactions. Some of the data already presented demonstrates this.

Whereas there are risks involved in participation in customary interactions (as with the boys who continue their customary athletic participation) when the person is familiar with consequences involved; the data also focuses

on the progressions toward unfamiliar experiences, thus risking selves in "new" ways, and problematically advancing toward self-care. The consequences of the interactions bear implications for development.

Aspects of risk-taking are clearly related to philosophies of management, (to be dealt with in the next chapter). The special case of AIDS, already described, demonstrated risk issues in managing a particular crisis.

Variations of risk-taking are intertwined with the technical work, the technical assistance work, and other work dimensions, particularly noted by subjects relative to errors made in work. Degrees of risk, both social and physical, are especially evident in the data descriptive of peer interactions. When risks taken become crises (physical damage or its potential), reorganization of efforts take place. Resumption of "regular" interactions follow the return to "normal", when an equilibrium is re-achieved. Experience with crisis management makes the shifting to crisis work somewhat "routine", at least with less chaotic interaction disrupting the management.

Given the above, how the hemophilia work fits into the schemes of these families' lives is important to examine. Varying directly with the age of the child, essentially considering when the child's self-care begins and is eventually established, the hemophilia work appears to be the most salient aspect of the mothers' work when the hemophiliac children are very young. The data frequently

indicate that the hemophilia care during the growing up years receives a high priority, with some other aspects or tasks of life often in abeyance.

Mrs. Massie spoke of doing housework when the baby napped or when he slept at night. She was most responsible for the hemophilia work in the early years so that her husband's priority tasks could be met. He felt one had to be rested enough to face the world,[312] recognizing that the money for the care had to come from his efforts, particularly to make physician availability and blood possible. He would sleep when his wife might be up with the child or with household tasks so he could write and earn money the next day.[313]

Other families indicated times when they would be up at night to tend to bleeds and pain. Some may sleep to enable their next day. Most recognize, though, that during hospitalizations or other emergencies, all "normal" life stops, with the drives back and forth filling time otherwise occupied with less critical activities.[314]

However, it should be noted that four of the mothers have full-time paid positions outside the household, and four have part-time, occasionally intermittent jobs. One of the latter works a shift when her husband is at home with the children, and schedules the job in such a way that she can be available if her son needs her when he is at school. She reported that sometimes when she returns home, just in time to prepare breakfast, pack lunches, and get the children ready for school:

> I've noticed . . . that he'll start picking on (his sibling) . . . just going out of his way to needle her . . . . "I've only been home 15 minutes and . . . I haven't heard a kind word said between the two of you".

This emphasizes her perception of the children's behaviors in relationship to her view of her responsibilities. Other times this mother has needed to respond to telephone calls from the non-hemophiliac child at school, reporting a headache and asking to come home, often when the hemophiliac boy was home from school.

Two of the other mothers have businesses which are based at home, with "built-in" flexibility, providing them with the potential to answer calls should their sons need them. One mother, in talk of pursuing employment during a period of unemployment, said,

> I never tell a company that I have a son with hemophilia . . . . I feel that if I tell them they wouldn't hire me. Once I am on the job for awhile they . . . have to know . . . . It never is (okay with the company). I just tell them that _____ is bleeding and I have to leave, and they get upset and . . . ask "Are you coming back (today)?" and I'll say, "No", and I . . . leave.

As already described, some mothers, in discussing their perceptions of the responsibilities they carry, talk about the relatively less work in the hemophilia care performed by the fathers. Still others note the particular roles of fathers relative to negotiating medical care for the children and supervising (monitoring) treatment. Trade-offs and/or strict divisions of labor follow particular patterns in individual families.

One mother talked of her divorced husband's interest

in the boy, his participation at hemophilia symposia and other visits. She indicated that this was new, that she wished he had shown some interest when she needed to carry the boy, as a small child with heavy appliances, on the bus for clinic visits. Shifts, thus, take place over time.

One mother pointed out a structural issue that carries implications for meaning regarding fathers.

> They had the camp on Father's day, which I don't agree with. This last time, and then again this year and the year before last, (the schedule was the same). This will be three years the boys don't have Father's Day with their fathers.

Responsibilities sometimes shift to an older sibling. The mother who comments that her daughter never was a baby may have organized work at the expense of "normal" play of the other child as the mother has always had to work.

However, at the unemployment referred to, the hemophiliac boy responded with a readiness to enable the family's "fitting in" of the various responsibilities. At 12, with great concern, he began writing letters to newspapers, saying he's "willing and able" to work. The mother comforted him by saying she's the caretaker now--his time will come.

The Massies noted when Bobby was old enough to be away for a time,

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> The burden has shifted.

Yet they noted,

> He (Bobby) hate(d) the constant surveillance, the negative glares and murmured cautions I (gave) him when he start(ed) doing something that might cause bleeding . . . . This role (is) deeply

> ingrained (and) may never disappear from (the) work of a parent./316

Mrs. Massie noted this is not the same as her responses to her physically able children.

Several of the mothers are active in the local Hemophilia Foundation, a couple with responsibilities for board positions and special events. Another spoke of her trying to encourage parents of other hemophiliacs to allow greater "normalcy" in the lives of hemophiliac children, this seeming to be a special mission to "fit in". Normalcy, in fact, relieves certain parental responsibilities at particular times, but may increase others.

All of the work fits into categories of anticipating or repairing damage. Damage control, for both physical and social goals, affects self and identity concepts. (The damage may also be to the models of normalcy.) Integrating the work, it appears, results from a setting of priorities and shifting of responsibilities over time. One mother spoke of how she saves her sick leave for times when her son is in the hospital, rather than to take it for herself. Another spoke of her idea of wanting to arrange a particular good time for herself, together with the children, which she contrasted with examples of those who want to be away from their children:

> My dream . . . of the kids go(ing) away for the week-end is to take them on a cruise, with the parents and the kids each hav(ing) their own section of the boat.

Even with thoughts of a vacation, the perception is that it

be in the context of the integrity of the tie to the responsibilities, as she further described the accessibility of parents to children so "we can treat them".

In a similar vein, one divorced mother, in responding to questions about a personal life for herself, thoughtfully expressed that she always thought she had to find a man for her son (not for herself).

The temporary quality to the hemophilia care given by parents (for the duration of childhood) is problematic. The data includes examples of young adult hemophiliacs who have not been able to leave their parents. In addition, extreme physical problems may render independence very difficult. The former also is reminiscent of the earlier era when the "treat 'em like normal" mandate, permitting much moving outward, was a less pervasive philosophy.

Developmental and Structural Implications

Coincidental with the children's taking greater responsibilities for their own care is their growing self-consciousness relative to their peers. Attempts made so as not to be perceived as deviating from the all-important peer models obviate efforts at protective self-care. Thus, non-attending to prevention or damage control in order to be a full social participant, may lead to injury, eventually highlighting difference through the necessity to reorganize work to tend to the latter.

Nonetheless, the families, especially the parents, are concerned with their children's peer relationships, which are equated with development. The family, of the various social units, as compared to schools and health care organizations, is the institution most likely to be integral with ongoing development over the years, by virtue of the very continuity and intensity that characterizes most of these relationships.

Schools may also be so-concerned, but continuities in relationships with school personnel generally last one year only, as institutionalized arrangements dictate. Whereas medical personnel have occasionally expressed developmental concerns, they are also less likely than parents to be in positions to directly influence development management, partially because of the intermittency of their interactions. They are most frequently repair agents, only occasionally involved as preventive and teaching agents.

It must be acknowledged, however, that the technological aspects of health care have direct bearing on child development, in that healthier (more normally functioning) bodies support this development. Technologies that permit more normal functioning, thus, are integrally related to "interest" in development.

Survival control, minimally in the picture for hemophiliacs, is integral with the work arrangements of the technical and medical institutions, but certainly apparent

in families, too. School organizations seldom consider this in their work.

Additionally, families, especially parents, although considering school or medical advice about their children's development, problematically modify or reject developmental and other advice. Their particular relationships with their children enable a "central" coordination of this management. In fact, parents frequently negotiate a balance between institutions as they effect development.

Continuities in peer relationships, supported by minimal disruptions such as those that may be imposed by illness or injury, are clearly goals for enabling the development of school age children. Paradoxically, damage control efforts, or special attention to avoiding injury, may be disruptive to peer interactions; yet so might the consequences of damage or injury. Normality issues are modified, then, and adaptations made in particular contexts to, nonetheless, maximize development. Consequences for development are considered, accordingly. How the children handle these issues, or how they pattern their interactions, are problematic relative to a "spoiled" identity.

Families may initially have particular models of normalcy, but with the adaptations required of disease care, are likely to settle for a modified version as they enable their children's development. Other adults may have insufficient awareness, partially because of their work focus in other organizations, to modify perceptions of

normalcy, thus to "understand" the chronically ill child's situation. Peer groups, functioning according to different orders, may be least able to "settle for less" than their own models of normal interaction and thus development. Relationships with peers during the school ages have a quality of intensity, even though individual peers may change from time to time. Hence, the school-aged chronically ill child is frequently within the least "giving" of the human environments. Some modifications of such peer responses have been observed, however, relative to selected, small friendship groupings.

Protective efforts for damage control, or to prevent body damage, are thus problematic relative to normal developmental interactions. Consequences for development follow the social relationships which have accordingly been experienced.

It is not unusual for sociological study to compare social interactions with drama and acting, even referring to persons as social "actors". Although using metaphors has the potential to convey inaccuracies in that seemingly simplistic interpretations are attached to complex situations and processes, it is easy to see that the mothers act as producers and directors, spotlighting the protagonists, moving props to make settings safe and directing supporting cast, who coincidentally perform in other plays, to enable the "stars'" performance. The protagonists eventually take on aspects of the direction,

often through a negotiatory mode, as the scenes change within acts. Behind the scenes direction may continue as the characters on stage seemingly act independent of back stage assistance. The plot unfolds, progressing sequentially to new acts, always with the potential for dramatic surprise. Gradually the protagonists shift toward developing as actors-directors, based on their previous experiences, yet with risks of "falling flat" or even losing their acting roles.

Chapter 8

PHILOSOPHIES AND STYLES IN MANAGEMENT: CONTEXTS FOR INTERACTIONS

Aspects of the work of the adults in the intimate environments of the children's worlds are caring and teaching. Already discussed in terms of the substance or objectives of caring, content taught, and persons taught, the data reveals philosophies and styles in these interactions. Frequently, the styles are rationalized relative to philosophies for management, both in child rearing and in child rearing while managing hemophilia. Problematically related philosophies and styles are evident, as well, in the children's responses and interactions.

Normalcy/Normalcy Modified

If there is any ideology that is at all prevalent, it is clearly that of normalcy. The data is replete with discussions of enabling "normal" childhoods. In fact, as presented earlier, the innovative medical treatments were specifically hailed as supporting a normalcy heretofore not possible because of treatment requirements entailing frequent transfusions at the hospital or in settings outside of the home, with technicians required to administer the particular procedures.

Yet, meanings of "normal" vary, as do the styles pursued to accomplish normalcy. To be different from the norm, the embarrassment over being singled out or not being

at one with a group is, at times, seen as a greater risk than the physical risk.

> (A mother talking): When he says, "Mama, I'm playing basketball; Mama, I'm playing baseball (like the others)" . . . I never let him know that it bothers me . . . because I don't want to mess him up mentally". (It would make him feel different from "normal").

This mother, as the others, envisions normal interaction as prerequisite for ongoing development (without mental or emotional disturbance). As the boys progress through the school-age years, being set apart from the group in uncustomary ways (relative to special care for the chronic disease they alone have) engenders their particular perceptions of social risk, implicit in the meanings attributed to the later social relationships.

The philosophies of and interactions toward normalcy are reflected in various ways. The Massies reported that they made a conscious decision that

> Bobby was going to be treated normally,[317]

They searched for situations where he could be treated "matter-of-factly".[318]

In fact, Agle and Mattsson, psychiatric researchers, advised that the worst environment for the hemophiliac boy is that he be in the exclusive care of a dominant, over-protective mother

> who would try to seal her son off from life and the world./319

Further "normal" experiences are presented, in discussions about going to camp, camp being "a part of childhood" for

the hemophiliac as it is for others. This is reiterated in several families, one father elaborating that they are a "sports-minded family", according to a family pattern set by his father and grandfather.

A single mother, recognizing sports interests as being particularly tied to the growing up of boys, reflects,

> I want him to take in some baseball games and just have a man to boy talk. You know, like women don't talk about the same things that they talk about . . . . Maybe something is bothering _____ and he really . . . doesn't want to talk to me about (it). He needs a man to talk to.

Wishing her son had such a relationship with his father, another mother said,

> If my husband was more interested in taking him on a scouting thing . . . I would (want) _____ to infuse himself . . . . At this point we do everything together anyhow.

With cultural contexts influencing these as prevalent attitudes, the Massies moved to France for a period of time where they felt hemophilia problems might be more peripheral in that the French "sentimentalize less" over children, and emphasize academics over athletics.

Contrasts or modifications of perceptions relative to normal participations are evident in other data, as well. In interviews at age 9, one boy presented himself with bravado, describing a lack of particular concern over hemophilia as he detailed near-misses, such as diving into streams where there were sharp rocks. It was interesting to note on observation that this differed from his relatively quiet, non-risk-taking interactions at school.

A sharp distinction relative to normalcy/non-normalcy

perceptions evolved in a discussion with one mother of a hemophiliac who had been interviewed by a newspaper columnist, but who staunchly disagreed with parts of the written result. The disagreement focused on statements about how she, the writer, felt so fortunate to have "normal" children.

Modifications or adaptations are made to ensure degrees of normalcy albeit with hemophilia. A mother said,

> It doesn't have to inhibit them if they realize that they just have to live in a certain way, that their life can be full and just as normal as anybody else's, but they have to learn that there are certain things they must do, certain ways of thinking about themselves, and that they have to be careful in certain ways . . . . In other words, they can do anything.

A sibling reported,

> Dad wanted him to just try things, (while) mother was nervous.

A mother revealed,

> His daddy doesn't want him to (do wheelies, which is a balancing on the back wheels of a wheelchair). I don't really care to see him do it, but I don't think he should be stopped from doing it. I am more relaxed with this because I lived through it . . . with the older boys, my brothers.

The normalcy may be compromised, relative to the problematics of taking risks.

A mother who has been urged by the medical personnel to protect her son less, to enable greater normalcy for him, said,

> I am trying, as I call it, (to) back away from _____ slowly. I'm trying.

Otherwise, she said,

> I will keep him from doing those things (where he will be hurt) . . . . I (don't) want him to (ride a bike) until next year, but that's because of me, you know. I'm afraid of him being hurt really bad.

Another set of parents explained their son's doctor's philosophy and elaborated on how they follow it.

> Don't over-protect. Don't try to keep him from doing things that other kids would do.

A 1940 clipping about a hemophilia family, presented during an interview, noted that the family's house was built away from other children so the hemophiliac child wouldn't be tempted. The general perception is that current participation of hemophiliac children and their families is moving closer to the "norm" of other children and families in the population, and that opportunities for normal development are being optimized.

A mother spoke of the effects of the disease on normal family life.

> It is not the easiest thing . . . for the family to relate to the hemophiliac.

She maintained,

> Hemophilia is a family problem . . . . When you find relationships have a hard time between children and between husband and wife, it usually stems from a problem due to hemophilia.

Several contrasted these issues with those of the earlier generation.

> The older generation . . . didn't want to talk about it . . . . People nowadays want to talk more.

> (The) earlier generation (parts of it) didn't want others to know. My mom never discussed it, nor did my aunt.

As to looking back,

They don't want to remember, I think.

Still, selectively, this mother shields her son from particular discussions, concealing, somewhat, details about the death of her first hemophiliac son (when that boy was approximately the current age of this son).

The AIDS crisis altered a philosophy and style regarding "open" discussion and learning.

I refuse to (have us) watch t.v.,

a mother commented when the news was filled with experiences with AIDS and the deaths connected with it.

> I think that what's filtered to them (the children) would be that they hear that AIDS does affect hemophiliacs, but . . . it is such a mysterious thing . . . something else that we have to put up with.

Treatment philosophies have changed, partially in association with technological changes. One boy reported the philosophy taught by his physician:

When in doubt, treat.

About five years earlier, the philosophy was different. A mother reported,

> When he was little, he used to bleed into his hip; and we would take him to the emergency and they would say, "Oh, watch it, put ice on it" and then it would get worse and worse, and finally, maybe 2 days later, they would say, "Okay, we'll treat it" . . . . (Now) if his ankle starts hurting and he treats himself right away, he is better by that evening or the next day, for sure. He may need another transfusion . . . as a back-up, but he's feeling better . . . . If he were to let it go for a day, he's in really a lot of pain, and then it takes a lot longer to get better.
>
> Now (even with a) stomach ache because he has the flu, but if he is not sure, we treat, and we don't

take a chance and not treat.

She continued,

> At _____ Hospital (until about 4 years ago), they were against his using crutches. They would rather (have) me carry him around . . . . They felt he would do more harm with the crutches by falling more.

This boy used to be hospitalized about 2 or 3 times per year, according to the older treatment philosophy.

> They weren't sure . . . . (They) would rather be safe by doing it that way.

Now, the hospitalizations are relatively rare.

The crisis of AIDS disease, associated with a series of social problematics and contaminated blood product transfusions within the general public, is specifically named as the variable responsible for recent changes in treatment philosophy, and thus reorganization of interactions possibly affecting development. Up until the recognition of AIDS and the possible connection to infusions, a number of hemophiliacs were being treated regularly, prophylactically, to "cover" them for various physical activities which would otherwise cause injuries and bleeds. Treatments following the AIDS discoveries were implemented only with bleeds (Jan., 1983) or,

> if he's going to be doing something in which he might be injured. We decided that it was too dangerous to take the chance of infusing him with something we didn't know about.

The family explaining this also recognized that one of the family members, a hemophiliac from the generation before, never did implement prophylactic treatment, as he was never "used" to it this way. Normal interactions of childhood

were a greater risk to him in terms of injuries. It must also be understood that adulthood requirements for hemophilia care differ in that potentials for injuries and bleeds are not the same as they are in childhood.

The dilemma over the treatment philosophy complicated by the AIDS was reflected upon by a mother.

> If (the) child (were) kept on prophylactics, his knee may not have "blown up" again. AIDS was very strong in the summer time. You don't know if you are giving him the products (and infusing AIDS) or not giving him the product and he is losing a knee.

New research for improvement of treatment continues to offer opportunities for new responses as well as potentials for changing philosophies. The founder of the Hemophilia Foundation, as quoted by R. Massie, said,

> One thing that seems to happen to fathers of hemophiliacs is an overwhelming desire to conquer the disease personally./321

Massie continued, regarding his outlook,

> It seemed at least possible to dream that with better methods of control, hemophilia could one day become a disease as controllable as diabetes./322

Comments from diabetics and their families reflect a different perception, relative to that perspective, noting how uncontrollable diabetes can be.

> All is not merry sunshine, even if many doctors and authors would have you think it . . . . Diabetes is an awful disease./323

A mother whose son has the particular hemophilic condition which may not always respond to treatment, lobbies for special research, and contemplates that she's

frankly

> jealous of the kids and parents who have kids with factor 8 because I hear things that are not available to us.

In discussion of research referring to the potential that a synthetic product may replace the blood products and their complications, a mother commented,

> I haven't read too much about it just because I want to wait until it is here and then I will read about it. I don't want to read about it and get all excited . . . and then still have to wait 5 or 6 years.

Once again, a comparative response comes from literature on diabetes. A young adult diabetic revealed,

> Through my mother's efforts, I've always had a real sense of hope that diabetes would be cured in my active life time . . . before complications of a serious nature occur. I still have that hope; but sometimes I tend to question the time clocks of the scientists. Another five years? Another? I get tired of hearing that./324

About the changes, past and future, a mother with family experience of 4 generations with hemophilia remarked,

> Even though I realize the problem, there is a way of realizing it and a way . . . (of) not realizing it at all . . . . It takes you time to live your life before you can realize how it must have been for others . . . . For _____ his future is unlimited in comparison to what it (would have been) 50 years ago. Unbelievable difference--incredible difference! I can see that.

Of the new treatments being contemplated and researched, she concluded,

> Fantastic!

Of particular interest is the fact that of the families and related literature studied, those with experience with

hemophilia or disease as a genetic disorder from other generations, tended to be more enthusiastic about changes that are possible. A difference in perspective qualifies their responses.

Parent Styles

Child-rearing and childhood encompass organization for management and teaching, integrally linked to philosophies and styles for their accomplishment. The forms these take vary. One mother, for example, sees her teaching and, indeed, her child rearing, in terms of the strict disciplining she utilizes. She claims that she, herself, was reared in this way. She is proud that the children "still mind" her. With regard to the hemophilia content of what she teaches, she includes that her son will learn to infuse himself "this year!", and he will "hopefully" learn to ride a bike "this summer". With regard to bicycle riding, which has been under discussion for a considerable period relative to arranging that a man teach the boy to ride, the mother continued,

> I'll go (to the meeting) and if I decide,
> which I have already decided, it will be okay.

Self-reliance is her particular message in which she takes pride by its emphasis, as well as pride in its lesson for her children. Her clear theme is that she is dependent on no one. This autocratic, self-reliant style (to the near exclusion, on many issues, of other-person-related interactions) is, indeed, followed by her children; that is, they follow her lead by heeding her instructions and

copy her model which demonstrates limited social interactions. She qualified,

> As they get older I change things, but it takes time for me . . . . I have a certain way and that's it.

Responding to a strict teacher's requirements of her son's class, whereby all of the children are punished for the infringements of a few, the mother said,

> Right now I want to tell the teacher, "No, they won't do this . . . ." (but) I say (to the children), "You have to go along with what she says".

This mother is a non-negotiator, except for negotiations she carries on within her self.

Another mother uses a psychological-type of style to teach her son about his activity management. Several years ago she had noticed,

> He would do some jumping off (the) deck. (He and his friends) would chase each other around and jump off the edge, and run around again and jump down . . . . It put . . . a lot of stress on ankles and joints . . . and the next day he (would) notice . . . a problem . . . with an ankle . . . . So we related that back to what he had done the previous day: "Do you think maybe it could be related to all this jumping you did?" The . . . next time he had friends over, they tried it again . . . . Then I noticed . . . he just, on his own, (stopped). I never said, "You can't do that, but I feel it's important to relate this (the cause-effect tie) back, so the child makes the connection . . . . I've always felt that just the parents' attitude toward the child is really important as far as not being constantly hovering over them, not trying to over-protect, allowing them the freedom to even have a few extra bleeds, if that need be, to give them the opportunity to try and . . . discover for themselves.

Other comments in the data collection are of this same

order:

> (Our philosophy is) not to be afraid to let him try.
>
> Be there and be needed, but don't try to smother the child . . . .

Responding to the school practice that couldn't allow "trying" activities, one of the older boys wrote an article he hoped would help others with hemophilia so such experiences wouldn't hinder their other social interactions.

Continuing in this psychological mode, a mother spoke of her early (when the boy was a small child) practice relative to involvement with her son's treatments. She tried

> not to be involved physically in the restraining of him (so that), thinking of psychological aspects, (he won't wonder), "Why is Mommy holding me and hurting me?" (I would, though) let him know I was there with him.

She continued,

> He yelled a lot, which is fine . . . . We encourage that.

And, currently,

> I don't want to push him into (self-infusions).

Selective permission for particular activities reflects parental styles. Whereas the strict mother has prevented bike-riding at ages when other parents were permitting this, the psychologically-oriented mother who permitted bike riding, tried to modify her son's plan to join a team. She concluded,

> I just don't feel it's a good thing for you.

She, however, clarified (regarding allowing bike-riding):

> That's one of the most anxious moments . . . to let your hemophiliac child go for the first time on (a) bike . . . .
>
> There is still that anxiety. I think that it is always there. You know, when is the next one (bleed) going to happen and how bad will it be? I think the unknowing aspect of this is the anxious part, of just not knowing.

Still another mother utilizes a more direct negotiatory style in her teaching and shaping activities for her son. The boy had proposed participation in a Japanese martial arts program. The mother quietly indicated that this needs to be "negotiated" (her term).

The age and the activity the child wishes to try has bearing on the consequences relative to the mothers' teaching style, essentially her philosophies. This above-mentioned negotiatory mother, at the time of her son's early childhood, reported that she "didn't let the child out of her sight" in order to prevent his getting into a physical problem. This style of management reflected her knowing that he was too young to learn what she might teach him about protecting himself. Her style evolved as the boy evidenced capacity to protect himself. She now comments on the "good judgement" he has developed.

Negotiatory styles were reflected in most of the households in terms of management by parents. There was evidence, too, that the negotiatory style co-existed with other styles. For example, negotiation and psychological considerations went into the decisions about participating in the martial arts program. The mother had thought it was

too rough, but felt,

> I thought he should have a chance to see what it was like.

Intermediating efforts in particular directions, as with camp participation, may co-exist with perceptions that an organization or its philosophy for management has inappropriateness.

> I think it is a good idea for them to get the boys together, but I don't think they should control the amount of "group" they do. Little kids should be controlled just like the parents control them, not giving them the ability to do their own things with supervision (like at camp) . . . but I'm an overprotective parent.

> You know, I think that . . . the doctors are different from us. They are doing it too young. If you take a 9 or 10-year old kid . . . that is fine because then they want the release from the parents; but a 6-year old doesn't want a release from a parent.

The above parent calls herself "over-protective", yet it should be acknowledged here that hers is one of the youngest boys in the study, and her style for management of this particular age boy is not unlike those of the negotiating mothers, utilized when their sons were younger. She now demonstrates a Parent/Director style, shaping the social interactions for her son. These styles shift with children's development and other events. A Parent/Director-type mother asserted,

> The parent seems to know the child better than the medical field.

Regarding self-infusion,

> I really don't feel _____ should be doing it on his own at this point. They (the doctors) keep on saying that the younger the better. I don't in

my heart feel this.

She continues to manage as per her own ideas.

A marked change in management of a boy's walking and non-walking took place in the time between two interviews (about two-months time).

Yes, it was my decision (to have the boy walk again), the mother clarified. Relative to contemplated surgery, she called herself

a stubborn mother,

deciding against surgery. She presents a mode opposite to the style of the fate-followers, vocally opposing such practices which had her hemophiliac brothers "always in the news" because of attitudes pointing to them as "poor boys".

As discussed, the AIDS crisis brought on new conditions with potential risk. The mothers with the most hemophilia experience, itself a condition which influences organization for work and style, actively took matters into their own hands on this and other issues, one participating in negotiations with the drug company for products known to be "safe", the other re-setting courses for the care of her son.

When the AIDS crisis first became known, the media carried many news stories with reference to this disorder and its significance for hemophiliacs. Teaching and related withholding became evident in the practices of most of these parents, as they attempted to deal with this information in the context of their interactions with their children. With one of the boys (one of the older boys),

some talk of AIDS took place in his presence in that, for a period of time, he developed symptoms that were studied as being possibly connected with AIDS; and as already described, all discussion of AIDS was actively avoided in the presence of a younger boy.

Relative to the implicating news about AIDS disease, a mother, here classified as a fate-follower recapitulated her responses,

> When I first heard about it, I was upset . . . . What am I going to do? But, I never told _____. They really made a big thing about it at first. I was upset, oh my goodness . . . that frightened me . . . . Then Dr. _____ had a talk on it so a lot of parents went to that. I also attended. I just sat there and listened. I had no questions. I just wanted to hear for myself and then I was okay.
>
> I don't . . . let that bother me . . . . _____ needs the medication . . . and what else can I do? If I don't give him the medication he is going to suffer . . . . So I go ahead and give him the medication.
>
> I know a number of families stopped giving their children the medication because they were afraid of the AIDS. Then I guess they are doing it now. I don't know, but I didn't stop.
>
> _____ (the boy) never said "I don't want the medication", and he had been watching the news. There is nothing else I can do about it so that is just the way it is.

She continued on more general topics,

> I told _____, I said sometimes things don't turn out the way you want. That is just the way life is. It is not going to be your way all the time, so that is just it . . . . It could be a lot better, of course, but I better be thankful, like my mother keeps telling me.

She then referred to other people who have more difficult problems.

Fate-following, managing what comes, and indicating little attempt to shape consequences is a style characteristic of a couple of the parents. One is a spouse of a parent who is obviously more negotiatory.

There is variation of parental style over time, and combinations of styles at particular times. The delineations here have some agreement with parent styles listed by Quint-Benoliel. The differences are primarily that the protective quality listed by this diabetes researcher appears in several of the categories here mentioned. Her adaptive mode is much like the negotiatory and psychological styles, and her manipulative delineation appears to be like the parent-director. Yet, her abdicative style has a different quality than fate-following. No parents in this group could be termed strictly abdicative, and none in her study were of the autocratic type found here. Perhaps a more quantitatively-oriented study, with larger samples in each substantive area, would bring these two works into closer agreement in these regards.

Children's Advice: Reflections of Philosophies and Styles

The boys' styles are reminiscent of data in Berta Bornstein's paper "On Latency", where she delineates these school ages into the 5 to 8 1/2-year-olds, and the 8 1/2 to 10-year olds. The former are more likely to be compliant relative to parental wishes, while the latter begin to question parental authority. The data herewith

demonstrates that the styles, while somewhat like requirements imposed by parents, are more likely associated with parent modes when the children's ages are in the early and mid-school ages, and not necessarily so in the near-adolescent years. In delineating styles, it is also evident that social conditions influence modes of management, with some children interacting in several styles.

In one of the study's method-strategies, each child was asked to consider advising a hemophiliac just younger than he about what to do when the hypothetical boy is in particular new situations. As to how to proceed with a new activity, one boy responded,

> I'd tell him to try it.

Another child was full of cautions for the imaginary hemophiliac. Both essentially indicated that the course to take was just like what each was actually doing, and much in agreement with their respective parents' directions.

The youngest boy in the group complies with parental guidance in terms of what he would advise other hemophiliac boys.

> I'd tell them to don't be tough and rough . . . . Don't be a macho man . . . . Don't fight with people.

Yet, as per information from his parents, he doesn't necessarily follow this advice himself.

One boy whose mother has allowed minimal interactions with others, has recently begun to attempt participation

with peers. His mother indicated,

> Now (age 13) he is at he point he will go ahead and try them and see how far he can go . . . . He tried to play basketball, (but) came home with both arms bruised . . . . He tried to play baseball, (but) let the ball go by . . . and the other kids got upset, but he doesn't care. He still tries.

The boy qualified that he doesn't play basketball in p.e. because

> It gets too rough (for me). The game heats up. Sometimes I play.

Thoughtful selection of activities is a general recommendation.

> Be real careful, don't play rough games, and (avoid) tackle football, (touch football is okay), hockey, and soccer.

Some of the boys, themselves, have tried these, but have gotten hurt, or have come away not liking them. One particularly cautious boy, a younger one, also advised not to play soccer in that there are

> lots of ways you can miss the soccer ball, and you would go flying . . . . Playing on slides is okay.

Others have suggested,

> You want to try a little bit of everything. No playing with hard balls (though). Almost all doctors say that.

Yet another said that if he is unsure of an activity,

> I usually do it. If it turns out okay, then (I) do it again.

A mother commented,

> If the mother doesn't accept it, (the limitations), it is harder to make the son accept it.

Advice about "telling" others was qualified by the

hemophiliac boys in a series of ways.

> (Don't tell) teachers (about your hemophilia) because the teachers (then) don't let (you) do hardly anything. Don't tell the teacher. That's what I would do if it was up to me . . . . They get all scared when you do get hurt.

About playmates, a subject elaborated,

> They blow it out of proportion . . . . Don't tell nobody.

To explain an injury, he says to others,

> My leg got messed up.

Earlier, when he would try to explain, he felt

> nobody listened.

Transition-type conditions, as required by adaptations to beginning school or attempted adaptations to "new" philosophies for management point to factors which may be associated with styles as yet not clearly delineated. Basically, as indicated, these boys interact in a generally compliant style; they specifically advise other hemophiliacs to do as they do themselves, which is also as their parents guide them, this particularly relative to discussing hemophilia with others.

A particularly compliant sibling, often given much responsibility for her brother's care is reported to feel that,

> sometimes she didn't like it (but) . . . she went ahead because that's her brother, so she would do what she had to do.

Several have specific advice related to health care itself. In selecting doctors one postulated,

> See if they understand what hemophilia is. See

if they can get into veins. That's one of the most important parts of it.

Another, in planning for himself, wants to make sure he doesn't contract AIDS from anyone.

I have enough problems now.

Adaptive patterns, a combining of parental styles with ideas shaped by their own interactions and cognitive advancement are more characteristic of the older boys and siblings interviewed. One boy accounted for his development in terms of conveying information about hemophilia to others.

> I waited a little bit when I was younger. When I was in 2nd grade I never told . . . any of the kids right off. I waited until I made a few friends. In 2nd grade I just told them not to push me around.
>
> (In 4th grade), I (told that) I had a disease in my body which made it hard for my blood to clot, so (don't) really play rough with me.

He explained that it is risky to tell someone that is

> not gonna really like you, as they'll tell it to some older kids and they'll start making fun of you.

Another remarked,

> In my opinion, the teacher you've got to tell, and you just tell her that if you're playing a rough game that you've got to stay out. For the kids, you may want to wait a little bit.

A sibling whose experience with hemophilia includes family members of several generations with the disease, said of herself,

> (I'll) probably have children . . . . I think about that sometimes because I grew up . . . extremely athletic and if I had children it might be hard on me to have to cope with it in the beginning. But, the way things are going nowadays

with science, I'm not really nervous about it.

She continued that hemophiliacs should

> tell everybody. I can't see why people can't talk about it.

She advised against overprotection.

> (They) are going to get hurt in their lives and there is no doubt about that. They have to learn to cope with it. I've seen it in my family where the overprotection has made people insecure about the outside world.

Her brother, one of the oldest boys in the study, maintains the philosophy which particularly reflects an <u>adaptive</u> style.

> You can't adjust the schools, <u>you</u> just have to adjust.

He qualified simply that schools should just understand

> the severity of it.

Several responded atypically. One of the youngest, in supposing a hypothetical hemophiliac boy arriving at his school suggested,

> For the first few days I think he should stay around me because I know most of the kids.

Another of the older boys responded with what is his own style, essentially <u>adaptive</u>.

> I just answer questions.

There are linkages suggested between parental styles and children's philosophies. It is worthwhile to emphasize that each child, in advising what he was already doing, was also advising styles of work not unlike those of the particular parents. The clearest example of comparabilities is, first, with the strict, self-reliant

mother's approach, which includes little teaching exchange of information, and her son's matching idea that, "Don't tell nobody (about hemophilia)". Their consequent "isolation", is characterized by their having very few social contacts they can regard as friendships. Then, the boy whose mother presents a psychological-type approach, encouraging thinking about physical consequences, is the boy who advocates trying an unknown activity. The negotiating type parent has the son who studies situations and determines how he can fit into them.

While views of taking risks are implied, it must also be emphasized that these boys are pre-adolescent. In adolescence, typically the process involves initiatives independent of parental philosophies and styles.[326] Relative to hemophilia, Mattsson demonstrated that, indeed, adolescents of "over-protective" parents who limit participation in childhood activities become the most "over-active" in terms of risk-taking activities.[327]

Looking toward self-care and eventual independence, the hemophiliac children do not hesitate to describe what they would like to be when they grow up. Four indicated that they would like to be doctors, although one of these qualified that he'd like to be a doctor or a baseball player. Two others were interested in business-related work. Another has in mind becoming a professional tennis player or a professional bowler or a football coach. Otherwise he's considering being a "cop",

> but they might turn me down because I'm a

hemophiliac,

> or a doctor or scientist to find the cure for hemophilia.

Several of the boys, included in their lists of potential careers, being a "hemophilia doctor". One boy elaborated on his wishes about hemophilia,

> (that) there wouldn't be such a thing . . . . (I hope researchers) will take the gene out of it.

Chapter 9

FURTHER IMPLICATIONS

The processes inherent in pursuing the foregoing research incorporated analytic work with data collection and notation of emerging findings. Implications have been presented along with data enumerations. However, it should be especially emphasized that the data's density reflects that not only do the various categories overlap, but that data frequently fall into several categories at once. Thus linkages became evident, and conditions which influenced sub-categorizations were illuminated.

In the study there are very clear connections between work processes and self development. Although these are confirming of theories already developed, they additionally take into account a particular stage of childhood which qualifies that self-development; the increasing self-care, coupled with new cognitive skills and heightened self awareness, produce differential consequences in terms of subsequent processes and ongoing development.

The school ages of childhood circumscribe the pivotal phenomena which, particularly in management of chronic illness, witness the essences of the transfer to self-care, with a major exception being the problematic of speaking up for oneself about hemophilia in social interactions outside the family, related to keen self-consciousness in peer groups at this developmental stage. Initially high priority tasks for a parent, interactions of

work-responsibilities gradually fall to the children's initiatives, rather than to those of their caregivers. However, critical events may again require a reorganization of labors.

Self-identities in the context of conscious awareness of differences from others, particularly at ages when group identifications are perceived as salient, are linked to these persons' not speaking up for themselves in ways that will emphasize their differences and/or taking physical risks in order to minimize the social risk of being different. Nonetheless, the physical condition continues to underline differences from general peer groups. These afflicted children thus lead tempered childhoods with requirements to tend to their physical problems, yet with efforts to maintain a social order relative to their peer groups.

Ironically, as these children develop and thus achieve capacities for their self-care, inclusive of risk control to minimize physical damage, their self-consciousness develops sufficiently that they minimize preventive efforts in order to achieve social interactions akin to those of their peers. Whereas they may not fully connect these interactions to future social relationships, being particularly conscious of current and "intense" social relationships, their parents, with additional perspectives of time, see the current behaviors as being influential for times ahead.

The work integrally involved, the strategies and the

styles, are within the aegis of minimizing risks. In a study including risk factors, that which is in jeopardy or "at stake" becomes crucial in understanding the issues. Clearly the maintenance of life--or staying alive--carries strong meanings for certain chronically ill children and their families. Sometimes directly referred to as a perception of their circumstances, and occasionally only alluded to, extreme vulnerability is a condition basic to the work entailed. For the children with hemophilia, however, this issue is not as salient as it is for children with other disorders.

Nonetheless, family members spoke of their earlier perceptions that hemophiliacs may "bleed to death", and of their efforts to avoid "death" discussions. A young school boy explained that he could die from bleeding, a warning he heard from his father; while an older boy referred to the anxiety he experiences when he's in the hospital, that he'll die. Still another reported that members of groups outside the family fail to understand the "severity" of the disorder.

A mother related that errors in her treatment work could damage her son "for life"; while another spoke of the life threat posed by surgery for her son. Several of the families discussed earlier losses of children, their own or siblings or uncles, due to their diseases.

The singular threat of bleeding is the constant variable for hemophiliacs, but throughout development the

problematic interactions are related to particular aspects of growth and development, thus changing over time. The "constant" variable or variables, thus the threat to maintaining equilibrium or at least recognizing basic vulnerability, varies from disease to disease. The hemophilia experience, as noted, is relatively stable, albeit with vulnerabilities, thus demonstrating a trajectory within which normal development is a potential. The example of cystic fibrosis, at this socio-technical juncture, is still illustrative of a trajectory with potential for ultimate decline and death.

Goals of work entailed in the management of chronic illness include efforts to minimize the chaotic or disorganizing events of health crises which are equated with risk, even risk for survival or, at least, the potential for not surviving. Strategies for limiting potential chaos are oriented, accordingly, with tragic overtones characterizing meanings of some crises and subsequent outcomes. Whereas being potentially out-of-control rings true for all social life, with responses made to experiences as they occur, strategies for such management of chronic illness are built to avoid those events which threaten basic equilibrium.

Whereas Strauss and Glaser have earlier affirmed this theme as a basic core in the lives of chronically ill persons,[328] this current study demonstrates the central problem faced by school age children in these illness situations as they are urged toward "normal" school age

behaviors which are in direct conflict with any "rules" they might have learned for limiting potentially damaging experiences.

If "normalizing" activities in everyday life can be seen as modifying participation in groups to attain and maintain a basic equilibrium as close to group norms as is possible, but inclusive of attention to the chronic illness management (minimizing potentials for crises), damage control will also be modified, problematically affected by developmental considerations. Certainly damage control includes all of the protective interactions described, those initiated by others as well as those of self-care. Whereas styles and strategies qualify those interactions, development into the mid-school ages denotes particular relaxation of these self-care/damage controls, to attempt to match behaviors of peers. Thus the balance in normalizing tips during this period. With the intensity of peer relationships at this time, and the relatively less interest of the mid-school age child in the broader perspectives of time, damage control becomes a lesser priority.

The normalization work thus changes in emphasis to achieve closer peer group identity. Over time, the emphases change according to development and relative to self-other properties. A parent or a non-parent adult may, for example, exercise stricter damage control when the affected child may not. Thus the balance between

normalizing and damage control shifts. It is proposed that in achieving adulthood (or at least in selected peer interactions), the shifts may again be weighted toward damage control. Critical in this determination are the perceptions the person has of the perceptions the problematic others have of him. The normalized interactions thus appear more or less like the behaviors of others, dependent on the issues as delineated here.

For school age children, the particular tasks of leading lives as "normally" as possible, take into account "normal childhoods", in which there is, culturally, strong sentimental investment. The prominence of peer group interaction, which includes the "rough and tumble" of childhood play, potentially challenges their physical selves, central in controlling physical risk. This issue is particularly salient relative to the play and interactions of school age boys and their perceptions of their social acceptance, a major focus of the current study. (Hemophilia in girls is rare.)

Whereas chronically ill adults may also strive toward "normalcy", minimizing their otherwise deviant participation relative to their social groups, they are not consistently confronted with same-age peers who have high regard, even placing "ultimate" values, on skillful, physically active behaviors in their group interactions. Adults may select a lesser degree of physical activity, even limited participation in athletic pursuits, thereby avoiding related potential injuries, and still maintain

"normal" adult lives. For school age children, temporally located in the socio-cultural milieu described, such behavior is "deviant" from the norms of their peer groups. Families described these school age years and those immediately to follow as "the peak" of such requirements. In adulthood, other, less threatening options for interaction may be selected, to which meanings of normalcy may still be applied.

It is noted that the normalcy ideology, masking vulnerability, may decrease particular protective efforts, thus, perhaps, relieving parents to a certain degree. Yet, the inherent risks have the potential to require reorganization of work to manage crises.

Comparisons with homogeneous groupings, where the differences of physical problems aren't prominent, and where the social order encompasses modified definitions, demonstrated differential self-perceptions relative to others and some differing consequences. It is assumed that children with various chronic physical conditions would also respond, accordingly, particularly taking greater social risks under these circumstances.

In considerations of turning points, or milestones, as they are called here, the hemophiliac children have such an event (or processes leading to such an event) that is unique or specific to them. Learning to infuse themselves takes on the meaning of a certain weaning from their caregivers, this enabling aspects of interactions with

peers more like the interactions of the norm. Comparative study of children with other disorders points to similar meaning to other such events. Yet, the growing independence doesn't quite match the also growing independence concomitantly taking place with peers. Deviation remains, albeit a "tempered" deviance when self-care is a reality. Milder physical problems are linked to lesser differences from peers, with resulting interactions less marked as "difference".

The major turning point for these children, referred to, becomes a major turning point for the caregivers, as well. In fact, with all else equal, there would be the potential for a return to a family order close to that which existed prior to the initial work with the hemophilia care. Discrepancies here are relative to other conditions, including a severity of physical problems requiring ongoing care by others, as well as parent-styles which resist allowing growing independence or "normalcy"-type participation. Perceptions of risk are at the core of these differentials.

Thus, the basic social process of work, as in the care of chronically ill children, is further illustrated as central to self-concept development and is potentially dynamic and shifting. Its sharing among and between persons continues to "balance" with children's development, generally yielding temporary orders, particularly in childhood and specifically where illness trajectories are relatively predictable and not dramatically directed toward

health decline.

Extension of life and its "quality" are explicitly factors at issue with the development of scientific technology affecting the chronically ill. The example of the AIDS impact and its new threats of death, problematically reversing the trend in the use of technological "advancement", influencing reconsiderations of older treatments, directly affected life "quality", particularly the degree of "normalcy" in these lives. Two aspects of life-quality are noted: one, that potentials for "normal" social interactions were decreased; and two, there was the perception that any non-treatment would also hasten body damage, such as joint destruction due to untreated bleeds.

Implications for generalization are inherent here, with consideration of potential "trade-offs", "complications", or "side-effects" of technological innovations. All with chronic disease in this socio-cultural era face these conflicts, especially in that equilibrium maintenance with the seeming paradox of focusing on normalcy, is the object of the work.

Following that work processes become incorporated with self-identities, it is no surprise that persons with "prior" experience or interactions relative to a disease, will utilize different styles for management, and will maintain philosophies different from those coming into like experiences for the first time as adults. That particular

social relationships affect later ones is substantiated in the data. Most certainly, the generational concept as noted may well be extended to other substantive areas. It should be noted that even after a number of years of experience in managing a disorder, mothers who have not had such experience from the previous generation, manage in qualitatively different ways, particularly relative to perspectives regarding the future.

A specific social process, here called "taking roles for another" goes beyond work processes involved in physically caring for another within family contexts. Inherent in these taking of roles in another's behalf is the ability to take the role of another. Understanding the generalized other must be a prerequisite for advocating in behalf of another. Shared meanings enable putting oneself in the place to explicate the position of another. In intimate relationships, as between mother and child, one "knows", often minutely, the perceptions held by the other, and can thus represent them. This puts parents in a particularly advantageous position for this work. Such persons present a "role" for another in behalf of the other person's interaction in another group to which the first person doesn't officially belong; thus the parent advocates for a child in the school setting. It is important to note that parents may play such roles for their children from very early childhood on, but don't necessarily relinquish these tasks even though other, more difficult technical aspects of their children's physical care have been

transferred to the children. There is evidence that taking roles in their children's behalves continues as parents note that the children do not (or cannot) perform accordingly in these school ages. Developmental self-consciousness is the basic rationale for these children's inability to so work, especially relative to their peers.

Such processes, of course, might be described for other types of "couples", for example, as one member makes arrangements or speaks for the other when the other isn't available or, for other social reasons, can't speak for himself. The difference in such instances is conditional, specifically, that it is not based on age-related developmental considerations.

As with all studies, although "links" may be demonstrated, missing links must also be noted. It would be exceedingly useful to be able to compare, further, groups "with prior experience" as opposed to those with "no prior experience". This could well extend to many experiences, not only those of illness. Relevant processes and their consequences could enlighten sociological thought. As per the substantive area of chronic illness in childhood, much further work would enhance understanding of sibling work and their perceptions. And, as in any longitudinal work, it would be very interesting to pursue study of these particular subjects into their adolescence, to follow their management of their physical and social activities, their risk taking, and particularly to examine

their speaking (or not speaking) for themselves, and who might (or might not) speak for them. The ongoing development as a focus for study might illuminate the preceding social processes.

Yet another aspect of implications requires consideration. Now knowing what this study has illuminated, what might be recommended? It appears clear that the work processes of the children and the family members should be further explicated relative to health and school personnel. "Gaps" or discordance between and among the institutions, inclusive of the family, might then be eliminated or at least minimized. The pivotal family person or persons who interpret meanings and perceptions of the child in medical and educational settings, might then be in a better position to interpret these institutions to the child.

Speaking for a child when he cannot do so for himself, particularly when doing so emphasizes his differences from the others, should be selectively and sensitively pursued, not to further emphasize his differences, but to convey sufficient and ongoing understanding to other adults who are in a position to enable peer group interactions. These other adults, in fact, might consider creative strategies for minimizing differences, even developing activities for all in a group that will not single out a "deviant" member.

There are obvious applicabilities of the various understandings relative to children with disorders other

than hemophilia, as explicated with comparative materials in Part I. Relevant qualifications are included in that section, as well.

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Letter approved by the University's Human and Environmental Protection Committee Committee, sent to a clinic's school age hemophilia patients and their families:

Dear _____,

Mrs. Evelyn Oremland, who participated with our summer camp staff last year and directed the children's production of the camp newspaper is pursuing a research project to study how the experience of hemophilia influences the social interactions of children. Aside from focusing on the effects of hemophilia on the interactions in the family, Mrs. Oremland has special interest in the relationships with friends and classmates at school. She would like to interview parents and patients from our hemophilia program, and may wish to make observations at school. We need your permission to have her contact you if you are interested in participating in her study.

Mrs. Oremland's study is a part of her work toward a Ph.D. degree in Medical Sociology at the University of California, San Francisco. Additionally, she is a member of the faculty of the Department of Education at Mills College. At Mills she directs the Child Life program, which specifically focuses on the responses of children to illness and health care and the approaches to help them master these experiences. You can be most assured that information from her research will be treated with the utmost confidentiality.

It is our hope that information from her study will be useful for medical staffs, schools, and families who are dealing with children with hemophilia.

If you agree to have Mrs. Oremland contact you for participation in the study, please sign the attached consent form and mail it to us in the addressed stamped envelope. If the child with hemophilia is old enough to read and understand the form, he should sign, too, if he agrees to be involved.

We shall be pleased to answer any questions you have about the study.

Thank you.

Sincerely yours,

_____,
Nurse Coordinator, Hemophilia Program

Approved consent form:

Consent for Participation in a Study on
The Influence of Hemophilia on the Social Experiences of Children

I (We) agree to participate in the study, The Influence of Hemophilia on the Social Experiences of Children. I (We) understand that this project will examine those aspects of children's relationships with each other and with the adults in their lives that are affected by hemophilia.

Mrs. Evelyn Oremland, sociology researcher, will interview patients with hemophilia, their parents, and teachers. Additionally, she may observe social interactions in the classroom and on the playground at school, when appropriate arrangements are made with the particular patients, families, and school personnel.

There are no risks involved in the study as it is planned. The potential for benefit is in the area of heightened awareness and greater sensitivity on the parts of schools, health care agencies, and families, regarding children with hemophilia.

I (We) understand that I (We) are free to decline to participate in the study or withdraw at any time without any effect on my (my child's) treatment or care.

_____	_____	_____
Date	Patient's Name or Signature	Parent's signature

Approval Number: 930819-03*

Notice in Infusions, newsletter of local chapter of the Hemophilia Foundation, September, 1983:

A Study of the Social Interactions of School Age Boys with Hemophilia

Mrs. Evelyn Oremland, a doctoral candidate in sociology at UCSF and a faculty member in the Department of Education at Mills College, is continuing her research of hemophiliac boys from the approximate ages of 7 or 8 to 13 or 14. Her particular focus is the study of how these boys view their activities at school, with peers, and with their health carers and families.

Mrs. Oremland is now inviting the participation of more boys and their parents, to add to those she has already known for several years. She would like to arrange for home visits for interviews, approximately 2 interviews between this Fall and mid-Spring being requested.

If the hemophiliac in your family is in this age group and you are interested in participating, please call Mrs. Oremland at her home _____ or at work _____ to leave a message, or write to her at Mills College; Department of Education; Oakland, California 94613. She requires that permission for the interviews be granted by both a parent and the boy and guarantees complete confidentiality. Interviews can be arranged during after-school times, early evening hours, or on week-ends, depending on family convenience and the distance she'll travel for visits. It is hoped that information from the study will be helpful to all who work with school age boys with hemophilia.

(Mrs. Oremland may be remembered for her hemophilia camp participation a couple of years ago, as she helped with the development of the first camp newspaper.)

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