PERSONAL AND SOCIAL EFFECTS OF
BEING A CARRIER OF HEPATITIS B

by

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Submitted in partial fulfillment of the requirements
for the Degree of Doctor of Philosophy

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1984
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MaryAnn Brichler Foley
THE PERSONAL AND SOCIAL EFFECTS
OF HEPATITIS B CARRIERSHIP

Abstract

by

MARYANN B. FOLEY

As one contagious disease is conquered, another takes its place. A decade of intensive research has brought the world-wide presence of the virulent hepatitis B virus under potential control by means of a vaccine specific for the disease. Other virus diseases spread by exposure to the body fluids of victims or carriers are also being studied toward their eventual control, but the unfortunate persons who retain an antigenic, contagious factor in their body fluids still face a lifetime of seeing themselves as a source of contagion to those who have had no reason to be vaccinated.

Who these people are, what their goals are, how they and those close to them cope with their condition, and its effects on them all are some of the questions that stimulated this research. It was anticipated that study of carrier behavior in sociocultural context might yield information on routes of infection. An interview protocol was designed to elicit responses that would answer these and other questions. Hepatitis B carriers in several end-stage renal dialysis units (high risk groups) in the Cleveland Metropolitan Area became respondents. Extensive interviews with
non-carriers, staff and patients, were also carried out. Demographic, situational and cognitive variables were considered in analyzing responses. Response categories were defined and operationalized by using a degree of response scale developed from interview responses. The mental images of the stigma of the disease held by staff and patient carriers and non-carriers were treated as part of the experimental situation, and were described with a view to the consequences of the perceived responses of significant others to contagiousness.

Analysis of the data following an exploratory design showed variations in beliefs about the real or believed stigma of disease carrier status to be associated mainly with staff/patient and carrier/non-carrier statuses. Significant dependency needs of carriers and health-care workers, as well as the anger, frustration and hopelessness that being out of control of their situation invoked among carriers and members of their networks, were recognized. Coping mechanisms and specifically the ubiquitous use of denial as the primary strategy for dealing with life-threatening disease are discussed.
DEDICATION

To the disease carriers

and

their care-takers
ACKNOWLEDGEMENTS

To all those patients and health care professionals who spent time with me answering questions,

To members of my advisory committee, Jana E. Hesser, Ph.D., J. Kevin Eckert, Ph.D., Jill Korbin, Ph.D., and Michael C. Smith, M.D., for their critical reading of the manuscript,

To J. Thomas Lanning, M.D., and Patricia Herpy, R.N., of the Community Dialysis Center, Satoru Nakamoto, M.D., of the Cleveland Clinic Foundation, and again Michael C. Smith, M.D., University Hospitals, for their permission, sponsorship, encouragement and moral support,

To Art Cross and Jeannette Maryo for taking on the chore of typing, and their patience through the many revisions, not knowing how many there would be,

To all my colleagues and friends, young and not-so, local and distant, who listened in empathy,

my deepest gratitude for your help.

To Dennis D. Foley, Ph.D., and Diane Foley, Ph.D., M.D., who supported me in many ways through this whole ordeal, my love and gratitude for being there. You remembered.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>ABSTRACT</th>
<th>ii</th>
</tr>
</thead>
<tbody>
<tr>
<td>DEDICATION</td>
<td>iv</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>v</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>vi</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>viii</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>ix</td>
</tr>
</tbody>
</table>

## CHAPTER

### I. THEORETICAL BACKGROUND

- The Problem ............................................. 1
- Purpose of Study ....................................... 5
- Literature Review ..................................... 6
- Theoretical Perspectives ............................. 13

### II. METHODS

- The Study Sample ...................................... 25
- The Setting ............................................ 30
- The Interviews ........................................ 37
- The Scales ............................................. 38
- Efficacy of Scales .................................... 40
- Influence of Regulatory Agencies on Study ........ 42

### III. ANALYSIS OF DESCRIPTIVE VARIABLES

- Means $\bar{x}$ Tests .................................. 50
- Staff-patient variable ............................... 50
- Degree of Response .................................... 51
  - Section 1. Social contacts ....................... 52
  - Section 2. Hygiene .................................. 53
  - Section 3. Information management ............. 54
  - Section 4. Fears, anxieties, stigma ............ 56
- Other variables tested .............................. 57
- Summary .................................................. 65

*Continued*
<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1</td>
<td>Neisser's perceptual cycle</td>
<td>15</td>
</tr>
<tr>
<td>Figure 2</td>
<td>A single strip resolution</td>
<td>17</td>
</tr>
</tbody>
</table>
LIST OF TABLES

Table 1. Expected HBV prevalence in certain groups ........ 2
Table 2. Expected HBV prevalence among physicians ........ 3
Table 3. Serologic prevalence of HB in agencies .......... 28
Table 4. Demographics of sample ......................... 30
Table 5. Effects of carriernesship. Means test .......... 50
Table 6. Mean DOR by staff/patient status ............... 51
Table 7. Mean DOR staff/patient X social contacts ......... 52
Table 8. Mean DOR staff/patient X hygiene ................. 53
Table 9. Mean DOR staff/patient X information management .. 55
Table 10. Mean DOR staff/patient X fear of stigma ........ 56
Table 11. Mean DOR by gender ................................ 58
Table 12. Age X mean DOR .................................. 61
Table 13. Education X DOR .................................. 64
Table 14. Education X LOU .................................. 64
Table 15. Items associated with HB. Frequencies .......... 82
Table 16. Level of knowledge before carriernesship ......... 90
Table 17. Level of knowledge since carriernesship .......... 91
Table 18. Responses to question II-7 ....................... 103
Table 19. Responses to question III-1 ...................... 107
Table 20. Degree of concern by staff/patient status ....... 110
Table 21. Responses to question III-2 ...................... 112
Table 22. Responses to question III-3 ...................... 113
Table 23. Responses to question III-5 ...................... 114
Table 24. Responses to question III-7 ............... 115
Table 25. Responses to question III-8 ............... 117
Table 26. Results of antigen tests in carriers' networks ... 119
Table 27. Responses to question IV-2 ............... 120
Table 28. Responses to question II-2 ............... 131
Table 29. Responses to question IV-3 ............... 136
Table 30. Responses to question IV-4 ............... 137
Table 31. Responses to question IV-5 ............... 139
Table 32. Responses to question IV-7 ............... 141
Table 33. Public response to hepatitis B ............... 204
CHAPTER I

How dreadful knowledge of the truth can be
When there's no help in truth

— Sophocles, Oedipus Rex

THEORETICAL BACKGROUND

The Problem

The problem of carriersonship of infectious diseases has been considered from the point of view of medical and public health concerns. However, carriersonship as a social status, and its effects on the carriers and on those who make up their social networks, have gone largely unstudied. There have arisen questions of ethical and humanitarian concern among medical professionals about how to deal with carriers, personally, as well as how to advise carriers and their families and friends on their interactions with one another.

This research studies the social and personal effects of being identified as a persistent carrier of the hepatitis B surface antigen, HBsAg, (formerly HAA or Australian antigen), which is intimately associated with viral hepatitis or hepatitis B (HBV or HB) (See Appendix D). This virus disease was recognized as a major infection of world-wide significance with an infection rate of 69% to 80% in a number of underdeveloped countries. In 1982 the Centers For Disease Control in Atlanta estimated that in the U.S alone, 200,000 persons, primarily young adults are infected with hepatitis
B each year. Over 10,000 patients are hospitalized with HB each year, and about 250 die of fulminant disease.

"Between 6% and 10% of young adults with HBV infection become carriers. The United States currently contains an estimated pool of 400,000-800,000 infectious carriers. Chronic active hepatitis develops in over 25% of carriers (100,000-200,000), and often progresses to cirrhosis. Furthermore, recent studies have demonstrated an association between the HBV carrier state and the occurrence of liver cancer. It is estimated that 4,000 persons die from hepatitis B-related cirrhosis each year in this country, and that more than 800 die from hepatitis B-related liver cancer." (ACIP-CDC, 1982)

The risk of HBV infection in various population groups is shown in Table 1, and the risk to physicians by specialty is shown in Table 2.

Table 1. Prevalence of all serologic markers of HBV in various population groups. (ACIP, 1982)

<table>
<thead>
<tr>
<th>risk level</th>
<th>prevalence of markers, %</th>
</tr>
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<tbody>
<tr>
<td>high</td>
<td></td>
</tr>
<tr>
<td>Immigrants/refugees from areas of high HBV endemicity</td>
<td>70-85</td>
</tr>
<tr>
<td>Clients in institutions for the mentally retarded</td>
<td>35-80</td>
</tr>
<tr>
<td>Users of illicit parenteral drugs</td>
<td>60-80</td>
</tr>
<tr>
<td>Homosexually active males</td>
<td>35-80</td>
</tr>
<tr>
<td>Household contacts of HBV carriers</td>
<td>30-60</td>
</tr>
<tr>
<td>Patients of hemodialysis units</td>
<td>20-80</td>
</tr>
<tr>
<td>intermediate</td>
<td></td>
</tr>
<tr>
<td>Prisoners (male)</td>
<td>10-80</td>
</tr>
<tr>
<td>Staff of institutions for the mentally retarded</td>
<td>10-25</td>
</tr>
<tr>
<td>Health-care workers frequent blood contact</td>
<td>15-30</td>
</tr>
<tr>
<td>low</td>
<td></td>
</tr>
<tr>
<td>Health-care workers no or infrequent blood contact</td>
<td>3-10</td>
</tr>
<tr>
<td>Healthy adults (first-time volunteer blood donors)</td>
<td>3-5</td>
</tr>
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Table 2. Physician risk of hepatitis B by specialty.

% showing HB antibody
(Debes, 1978)

<table>
<thead>
<tr>
<th>Specialty</th>
<th>%</th>
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<tr>
<td>surgery</td>
<td>28</td>
</tr>
<tr>
<td>pathology</td>
<td>27</td>
</tr>
<tr>
<td>pediatrics</td>
<td>21</td>
</tr>
<tr>
<td>internal medicine</td>
<td>18</td>
</tr>
<tr>
<td>anesthesiology</td>
<td>17</td>
</tr>
<tr>
<td>obstetrics/gynecology</td>
<td>16</td>
</tr>
<tr>
<td>family practice</td>
<td>16</td>
</tr>
<tr>
<td>nonpatient care</td>
<td>4</td>
</tr>
<tr>
<td>all others</td>
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</table>

Blood from infected individuals is the most frequently infectious body fluid in transmitting HBV. Other body fluids such as saliva, semen, urine, tears, vaginal secretions, bile and breast milk have also been shown to have the potential to transmit hepatitis B. Despite careful technique, accidental needle-stick or cut, contact with blood while performing office procedures, breaks in surgical gloves, contact with contaminated vomitus, spills or splashes while handling contaminated body fluids and pipette accidents serve as routes of transmission for health-care personnel. Additional modes of transmission for non-medical personnel include sexual contact with an infected person, parenteral drug abuse, dental procedures, hemodialysis, ear piercing, acupuncture, tattooing, sharing toothbrush or other utensils with an infected person.

The responses to carrier state of the newly identified carriers interact with the responses to carrier state of all who deal with them: medical professionals, relatives and friends. Carriership resulting from nosocomially contracted hepatitis B is of especial concern to those in medically related occupations who deal with
chronically ill and institutionalized patients. The continual and progressive interaction between the victims of carriership and those others most important to them carries implications beyond the limited environment of the hemodialysis centers in which most of the interviews and observations for this study were done.

Respondents in this study have raised questions similar or identical to those currently being raised and reported in the popular press concerning such other forms of carriership as venereal herpes, acquired immune deficiency syndrome (AIDS), and even non-contagious genetic conditions such as sickle-cell anemia and Tay-Sachs disease. Questions being raised are such things as: How will this affect relationships with the rest of my family? Can I ever have sexual intercourse again without endangering my partner? Can I even touch anyone else safely? And for those who are in a medically-related profession or occupation, in addition to all those above, there are: How can I deal with patients without risking their being exposed? Should I consider giving up my occupation and going into some other form of employment? Blumberg (1976) discusses further questions dealing with institutional ethics and societal policy on this problem.

At the present time, no chemotherapeutic way of "curing" hepatitis B carriers has been found (Motulsky, 1977; Ommen & Motulsky, 1978) and the new vaccine has no effect on carriers (ADIC-CDC 1982). However, in April and May of 1983 there were at least three health care programs on local television monitored by the author during which hepatitis B was used in some way by the
physician discussants as a model for AIDS, cytomegalovirus (CMV), herpes and other "new" diseases presently suspected of being contagious. As medical technology develops an increased capability to identify occult biological traits of individuals, such research as this will be useful as a model in suggesting how to study the newer problems.

Purpose of Study

While it is expected that in the near future the hepatitis B vaccine will protect those who have not yet contracted the disease, the carrier state already existing in the pre-vaccine population has so far not been affected. Results of research in the late 1970's using interferon, ribavirin and other antiviral agents to treat HB and to clear the blood of HBsAg have been ambiguous (Maugh, 1976). There are no such agents known to be in use at this time for such purposes, locally or elsewhere, and no Centers for Disease Control—Atlanta recommendations for such therapy. Therefore, there is still a need to consider risk from present HB carriers, as well as those who may carry other kinds of diseases or conditions, whether contagious or genetic.

This study was undertaken, therefore, with the purpose of gathering more information on the perceptions, beliefs, values, knowledge and behavior (Kleinman, 1980) of HB carriers, and using this information to extend the limits of knowledge about carriage. Anthropological methods and techniques of searching for meanings by interpreting utterances and behavior concerning the effects of hepatitis B carriage were employed, and contributions
to methodological theory and practice were additional outcomes of the research.

**Literature Review**

The few published studies of carriers of diseases are based on either massive screening programs or small pilot studies involving interviews with a few individuals. With few exceptions studies show that massive screening for occult conditions of genetic origin have been ineffectual at best and damaging or stigmatizing at worst (Stamatoyannopoulos, 1973; Powledge, 1974). A notable exception to this generalization is the screening program for Tay-Sachs disease. Major factors allowing the success of this program are believed to be its voluntarism, its supportive educational efforts, and its excellent organization. Many Jewish groups were requested to participate in all aspects of the program, and carriers were offered follow-up procedures such as amniocentesis and therapeutic abortion. These procedures allowed the carriers to choose among positive options instead of having passively to accept an unyielding hard fact. Although contagion was not involved in Tay-Sachs, identification of an occult condition having the potential of stigmatization might have become a serious problem, but was lessened by careful planning of an integrated program (Powledge, 1974).

A study of the stigmatization of disease was done in a Louisiana facility using patient and staff responses to the chronic leprous state (Gussow, 1964; Gussow & Tracy, 1968). The authors concluded that a damaged self-image due to a positive diagnosis of
leprosy was mitigated by the development of a theory of stigmatization based essentially on denial of blame, a common defense mechanism. They explained that this effort of an organized, isolated group composed of staff and patients allowed them to define their own reality in a way that permitted them to live with the inevitable — unrealistic as that reality might have been vis-à-vis the "outside world".

A Scottish physician in general practice studied 18 cases of typhoid and paratyphoid carriers for a year after they were identified (Sharp, 1966). Among these individuals he found 6 instances of moderate to severe emotional instability, and 10 suffered from depression. Over half of the carriers bore self-imposed social restrictions over and above those imposed by the Edinburgh public health authorities. No psychological tests were given the carriers, and psychiatric labels (depressed, hysterical) were assigned to them by subjective assessment. There is also evidence of class, age and sex bias on the part of the author of this study. Women were labeled hysterical but with similar responses, men were not; aging people were "hypochondriac"; and occupations were listed as socially explanatory factors for class-labeled behavior. Continued, obligatory contact with the health department contributed to heightened concern among the carriers because of the emphasis placed on personal hygiene and the onus of regular surveillance. The major conclusion of the paper was that in the United Kingdom, organized control measures are necessary to minimize the risk of infection spreading to the rest of the community, and that continued
surveillance was "beneficial".

In 1976 Blumberg and Hesser suggested that behavioral factors could constitute a major variable in accounting for 1) the diverse patterns of HBV infection and 2) responses to HB carriertship (Blumberg, 1976). Hesser (1976) did the first pilot study (n = 7) of HB carriers that focused on the effects of carrier status on individuals. She found that indeed there were certain severe personal and social consequences for some respondents as the result of being identified as a carrier.

In the only other study on HB carriertship we could find, Kiernan and Powers reported that 4 of 10 hepatitis B carriers reacted "inappropriately" to the risk of disease transmission (Kiernan & Powers, 1979). Three under-reacted, thus potentially jeopardizing others, and one over-reacted by severely restricting social activities. Psychological testing showed the respondents had high levels of anxiety and depression. The authors speculated that under-reaction may result from misunderstandings of the information provided by the carriers' primary care physicians or from the denial or minimization of the implications of the disease. Their discussion of the one case of over-reaction characterizes the patient as an obsessive personality, but they do not elaborate on this label. Neither do they define what they consider appropriate responses to the carrier state. They recommended that carriers should be checked regularly for "appropriate" reactions and be provided with counseling as needed.
In a later study (1982) these authors had their study population of carriers (now increased to 13) answer three sets of forced-choice questions concerning: 1. the likelihood of various routes of infection; 2. how they felt about others' knowing about their carrier state; 3. restriction of activities. Though they maintain a regular counseling program on both HBV and esrd, their results were consistent with those in this study. On a scale of six, they were asked to rate the probability of various behaviors' causing infection. Furniture and breathing the same air were the most frequent on the most unlikely end of the scale and donated blood and re-using a hypodermic needle were named as extremely likely to cause HB in the receptor. Although they had received counseling, physical contact was rated toward the unlikely to cause infection rather than toward the likely. This denial of knowledge of infection transmission was a common response in the present study, also.

In summary, these studies found a range in responses of individuals to HB carrier ship, but they clearly indicate the potentially damaging impact of identification. Excepting the Hesser study, crucial social, economic and demographic variables, which interact with psychological and medical effects of carrier ship in an escalating or exacerbating manner, were not examined. Because of the hepatitis B risk factor for a number of people in medically related occupations, there is widespread concern in several countries about the possible appropriateness of restricting the behavior (and civil rights) of HB carriers. Blumberg (1976) suggested, however, that an entire group
of people should not be stigmatized and restricted merely on the basis of poorly documented but widespread beliefs about the infectivity of HB carriers.

The meanings that symptoms of illness have for patients influence how and when they decide to deal with a health problem (Good and Good, 1980). The person with a chronic health problem creates a personal belief system centering on that problem in order to deal with the kinds of stresses perceived as resulting from it. In a study of esrd patients De-Nour and Czaczkes (1971) enumerate 1. uncertainty of the future, 2. threat of death, 3. dependency, 4. fear of medical complications and 5. changes in body image, as perceived environmental strains with which end-stage dialysis patients constantly live. The kind and intensity of these strains vary with the disease and the individuals subject to them, and constantly change due to changes in personal relationships and advances in medical knowledge. For these reasons both the kinds of stresses and the methods patients and staff use in coping with them are unusually resistant to identification, classification and generalization.

To the stresses and strains of renal failure, hepatitis B carriership adds a novel ingredient: with a serious viral disease they are now potentially a source of contagion to others in much the same way as are those who have contracted AIDS and venereal herpes. This research studies whether there is a discernable difference in effects of carrierhip between carriers and non-carriers and between
staff carriers and patient carriers. All four of these categories of people have been given the opportunity to discourse on their condition, and their responses have been analyzed and compared.

Once these strains have been recognized and (in most cases) become fearful images of the future, the individual attempts to lower or resolve the strain and its resultant fear by some sort of reactive behavior known as coping. The main types of coping behavior that have been recognized are problem-focused and emotion-focused, and both types are used in all situations (Folkman and Lazarus, 1980). In her study of kidney transplant/dialysis patients Bohnengel (1982) used Rotter's locus of control theory (Phares, 1976) and his internal and external locus of control categories to discuss the coping strategies observed to be in use by her informants. She classified 6 major kinds of coping mechanisms, 3 internal and 3 external, and subclassified these into 16 different specific strategies for 17 patients, most of whom used more than one kind. This is a major problem when more than one major variable (disease or condition) exists in a group being studied: each individual, already embedded in a unique set of phenomenological or environmental circumstances, commands a unique set of coping behaviors which have so far defied other than either the most specific (each individual) or the most general of classifications and explanations. She found it necessary to use both internal and external categories for all patients, and reclassified them from one to the other, sometimes several times during the course of their progress. Her work clearly illuminates the difficulties of teasing
apart physical and psychological effects of illness. It is also an excellent argument for anthropological or holistic studies which may uncover relationships between levels or kinds of phenomena that cross over the usual disciplinary boundaries and may lead to new understandings in several fields.

De-Nour and Czaczkes (1971) review almost two dozen psychiatric studies of dialysis patients and find wide discrepancies in many of their findings. They report some workers as seeing the same group of patients showing well-being while others reported their showing severe depression, and the same patients showing from full rehabilitation to dysfunctional depression and anxiety. The authors do not grant that these psychiatric discrepancies are due to the patient's organic condition. Rather, they argue that the idiosyncracies in perception of the health-care workers (in this case, psychiatrists) account for the differences. They state that dialysis is now "an established medical procedure, and, when no psychological problems interfere, the patients are on the whole well dialyzed" (p. 533). But discrepancies in descriptions and findings, not success of the dialysis process, was the issue being addressed. Without quibbling over a definition of what constitutes a "well dialyzed patient" or a "good dialysis", the author (Foley) disagrees that among the hundreds of people that may be dialyzed daily in a given unit, conditions for everyone are so homogeneous and repetitious that this variable may be taken for granted as "controlled for", and thereafter ignored. Beyond this assumption in their (De-Nour et al)
study and the studies they cite, the patients are not queried, but only the staff are engaged in discussion, and the piece is written from their point of view, with the research scientist covertly validating it.

However, as Kleinman (1980), Mauksch (1973) and many others by now have pointed out, the patient's perspective also must be studied in order to obtain a fuller understanding (and possibly explain some of the earlier published contradictions) because the patient is as much a participant in the interaction as is the staff or the audience (research scientist-observer). The care-taker is as dependent on the patient as the patient is on the care-taker to make sure the necessary goals are accomplished. Nor may the environmental situation on a given day be ignored. On many occasions during my visits to the various dialysis units I was greeted on my arrival with some variant of a statement such as this: "Good luck on getting anything useful today. Everyone is hyper because in the last 24 hours we've had 4 cardiac arrests, one death by heart failure, 2 bad bicarb results and 2 patients show up with anemia." Oddly enough, on those days the author took some of her better interviews. It was probably a good distraction for them, and maybe a greater effort was made by all participants.

**Theoretical Perspectives**

In the last few decades, a "more principled and powerful formulation of the social organization of social behavior" that is developing into a generalized approach to the nature of human social life, has shown its value in a number of subdisciplines in social
science. In an economic, ecological or adaptational context this approach has been called reciprocity and interaction strategy (Whitten and Whitten, 1972). It is an interpretive or hermeneutic approach that incorporate elements of social exchange theory. McDermott and Roth (1978) list a dozen or more different labels for various versions of the approach as used by various academic disciplines, including interactional and cognitive theory. Figure 1 is Neisser's (1976) schematic representation of this theoretical model which Bock explains as follows:

"Guided by our general maps and the specific 'perceptual schemata' embedded in them, we sample the information present in the environment; this process frequently leads us to modify our conceptions of the world. Our new conceptions then direct renewed exploration, creating a continuing cyclical process. ...I fully endorse Neisser's statement that 'actions are hierarchically embedded in more extensive actions and are motivated by anticipated consequences at various levels of schematic organization'." (Bock, 1980:241)

Two elements are necessary in the discussion and understanding of an interaction: a schema and a strip. A schema is a general term for the goals, frames (situational contexts), and plans (for behavior, such as coping) which ethnographers use to talk about the ethnographic tradition and experience. (See Figure 1.) "A strip... is any bounded phenomenon against which ethnographers test their
Figure 1. Neisser's "perceptual cycle" as reproduced in Bock, 1980. Used by permission.

1. For another kind of visualization see mazeway model of Wallace (1961, 1970:10).
understanding of the group (Agar, 1982:789). The term, introduced by Goffman (1974), might refer to a social act, a formal or informal interview, or even to a document (Figure 2).

The process of constructing an ethnography focuses on the differences that appear when different traditions (of the group studied, the ethnographer, and the ethnographic audience — the academic professionals) encounter each other. When differences appear among the traditions of each, something does not make sense, and a starting assumption of "perfect coherence" is violated. These differences are called "breakdowns" and signal disjunctions among the traditions or schemas. The problem for ethnography is to give an account that eliminates (or explains) breakdowns (Agar, 1983:783).

A coherence → breakdown → resolution sequence is what ethnographers seek to construct from their data. In operationalizing this model, schemas are applied to strips (or a cultural rule is applied to data) until a disjunction or non-fit occurs because some expectation defined by the schema used was not met.² The schema is modified and tried again, and again, and again.

² Chapter IV, section 4, contains more detailed discussion and examples of the operationalization process for this study, ref. Pelto and Pelto, 1978:39.
In most studies this "single strip resolution" is not sufficient. Many such sequences must be traced, often down obscure alleys, until some semblance of a reasonably coherent explanation begins to appear. The study is bounded by the content of all participants' experience, knowledge and effort. Hundreds of such sequences as diagrammed in Figure 2 are traced to produce an ethnography. In the present study, each response to each question is the basis for at least one strip, and many times, more than one, because each response is the current conclusion of the respondent resulting from a set of prior circumstances having been brought to a resolution.

McDermott and Roth state a basic assumption of this view of social behavior:

"...a person's behavior is best described in terms of the behavior of those immediately about that person, those with whom the person is doing interactional work in the construction of recognizable social scenes or events." (1978:321)
Mauksch (1973) details further assumptions of this approach in his discussion of the "negotiated order" of the hospital as a setting for the processes of cure, care and core. Cure is the mandate to heal; care is the supportive and compensatory mission of the helping institution; and core is the process system which seeks to maintain the institution's survival (ibid., p. 820). Patient care is a composite beyond the exclusive control of those involved in it face-to-face, and is produced by a negotiated system of interactions which yield "accommodative consequences between ideologies, systems, roles, and tasks" (ibid., p. 818). This premise leads to the assumption that patient care is an independent variable that "modifies the institution and its processes as it is shaped and produced by organizational forces" (ibid.).

Katon and Kleinman (1980) discuss why, in addition to the biomedical model, a multilevel analysis is often required for an expanded view of the problem. They call this a biopsychosocial approach and describe it as the "simultaneous interplay of biochemical, behavioral, psychodynamic, family and cultural systems" rather than the limited picture based on only one of these determinants of clinical reality. "It suggests a number of therapeutic interventions to be applied together or in sequence to break the feedback loops maintaining [recalcitrant] behavior."

During the observation of an intern taking the case history of a newly-admitted stroke patient, the author became aware that the elderly woman had lost some degree of mental function and had forgotten certain incidents in her life which were relevant to her
case history. Adhering to the standardized information he was assigned to elicit from her as a new patient at the hospital, he rarely glanced at her, but read ahead to the next question as he was writing the answer to the last. Unless someone took another history from a relative, much that had happened to her before her recent stroke went unreported either because she forgot or believed it was irrelevant. She had told me earlier of several allergies, but when questioned about allergies by the young physician she denied having any at all. At this particular unit, charts were often checked by a supervisor’s reviewing it with the patient or a relative, but if they were understaffed at the time of an admission, they may very well not have been repeated. Since "illness, as a personal and social reality are inextricably bound to the medium of language and signification" (Good and Good, 1980; Twaddle, 1980), the treatment process could be in jeopardy if such incidents occurred frequently.

This is a simple case of loss of function accounting for non-compliance. Due to short-term memory loss, the woman consistently forgot the instructions she was given by the medical and nursing staff and after a while they became exasperated with her and treated her as though she were being deliberately stubborn because of her own "set ways", seemingly unaware of her recent loss of function.

Unlike other theoretical models borrowed from other sciences, it is not only possible but probable that several social structures coexist within the same social space at the same time. A corollary of this assumption is that the participants in the system occupy
separate roles in each of the social structures simultaneously. An intern or resident, for example, may be doctor, student, friend, colleague, husband/wife and other things to other people, all at the same time. A registered nurse may be subordinate to a physician and the supervising nurse on the floor, superordinate to licensed practical nurses, technicians and orderlies. To a patient the RN may be perceived as healer, mother, counselor, et cetera. The behavior produced in an encounter is dependent on the other person and the particular social context in which they encounter each other. Necessary to a fuller understanding of behavior and its outcome is to examine the situation in which the action is occurring and as much of the total social environment as possible.

Lewis (1980) writes that "behavior of the person who is ill is influenced by the setting and the person's perception of the situation and the people in the setting". The social costs or benefits, such as "loss of time at work, effects of an open declaration of disability or impairment, a possibility of evading unwelcome duties or obligations because of illness, all may complicate how and when someone decides to seek advice or treatment". That illness carries such meanings is apparent when we understand that "we have all learnt to recognize that there are social constraints and rules which govern the conditions for which we can expect sympathy, ridicule, or help". The assistance of others is also conditional on their evaluation of the person and the illness, cost in time and money, and the urgency and capacity to help. "Social behavior in illness is by definition an interaction
with others: to forget the others leaves us blind to influences that may have shaped and motivated much of what one did when he was ill" (ibid., 160).

In their discussion of the meaning of symptoms, Good and Good (1980) add another dimension to the discourse on meaning in illness. In order to explain patient non-compliance they begin by distinguishing between the empiricist model of clinical reasoning based on biomedical knowledge and logic, and an approach based on the dual recognition that "human illness is fundamentally semantic or meaningful" and that "all clinical practice is inherently interpretive or 'hermeneutic'." They explain that sickness becomes a human experience only as it is perceived, evaluated and communicated by the individual victim. The personal and social reality of illness is constructed from the popular medical culture in a given society. The Western tradition of medical culture has been syncretized with the various folk cultures of all the people who have immigrated to the United States, and consequently there is a large number of highly individualistic beliefs about disease etiology in the country. Most of them contain elements of both traditions, their own and those of Western medicine. Good and Good, Kleinman (1980) and many others who are quoted in their summaries of the study field believe this is an important reason for misunderstanding, non-compliance, frustration, hostility and lack of treatment success with certain patients.

A case dealt with in more detail in a following chapter
describes a young woman whose kidney and hepatitis problems were more recent additions to a skeletal malformation she had suffered from birth. A group of faith healers (Twaddle's (1980) "circle of others") persuaded her to stop dialysis and all medication for several weeks, after which she reappeared at the dialysis center in critical condition, needing hospitalization. Thereafter, many staff members showed little patience with her and treated her as though she were somewhat mentally incompetent. She was not. She was "merely" tried to her limits, and as a "discredited" and "decrepit" (Goffman, 1963), lonely, low-income immigrant who had been abandoned as an adolescent by her parents when they were divorced, she was conveniently overlooked when she demanded attention.

Ethnographies are a function of the different traditions of the ethnographer, group studied and the intended audience. A change in any one of the three causes content to change with them. "The 'definitive' ethnography does not exist" (Agar, 1982:784). This makes it impossible to repeat a particular study; all we can do is a restudy in a different time, often by different people. "We no longer try to describe 'a cure'. We try to bridge different traditions. An ethnography becomes a connected collection of bridges relative to the traditions that go into the encounter" (ibid., 792).³

³ In an effort to keep this exposition useful to others than cognitive ethnographers, the many different terms of dozens of theorists and philosophers of science have been avoided. The nomenclature of the author being quoted, or a generalized
Chapter II discusses methodology in terms of the actual research data as well as the circumstances under which it was collected and how it was decided what to collect. The project itself became a changing thing by the time all the individual personalities and the organizational forces were through with it. Chapter III describes interrelationships among the demographic and derived variables and what they may contribute to the understanding of carrier behavior. A few simple descriptive statistics aid in this description. Chapter IV continues reporting results of analyzing the data, but adds depth and meaning to the participants' behavior by comparing and contrasting the staff and patients, carriers and non-carriers, perspectives on carriernesship. Problem-focused (e.g., wash hands frequently, use disposable cups and plates) and emotion-focused (e.g., denial, information control, depression) coping behaviors are described. These are composites of the interactional or negotiational process as told to and observed by the author in the actual context under study. Denial behavior is discussed in Chapter V as a major example of the interrelationship of levels of perception, organization and (the resulting) behavior.

anthropological vocabulary, have been used. Several meanings for one work or several words for close, but not identical concepts are confusing. I have tried to eliminate some of this type of confusion because this is essentially an applied study and not meant to be primarily a theoretical treatise. Major discussions which were helpful in building the author's perspective for the discussions in this paper were those of Agar (1982), McDermott and Roth (1978), Goffman (1963, 1974), Mauksch (1973), Kleinman (1980), and Mechanic (1969, 1978).
Finally, Chapter VI summarizes what has gone before, discusses the relevance and significance of the findings, and offers suggestions and questions for further areas of study progressing toward a fuller understanding of carriesthesia. The current high concern of the public as reported by the news media makes the study of being a carrier of a viral disease an important and timely topic. The factors involved may offer clues to a better understanding of everyone's responses to those infectious viral diseases which are presently a concern. As a model with suitable modifications this study might also be of value to those studying non-infectious genetic conditions which in the past have stigmatized their carriers.
CHAPTER II

METHODS

The Study Sample

The data for this study were collected between May, 1980 and November, 1982. Twelve physicians in the Cleveland Metropolitan Area who head agencies or hospital units judged to be in the high HB risk category were contacted for possible participation in the study. The units contacted included hemodialysis, gastrointestinal diseases, surgery, blood banks, and chemistry and blood laboratories in both private and tax-supported institutions.

Minors, prisoners, drug abusers and the mentally retarded were eliminated from consideration for several reasons. 1. The participants could give the kind of information needed for the study only if they were mature individuals, conscious of what they were saying and aware of what they were doing. 2. They had to participate voluntarily in order to insure as much as possible that their answers were honest and accurate. 3. The study was not of an emergency nature, necessitating life-or-death heroic measures for sampling. To the contrary, every effort was made to provide and maintain a comfortable, pleasant, positive, "laid back" encounter. 4. We wanted to protect them and better assure the confidentiality of their carriergship. It was easier to justify the need to identify carriers and breach their anonymity if they were in full command of their faculties when they consented to participate. An important
part of the first stage of the interview was to let them know the importance to the study of each individual's contribution.

Five of the physicians declined to participate because they had either no carriers or no HB problem. Seven agreed to participate, assuming their institutional review boards (IRBs) approved the research proposal. Of these, the interested personnel at one institution were unable to comply with their IRB's conditions for approval and withdrew from the project. The IRB of one of the other agencies came to the "unanimous opinion that the essentially healthy carrier of HBsAg would not be an appropriate group for the study", and refused participation. Remaining to participate were four dialysis units and the blood and chemistry labs of a teaching hospital.

All 12 of the physicians originally contacted were asked whether they knew of any local epidemiological data on either hepatitis B or HB carriership. All disclaimed knowledge of any such data, or of any agency that was accumulating such data in 1980 when the study was begun. In order to get a rough estimate of the prevalence of HB carriership in the Cleveland area, unofficial Red Cross Blood Bank figures for 1980 were solicited. The estimate below is offered with caution because Red Cross volunteer blood donors are a select group, not entirely representative of the general population.

There were approximately 176,000 units of blood donated to the Red Cross in 1980 of which, perhaps, no more than 10,000 were repeat donors. At the national rate of incidence of HB carriership in this
country used by Szmuness et al in 1980, a 166,000 person sample from
the general population should yield between 166 (0.1%) and 1660 (1%)
people who remained HBsAg-positive on at least two occasions at
least 6 months apart (CDC-IPAC, 1982), for an average of 913
carriers. Red Cross records for 1980 showed only 63 cases for which
laboratory test results showed HBsAg positivity, or 7% of the
expected number. As stated above, this is a select, healthy sample,
and therefore the expected rate is low compared with the expected
number based on the national average, and is not meant to be quoted
as even near the real figure. However, it is in line with the
subjective estimates of the local physicians from the various
institutions who were originally contacted. The figures agree with
the estimates of dozens more local health-workers who have been
asked about their awareness of the frequency of HB. While a number
of groups at high risk for HB are not represented in the above
sample because of Red Cross screening and cessation of the use of
paid donors, it would still seem that the Cleveland area has been
fortunate to have many times fewer the number of HB carriers than
the nation as a whole.

In the first year of the study (1980-81) gross data on four
dialysis units were gathered. (Staff and patient populations in
dialysis units are constantly changing, so also these data will con-
stantly change.) Two carriers who later converted to antibody
positive (AB+) (see Appendix D) were recruited to participate from
the blood and chemistry labs of one of the teaching hospitals.
There were two dialysis centers, each one housed in its own building, and the two in-hospital units with which each larger outpatient center was (most closely) affiliated.

<table>
<thead>
<tr>
<th>Total</th>
<th>HB</th>
<th>% HB</th>
<th>HBsAg+</th>
<th>% Carriers HBsAg</th>
</tr>
</thead>
<tbody>
<tr>
<td>patients</td>
<td>267</td>
<td>106</td>
<td>40</td>
<td>26</td>
</tr>
<tr>
<td>staff</td>
<td>144</td>
<td>29*</td>
<td>20</td>
<td>3</td>
</tr>
</tbody>
</table>

*One unit runs only Ag+, not AB+, tests on staff, so this figure is probably low. HB refers to history of hepatitis, or AB+, or both. (App. D)

Table 3. Serologic prevalence of HB and HBsAg in agencies studied, 1980.

Table 3 shows how many staff and patients in all units studied had a blood test positive for antibody to hepatitis B (HBsAB+), and how many had persistent HBsAg+, identifying them as carriers.

Hepatitis B vaccine became available in late 1982 for high-risk populations such as those at dialysis centers. With the vast majority of staff and patients choosing to have the vaccine, there should be fewer or no new in-house cases of hepatitis B or HB carriageship. New patients coming into the unit, unvaccinated and already infected, would be the only source of new contagion, and a risk only to members of their social network who were unvaccinated.

The data in this study show that 20% of the staff and 40% of the patients developed either a subclinical or a more severe form of hepatitis B, and about 10% of the patients and 2% of the staff became carriers. These figures correspond to the national average for health-care institutions at present, but should drop off and approach zero in the next few decades because of the vaccine (Szmuness et al, 1980; CDC-IPAC, 1982). Knowledge concerning
carriers and carriernesship, however, is still pertinent and necessary, considering the plethora of new diseases that seem to keep appearing just as older ones are being conquered. Lassa fever, AIDS and herpes are all suspected of having viruses and human carriers implicated in their transmission (West, 1983).

Sufficient HB carriers to carry out certain planned statistical studies never became available, even though data collecting was eventually extended over two years. A total of 32 people, medical staff and patients, were identified as carriers in the participating agencies. A sample of 30 was achieved when all but two agreed to participate. An additional 15 non-carriers from the same dialysis units were chosen for comparison interviews on selected subjects. An approximately matched list of non-carriers had been prepared for interview comparison when the author had to interrupt fieldwork for several months because of an unexpected hospitalization unrelated to the research. On resumption of work, she found that HB vaccine had become available and most antigen and antibody negative staff and patients had taken advantage of it. Attitudes and images involving HB had changed because of a lessened fear of its consequences and since this changed the psychological setting of the dialysis units, it served to terminate the research. Further research concerned completing the record of organizational structure and filling in other lacunae for a more complete description and understanding of the units. Table 4 shows some demographics of the sample interviewed before introduction of the vaccine abruptly ended this
part of the study.

<table>
<thead>
<tr>
<th></th>
<th>Carriers</th>
<th>Non-carriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>12</td>
<td>8</td>
</tr>
<tr>
<td>Male</td>
<td>18</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Patient</td>
<td>24</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>14</td>
<td>10</td>
</tr>
<tr>
<td>Black</td>
<td>16</td>
<td>4</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-40 Yrs</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>41-60 Yrs</td>
<td>14</td>
<td>5</td>
</tr>
<tr>
<td>61 &amp; Over</td>
<td>7</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 4. Demographics of sample.

The Setting

This research was conducted at hemodialysis centers either in or affiliated with two large teaching hospitals. Other hospitals in a wide area send their patients in need of dialysis to one of these centers. The in-hospital units were small, having an 8 to 12 bed capacity. The independent units were within a mile of the associated hospitals. They had from 16 to 30 stations, and dialyzed up to 208 patients per week. One unit will soon be able to accommodate 256 per week, when the equipment on order is installed. The units are adding patients at the rate of about 5% per year, and the dialysis population is getting younger, on the average.

When patients' kidneys fail due to one of several physical conditions, there are few alternatives to treatment: kidney
transplant, end-stage renal dialysis (esrd) or death. Only a few organs become available for transplant each year, so the only viable alternative each year for most of the victims of renal failure is hemodialysis. This process pumps their blood through a machine that cleanses it of waste products and removes the excess fluid the kidneys are unable to collect and expel.

Most patients come three times a week for a four-hour treatment, although there are a few once or twice a week schedules. Into a vascular fistula surgically installed in the forearm (occasionally the thigh), two needles are inserted to draw off the patient's blood and return it to the body after it has been processed through the dialysis machine. After circulating through the machine for about 4 hours, with constant monitoring, the blood is detoxified and the patient is taken off the machine and returns home — or to work, or wherever.

The machines' pumps, monitors, etc., set up a noisy clatter, and buzzer signals and warning bells make up a constant background noise. Together with the miniature television sets installed at each station and the radios some people prefer, there is a noisy veil of privacy around each station without a physical wall or curtain around each chair.

The in-hospital dialysis units are much smaller than the independent installations and need to accommodate only up to 12 persons (and usually fewer) at a time. They are treated in beds, whereas in the out-patient units Lazy-Boy or Barca loungers are used. The hospitalized dialysands are patients institutionalized in
the early stages of preparation for dialysis during surgical fistula installation, or for fistula repair, or dialysands who are having additional distress of some kind such as cardiac or pneumonia episodes. Once they have recovered and are once again ambulatory, living at home, they return to the larger, out-patient units.

Because the fistula have to be activated three times a week through the skin, extreme care is taken to avoid infection. There is always some leakage of blood and great effort is expended to minimize bleeding. From 1 to 6 machines are set aside in the units to be used only for those whose blood tests out positive for antigens or antibodies. There is one machine for each chair or station which is carefully cleaned and decontaminated after each use. Usually, members of the staff who have tested positive for the antigen or antibody of hepatitis B care for the patient carriers, but in emergencies this rule may be ignored. The disposable products of each HB+ patient's treatment are carefully collected after the dialysis session is ended and packaged in a special, marked container warning others of contamination. It is disposed of in a different manner that the rest of the units' trash. Finally, there is usually a separate bathroom for the use of all hepatitis carriers.

Rubber gloves are available to any staff member who chooses to use them for the protection of both the patient and care-taker. There were few observations of the routine use of gloves, but when accidents caused some HB+ blood spillage, usually everyone who
participated in the clean-up wore the disposable gloves.

Every effort is made toward the comfort and relaxation of patients undergoing dialysis. They continue to wear street clothes, and many keep on their shoes. However, there is no eating or drinking in or around the dialysis stations. Because removal of fluid is one of the main functions of dialysis, only ice is offered patients if they complain of thirst.

For the staff, and the relatives in the waiting area who provide transportation for the patients, there are a canned soda machine, a station for instant coffee or tea, and in one unit a coin-operated candy machine. A microwave oven is available for those who want to heat their lunch or dinner. A large-screen color television set is also available for off-duty use.

Supervisors have offices a short distance from the dialysis rooms, and technicians share offices that open directly into the treatment rooms. There are 3 large rooms with 8 stations to a room, four on each side facing each other. The rooms are separated by floor-to-ceiling walls with large openings at both ends to accommodate bulky equipment. More such rooms are being prepared in another part of the building to expand their capacity. One room has an isolation set-up for several carrier patients to be dialyzed simultaneously. There are walls between the isolation stations, but they all open onto the central area of each room where there are stools and chart-racks for the convenience of the staff.

Instead of describing all four units' schedules, three of which are pretty much integrated with hospital routine, the fourth and
largest unit will be described: Most hands-on personnel (nurses and technicians) work four 10-hour days with 3 days off. This allows them greater personal freedom to engage in other activities and is considered necessary for them to get away from the life and death responsibilities and often, disappointments, of their stressful occupation. A blank schedule is posted, and staff members are periodically requested to sign up for their preferred days and hours of duty. The supervisor then attempts to come as close as possible to meeting their scheduling preferences. At this unit, three dialysis periods are scheduled daily, six days a week, from 6:30 AM to sometime after 7:30 PM. With flexibility in the times that shifts start up, 10-hour days cover the schedule and people are happy with the extra day off. At this unit, staff time is flexible (with pre-arrangement) so long as a minimum number report for duty to cover all necessary tasks, and the full staff is present during peak-load periods.

In addition to registered nurses with and without a baccalaureate degree, the staff consists of licensed practical nurses, several dietitians, several social workers, liberal arts college graduates who are trained-in-practice as technicians in the unit, and a clerical and office staff. The physician in charge of the unit has an administrative assistant (non-medically trained). When the physician is absent from the unit for associated duties such as conferences, speaking engagements, etc., there are residents from the teaching hospitals and senior staff members from several other
hospitals in the immediate area (who send their dialysis patients to this unit) to cover for him. A strong effort is made to have a physician in-house as long as there are patients being treated.

Technicians, nurses and (less frequently) physicians do the hands-on care and examinations. In emergencies, all levels of personnel responsible for that particular patient assemble at the station, observe the examination, then withdraw with the patient's chart to discuss the case and contribute to the resolution of the emergency. The dietitians educate the new dialysis patients in the diet changes and intake limitations necessary for renal dialysis. Later if there develops a need for further diet modification, as for diabetes complications, weight loss, fluid gain, or other problem, there will be further sessions with the dietitians. The social workers have something of a dual role. In addition to acting as counselors for emotional problems resulting from the need for dialysis and trying to anticipate problems before they become serious enough to interfere with the dialysis process, they are also facilitators. They provide liaison between the patients/patients' families and the various medical, insurance and social agencies involved with patient maintenance. Aid in providing transportation to and from the dialysis unit, getting food stamps, social security or other benefits are usually handled by the social workers. The clerical staff has minimal contact with patients and usually works a normal 8 to 5 shift. There is a maintenance crew member on duty at all times.

The Director of Nursing and the Supervisor of the technical staff
work out schedules, monitor the flow of activity in the unit, and are on call for questions, advice and emergencies. The senior nurses function much as nurse-practitioners, and assume responsibilities such as first-year residents might do in a hospital (with the exception of writing prescriptions). Since they are first to be notified in an emergency, they make preliminary diagnoses and direct care of the patient until the physician arrives. Interrupting the flow of the dialysis process is avoided whenever possible.

The care and comfort of those on dialysis is an occupation that demands some degree of constant attention to the patients and the machines. Except for the few patients who have successful kidney transplants, there is only one way they will leave dialysis - by death. Staff and patients are forced to get along with each other even if they don't especially like one or another of their group. This realization weighs heavily at the back of the minds of staff members, and is a contributory factor to the need for a period of mental refreshment at the end of each work week. While not every member of the staff is always at their best, by and large most staff members on most days try to be optimistic and kind to frequently cranky patients, and helpful with each other. There is a lot of humor and laughter in the dialysis unit on most days as a counterbalance to the pessimism that patients may feel. Any setting involving chronic illness has certain well-known problems (De-Nour, 1972; Gussow, 1964) which change day-to-day. To make the best of it
with kindness and humor is often the most that can be done.

The Interviews

Two interviews of 2 or more hours each were conducted with each respondent. (Later, further data were gathered in shorter interviews to complete needed information). This schedule was modified on occasion around the convenience of the individual, and either one extended interview or three or more shortened interviews might have been held. Each interview was guided by the use of an outline for eliciting demographics and case history, followed by questions about hepatitis and carriernship and their consequences (Appendix A.) During this latter part of the interviews the respondents were encouraged to discuss their beliefs, values, feelings and perceptions concerning disease (as a physical condition) and illness (as the cultural meaning of the dysfunction to the patient).

All questions were not asked of carriers and non-carriers in the same way because of the highly speculative nature of the non-carrier responses if asked to imagine themselves in the carrier situation. Vocabulary was also modified to match the respondent. To get at the same type of information alternate versions of the questions were used, e.g., "What things do you do (or not do) with (or in the presence of) carriers?" or "What symptoms have you noticed in people suffering from HBV?"

Participants were requested to estimate for themselves (using the simple scale: high, moderate, low) how much concern their knowledge of hepatitis was causing them, and to discuss the nature
of their concern. From these answers, and from observations and reports of other kinds of behavior in dialysis units, were derived a degree of response scale (DOR), a level of understanding scale (LOU), and a degree of concern scale (DOC), all of which are described in the section immediately following.

Interviews were conducted in the health-care agencies. Two hospital staff technicians felt more comfortable being interviewed in an office on the university campus. Some patients chose to participate either before or after their dialysis treatment, but most chose to do it while they were on the machine. The general background noise level in the dialysis units provides a surprising degree of privacy. Staff respondents were excused from floor duty during slow periods in order to participate, and they were interviewed in a nearby office.

The Scales

Degree of Response or DOR. In order to compare responses among the participants and to be able to generalize about them, it was necessary to devise tools for comparison. One of these is the degree of response (DOR) scale. All of the various kinds of responses pertaining to hepatitis and carrierginess given by those interviewed were listed. With the help of two physicians over two working sessions these responses were grouped into four categories: 1) social contacts restrictions, 2) hygiene, 3) information management, and 4) fears, anxieties about stigma (see Appendix B). Items in each category were also ranked by their perceived degree of importance in avoiding risk of infecting others and/or lessening
emotional trauma, but this was not measurable from given responses.

Forty-seven items were listed, and these were separated into positive and negative type statements, such as "I always wash my hands after..." or "I never bother to separate my utensils...". Each transcribed interview was examined for mention of all items listed, both positive and negative types of statements. Subtracting the negative statements from the positive statements resulted in scores ranging from +20 to -8. This became the degree of response or DOR scale. A positive or negative number indicates immediately whether a person feels she/he is being careful or could be doing better in this respect. It assumes they respond to the degree of danger they perceive in the situation.

**Level of Understanding or LOU.** In a 1976 study of compliance in a dialysis unit, Borkman raised the question of how well patients understood the constraints under which they were forced to live. She asked staff members to estimate (guess at) patients' I.Q. and tested these scores for an association with staff members' assessments of understanding and compliance. She found staff assessment of patient intelligence (I.Q.) was not a significant factor in staff assessments of either understanding or compliance, but that staff members' predictions of how well they thought a specific patient could understand was a much better predictor of compliance (Berkman, 1977). Following this lead, the level of
understanding scale (LOU) was devised for this study.¹

The interviews were scanned for all responses to certain questions pertaining in any way to hepatitis and carriherohip. The number of "don't know" responses for each person was totaled and became the level of understanding or LOU score. Since their answers to these questions also indicated their degree of comprehension of the issues of contagion and risk to others, this measure may also be thought of as an indirect judgement of risk. A very high score indicates a very low level of understanding of the topic, and vice versa. The range of LOU scores was 0 to 15. Thus a person with a score of 15 answered "don't know" to all questions in the category, exhibiting no knowledge, and therefore, no basis for understanding the subject.

Degree of Concern or DOC. A third scale at the ordinal level, having the categories high, moderate and low, was based on question III-9 (See Appendix A) which asked respondents to assess their own level or degree of concern in response to hepatitis carriherohip. Because of its low level of precision it was of limited value, but in general it was useful as a comparison with the DOR and LOU, which indicated to the observer the respondents' level of self-awareness.

Efficacy of Evaluation Scales

The degree of response and the level of understanding scales were tabulated separately from two different kinds of data: the DOR from

¹ Questions II 1 2 3 5 6 9 10, III 1 2 3 4 5 8, IV 3 4 6 were used in developing the LOU. Interviews which necessitated less structured format were scanned line by line of text.
the specifics of the narratives, and the LOU from simply whether respondents knew (or thought they knew) anything about the various topics under discussion. Since these scales could also be collapsed into ordinal, grouped data, it was initially anticipated that they would be used for the chi-square test on hypotheses based on a number of independent variables: age, sex, ethnicity or race, marital status, socioeconomic status (SES), network size, education and others derived from the data. However, the sample is so small that in 2 × 3 or 3 × 3 cell blocks, many cells contained only 0 or 1, thus invalidating the test. Respondents did not spontaneously provide sufficient or similar enough information to use the physicians' rankings of the elements of the DOR scale (Appendix B), so this additional scale remains unused. Carrier respondents' answers were based on their actual recalled experience, whereas in some cases non-carriers chose to discuss the subjects as what they thought they would do if they were carriers, based on their observations of carriers. Having been denied access to healthy carriers, there was no way of defining a true "control" group to compare with the HB carriers in dialysis units. Using staff and patient non-carriers in the same dialysis units was the closest available comparison sample.

Not until the field part of the study was concluded was it realized that question III-9 would have been more effective as an interval choice ("On a scale of 1 to 10...") than as merely an ordinal choice (high, moderate, low). This would have given a better associational test than chi-squared.
As it is, the response and understanding scales and the one consisting of self-assessment of concern based on question III-9 together describe individuals and groups of individuals based on different criteria. Staff-patient status and carriernesship were the variables most predictive of behavior responses. Gender, age, education and SES were also predictive, but not as well. These results were consistent with what is considered a great strength of the ethnographic method of research, i.e., extended participation-observation over a lengthy period of time. If intuition may be seen in the mathematical sense as experiential learning, it could be said that the results are intuitively in agreement with the understandings built up during the course of study.

Influence of Regulatory Agencies on the Research

When research is conducted on human subjects, the institutional (IRB) and governmental (NIH) requirements and restrictions create paradoxes which give rise to "unintended and potentially harmful consequences that fall...on the scientific establishment and science" as well as on the respondents (Reiss, 1979). Rather than philosophically discussing all the potential problems that could arise from this source, only those major ones which pertain to this study will be mentioned. Here, then, is the natural history of a research project.

1. The a) structure, b) methods and c) results of the research project itself were strongly influenced by the imposed regulation of informed consent and the signing of a consent form. Methods of
dealing with privacy and confidentiality were also scrutinized, criticized, and in some cases modified.

a) The structure of the study went through several stages of development as the exploratory interviews with the twelve physicians (see p. 25) progressed. When it became clear that the sample number was going to be too limited for certain tests, an attempt was made to expand the number of organizations from which respondents were to be drawn. This would have included otherwise healthy people from various hospital attending physicians' out-patient lists as well as the renal failure patient carriers and their care-takers. The major and minor agencies supplying blood and blood products refused to participate or had no names to contribute. One institutional review board insisted that protection of privacy of their out-patient HB carriers be assured to the extent that only their physicians could make the initial contact. This proved too cumbersome to carry out so the sponsoring physicians at that hospital regretfully withdrew from the project. As a result, not only the structure of the study, but the methodology as well had to be modified again.

b) There was now no group to compare with the carriers who were regularly and permanently associated with health-care agencies. Separating the effects of dialysis from hepatitis effects would have to be deduced from staff (nondialysis) carriers and non-carriers, and non-carrier dialysis patients. Non-staff, non-dialysis carriers were unavailable. The sample was too small for the planned hypothesis testing of the significance of the selected variables. At this point, it was decided to extend observation time and to
depend more heavily on longer narratives, simple descriptive statistics, and associated observations in the units before, during and after the interviews. The study shifted from its emphasis on quantitative description and hypothesis testing to qualitative description and analysis which could generate hypotheses for further study.

Gussow and Tracy's 1972 survey of the general public's attitude toward leprosy showed it to be about the same as the attitude toward tuberculosis and other infectious diseases, but nothing so extreme as to cause undue anxiety or stigmatization to the victims of Hansen's disease. Therefore, as a final gesture, the informal interview of a small sample of the public's attitude about hepatitis B was added to the data collection for this study (see Appendix C). It was done in April, 1983, and showed no public awareness either then or in the past of a risk of contracting hepatitis, although fear of catching colds, influenza, pneumonia and venereal herpes were mentioned. Nor was acquired immune deficiency syndrome (AIDS) mentioned, although by July, 1983, the national news media were reporting near-panic in some groups over the possibility of contracting this high-mortality, but relatively rare, disease. A number of references comparing AIDS and herpes to hepatitis B were made in the media and reported along with the information that there was now a vaccine for hepatitis B, but not for AIDS or herpes.

In any case there is slim or no evidence that the basis of patients' fear of stigma over hepatitis is derived from the general
public although the present fear of herpes and AIDS could spread to be inclusive of hepatitis should a general panic occur. This, however, seems unlikely, and the search must be elsewhere for an understanding of some of the responses to carriehship of hepatitis. The same could not be said at the present time (early 1984) about the other two diseases.

c) When they learned they had a choice and were not required to participate in the research, some respondents downgraded the importance of the project. The research scientist had no clear, permanent status in the dialysis centers against which to bargain with the patients to establish a workable relationship through time. Patients comply fairly well to the "do this/do that" orders on the part of the staff members who dialyze them, the compliance being the negotiated trade-off they give to the staff in return for their good-will and services. The researcher has only novelty, interest and empathy to trade for respondents' participation, and cannot expect willing compliance to a peremptory order to cooperate in a physical act that entails a great deal of introspection, honesty and accuracy. Persuasion is our only coin. Experience evaluates the validity of the responses.

However, be it said that the author was more comfortable with as full an explanation to the respondents as they were able to understand without prejudicing the quality of information for the questionnaire results. The more they asked to have explained the more interested and cooperative they became.

2. The waiting time for the research scientist between
submitting the proposal to the various IRBs was one week to four months, with no association between length of time and acceptance or refusal.

About 12 months' time here and there eroded away in waiting for IRBs' action after submitting the proposals. Futile attempts were made to explain to some IRBs why their medical model of research involving the simple relationship of experimenter-subject was not relevant to social science. However, they felt they had to review everything from the same point of view or jeopardize their government funding. The lack of physical risk and the methods (questionnaire, intrinsic confidentiality of statistics, etc.) as a matter of fact, exempted the study from all but their own (IRB) rules by recent NIH reassessments (Hessler & Galliher, 1983).

3. Replication of results or restudy is made almost impossible by the confidentiality assurance. Such assurance, by the way, should be qualified because government agencies can force disclosure.

Clearly, the study lost a certain amount of potential significance and impact when it was forced into the mold of governmental and medical agencies' regulations. Some workers have even speculated whether studies that fully comply with all regulations can be called "science" (Reiss, 1979), while others deliberately flaunt the rules, openly or clandestinely (Hessler & Galliher, 1983). Most researchers simply ignore the ethics question, and do as well as they can by it.

4. As the result of the project reappraisal necessary because
of the final achieved sample size, the methodology had to be modified. For a study of hepatitis carriers there are several research methodologies available, each with its own advantages and disadvantages. As the study progressed, a subtle change in emphasis on the part of the research scientist was (at first unconsciously) taking place along with the growing realization that there would be a smaller sample than planned. Instead of looking primarily at the effects of carrieryship, it became ever more apparent that the meaning of the effects was increasing in importance for understanding (Good and Good, 1980). A new focus of study, the meaning of these effects in the context of renal failure (patients) versus otherwise healthy carriers (staff) needed to be explored in order to understand better the depth of the problem.

The same situations, actions, interchanges and even words had different meanings for different people. Among the staff (carriers or non-carriers) practically each individual saw different meanings in the carrieryship situation and interpreted it uniquely. Meaning was stated by the author as being important in the original research proposal, but it became even more important, now. The methodology was shifted to accommodate the modified nature of the problem which was to look more deeply into the interactions with others in their immediate environment, and at the cognitive categories they developed and used in their negotiated behavior, instead of merely effects (Lewis, 1980). It was possible to go back for a time and pick up further responses from those respondents already interviewed so that the necessary new information would be consistent. It was
not possible to do a perfectly matching job between the staff and patients because, except for a very few cases, the patients were not able to be as critical and specific as were the staff. The staff were not facing end-stage renal failure, and all the attendant dialysis problems, concurrently with HB carriergship. The result is that some topics receive fuller discussion in either the staff or the patient section than in the other. Consistency is often an unattainable goal in the field. However, the closer and longer interaction with the personnel and patients necessitated by circumstance contributed to better understanding. The behavior of staff and patients became much more meaningful day by day.

Since it is the theoretical orientation of this study that behavior yields to understanding best through uncovering the meaning given to it by the participants, that part of the original proposal methodology described as qualitative and exploratory became more important. Bohnengel's (1982) study of kidney transplant patients relates this theoretical perspective to her methodology in this way:

"As the subjective nature of reality is considered to be essential to interpreting the association of events and behavior, to reduce the parameters of data collection to only the objective elements would be to lose the essence of their meaning. This is not to say that research must be limited to a series of subjective reports, but rather recognizes that the objective perceptions of one who has never experienced [the problem] has far less import. Instead, through eliciting the [respondent's] perception of his encounter, the aim is to delineate the shared assumptions of those engaged in a common experience without losing sight of the unique meaning for each individual." (p 33).

Using the outline of the interview topic question (Appendix A),
the goal was to have the respondents comment as spontaneously as possible on the topics in the last three sections of the outline. The answers, plus the observations of their interactions with the staff, would not only elicit but also give meaning to the effects that carriersonship was having on them. Since no such prior study had been done, the methodology may be crude, but it was begun without the knowledge of what variables would prove to be significant, either to the carriers or to the research study.

Apparent and real contradictions often appear in the data when an open-ended interview technique is used over a period of time. No excuses are necessary for these anomalies because human beings are often self-contradictory, and their responses and behavior are reported as heard and seen. Then, too, the same stimulus can and does give rise to different responses even by the same person, depending on variables such as setting, situation, context, others present, physical condition, time of day, season of year, et cetera. It is a measure of the explanatory power of the research scientist's theoretical perspective how well the contradictions, differences or "breakdowns" (Agar, 1982) are able to be woven into the overall fabric of the ethnography. Further, it may be that the significant elements necessary to placing certain aspects of human behavior in perspective acceptable to all may come from one or several of a number of disciplines and have yet to be formulated or discovered.
CHAPTER III
ANALYSIS OF DESCRIPTIVE VARIABLES

In this chapter are given the results of tests showing relationships among the demographic and derived variables and what they contribute to the understanding of carrier behavior. Even with the simple statistics given here, which were all that the sample size allowed, a picture of the group under study, and its problems, begins to form.

Means X Tests

The staff/patient variable.

<table>
<thead>
<tr>
<th></th>
<th>Carriers X</th>
<th>Non-carriers X</th>
</tr>
</thead>
<tbody>
<tr>
<td>staff</td>
<td>20.0</td>
<td>9.7</td>
</tr>
<tr>
<td>patients</td>
<td>9.8</td>
<td>8.5</td>
</tr>
</tbody>
</table>

Table 5. Mean number of responses listing effects of carriernship by staff/patient status. Range 1 to 24.

The mean number of total responses to questions concerning carriernship (Appendix A) by staff members who were also carriers was significantly higher than the mean of any other group (Table 5). Patient carriers averaged about the same as staff non-carriers, with patient non-carriers only slightly lower.

Staff carriers bear a double load of responsibility: first as carriers themselves, and then as health-care workers responsible for others. They are far more conscious of infectivity risk on a moment-to-moment basis than either patients or non-carriers. The
staff/patient variable in terms of responses to most subjects was second in significance only to that of the presence or nonpresence of carriageship.

**The DOR: degree of response scale.**

Table 6 shows the staff carriers' mean (X) degree of response or DOR value to be several-to-many times higher than patient carriers and non-carriers. Their degree of concern based on self-assessment places

<table>
<thead>
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<th>Non-carriers X</th>
</tr>
</thead>
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<tr>
<td>staff</td>
<td>14.8</td>
</tr>
<tr>
<td>patients</td>
<td>-1.3</td>
</tr>
</tbody>
</table>

**Table 6.** Mean degree of response (DOR) value by staff/patient status. Range: 20 to -8.

5 of the 6 staff carriers in the high or moderate levels of concern, with the remaining respondent vehemently denying a high degree of concern, although this person scored the very highest on the DOR scale. (Becoming antigen-positive was a severe blow to the professional self-image of this individual, and one which has not yet been resolved. Although several staff carriers talked about retraining for a different profession, this individual is already a year of evening college into the new field.) A mean DOR value in the negative range for patient carriers reveals they are more conscious of things they are doing improperly or not doing at all than the other groups. This last statement is further explained immediately below in the more detailed analysis of Section 1 of the DOR scale results. (See Appendix B.)
Degree of response scale. Section 1: Social contacts restrictions.

<table>
<thead>
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<th>Carriers</th>
<th>Non-carriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>staff</td>
<td>3.5</td>
</tr>
<tr>
<td>patient</td>
<td>-0.42</td>
</tr>
</tbody>
</table>

Table 7. Mean DOR scale responses by staff/patient status on social contacts restrictions.

Carriers responded more vigorously than non-carriers in both negative and positive directions. The mean DOR value of 0.0 for staff non-carriers reflects a balanced, objective view of the problem, with about the same number of positive as negative behaviors, and in low numbers. The smaller, negative scores of patient carriers resulted from their mentioning a) few items and b) more instances of lack of avoidance behavior, while staff carriers mention both more items and more occasions of active or positive avoidance behavior. This is to be expected from staff members, since their occupation is intimately associated with intensive physical contact of various sorts with the patients.

While most staff carriers chided themselves for not doing certain things (e.g., refraining from hugging relatives, washing hands more often), the total number of things they did do to maintain high standards of proper behavior evidently outnumbered their self-perceived deficiencies. The HB epidemiology figures in Table 4 on page 32 substantiate their record of risk as just at the average for the U.S. for such units, though some staff members guessed their record to be higher. Considering the fact that none of the agencies in this study discriminates against dialyzing
antigen-positive patients as many do in other parts of the country (and the world), this record must be partly the result of a well-internalized set of constraints on staff members' behavior. The dialysis units observed in this study were characterized by a relatively high degree of behavioral autonomy on the part of technicians and nurses, with an accompanying degree of responsibility which is obviously well-placed. The greater the autonomy allowed the individual, the greater is the necessity to rely on internalized constraints on behavior.

Degree of response scale. Section 2: Hygiene.

<table>
<thead>
<tr>
<th></th>
<th>Carriers ( \bar{X} )</th>
<th>Non-carriers ( \bar{X} )</th>
</tr>
</thead>
<tbody>
<tr>
<td>staff</td>
<td>4.5</td>
<td>2.0</td>
</tr>
<tr>
<td>patients</td>
<td>0.125</td>
<td>0.93</td>
</tr>
</tbody>
</table>

Table 8. Mean DOR scale responses by staff/patient status on hygiene.

Staff concern with hygiene is greater than patients' concern in both carrier and non-carrier groups. When asked how they thought they contracted HB, 50% of the patients said they didn't know. Staff members will not, perhaps, know the particular incident, but instead will enumerate a number of possibilities to which they are constantly exposed: small breaks in their skin from frequent washing, improper waste disposal, needle-sticks, etc. A small number of non-carrier staff and patients seemed resigned to becoming Ag+ sooner or later. "It's just a matter of time, I guess. I've been lucky so far".

Generalizing from all interviews on this section, staff members' concern, whether they were carriers or not, was deep and
genuine that their charges not be exposed to HB. Without exception, they reported responses varying from mild chagrin to strong and lasting frustration when they themselves became positive. No dialysis staff member has been reported by either a patient or another staff member as being responsible for a specific patient's becoming Ag+, although there are several documented incidents that associate a particular Ag+ patient with new cases both in the dialysis units among staff, and in their families or social networks. In all three of these latter cases, the person had been told the risk of contagion was low and not to worry about it. So they didn't, and accounted for at least 10 known secondary cases of (mostly) icteric (symptomatic) hepatitis B. This does not explain, however, why the majority of patient carriers who have behaved in similar ways because of similar counseling and information-processing, were not responsible for further cases, also.

Degree of response scale. Section 3: Information management.

McDermott and Roth (1978) consider information management (Section IV) one of the three "major organizing metaphors" of interactional accounts of the organization of behavior. The other two are the search for communicative codes and eliciting native knowledge, (see Chapter IV:4 and Appendix A). Studies usually focus on just one of the three. They point out, using Goffman's primal scene of when a person with a nose meets a person without a nose, that the participants have to handle the situation in some way. How they handle it influences all of their subsequent interactions. "We
all must manage information to minimize such troubles; whether we
know it or not, we all do what can be called fabricating, lying,
covering up, and contradicting" (1963: 334). (Emphasis added.)

Goffman acknowledges that an individual "with a reason to fear
stigma may attempt to cope with the fear by controlling what others
in their environment know about the stigmatizing circumstances"
(ibid.). If others know little or nothing, there is little reason
for a negative reaction toward the carrier. Therefore, limiting
what and how much a carrier believes it necessary to tell to however
many it needs to be told can control others' positive and negative
responses to one's condition. The individual believes that such
control of "fact" will limit the kind and amount of information in
which others base their behavior toward oneself. They make the
assumption that they are the only (or at least the chief) source of
relevant information, and as such are the primary controllers of
others' behavior toward them.

Distinct differences toward management of information about HB
 carriership appeared between patient carriers and the other three
groups (Table 9).

<table>
<thead>
<tr>
<th></th>
<th>Carriers $\bar{X}$</th>
<th>Non-carriers $\bar{X}$</th>
</tr>
</thead>
<tbody>
<tr>
<td>staff</td>
<td>2.33</td>
<td>1.78</td>
</tr>
<tr>
<td>patient</td>
<td>-0.042</td>
<td>1.57</td>
</tr>
</tbody>
</table>

Table 9. Mean DOR scale responses by staff/patient
status on information management.

Patient carriers are much more reluctant to reveal their
antigen-positivity to others than are staff carriers, or than non-
carriers think they should be. "It's none of their business" or
"There's no need for them to know" were the most frequently given reasons for not telling others about carriership. Most carriers would not have thought of informing physicians (other than in the dialysis unit, who should already know), dentists, barbers or hairdressers. It is also probably associated with denial of the problem, a coping strategy already well-known in the literature of dialysis, (DeNour & Czaczkes, 1971), and which will appear again below. Non-carriers and staff carriers feel a bit more strongly about the need to inform those who perform personal services.

Degree of response scale. Section 4: Fears, anxieties about stigma.

<table>
<thead>
<tr>
<th>Carriers</th>
<th>Non-carriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>staff</td>
<td>4.5</td>
</tr>
<tr>
<td>patient</td>
<td>-0.54</td>
</tr>
</tbody>
</table>

Table 10. Mean DOR scale responses by staff/patient status on fears and anxieties about HB stigma.

Staff carriers' DOR score is far higher than any other group, giving away the fact that they are indeed highly concerned about their antigen-positivity. The discursive answers by staff and non-carriers (as well as a few carriers) focused on different concerns, depending on other variables. Married or (especially) paired individuals agonized over the possibility of infecting their mates and children. Unmarried people wondered if they should ever marry, and at least two marriages were reported to have broken up, at least in part, because of the spouse's carriership. One person feared the loss of custody of a child, and as already reported above, several staff members considered changing occupations. In the early years
(early 1970s) when this problem arose, there was no institutionalized routine for handling compensation, and people feared being summarily fired or "furloughed" without an income for months, until recovery. One woman staff member who was the sole support of her child had no income for over 6 months due to a bureaucratic misunderstanding over workman's compensation. Two people reported job discrimination because of HBsAg+ when they tried to change jobs. Several respondents reported the difficulties of traveling, especially in the South, because the social worker doing the advance booking for them was unable to find a unit who would accept positive patients. In one case, a couple who had already retired to Florida were told to "Go back to Cleveland, because we don't have the facilities to handle you here". The negative scores among the patient carriers again document their denial of the problem, while the staff and non-carriers are more positively oriented, active and voluble in the expression of these concerns.

There were also two instances of unrealistic anxieties. Two older, black males interpreted it as racial prejudice when they were initially placed on "special" (isolated) stations for dialysis, but now claim to understand why they were so reassigned. Being placed on the "special" units, however, is still seen as stigmatizing by several carriers, and resented even though they may claim to understand the reasons for the "discrimination".

Other variables mean $\bar{X}$ tested against degree of response.

Gender. Women seem to consider carrierness more a fact of
physical existence than men, who see it as a personalized fault of imperfection which they find difficult to incorporate into their body image. Therefore, women are less loath to conceal it. "I want my grand-daughter to know why we can't drink from the same glass or eat from the same spoon, like she does at home." Male carriers had a lower response to carriersonship than respondents in any of the other three categories (Table 11). Because of the low and the great number of negative scores of males and degree of difference in the

<table>
<thead>
<tr>
<th></th>
<th>Carriers X</th>
<th>Non-carriers X</th>
</tr>
</thead>
<tbody>
<tr>
<td>female</td>
<td>4.8</td>
<td>4.9</td>
</tr>
<tr>
<td>male</td>
<td>0.0</td>
<td>5.6</td>
</tr>
</tbody>
</table>

Table 11. Mean DOR value by gender.

responses, case histories were re-examined. Women, in general, were more eager to discuss their problems about carriersonship, whereas men seemed to find the topic unpleasant and many denied its being any kind of a problem. Women mentioned more anxieties about extra hygienic measures in dealing with the problem around other people. The small and often negative values of the degree of response scores of male carriers reveals that they report fewer behaviors and more lack of avoidance behavior, lack of expressed concern, than female carriers. Although this generalization applies to a majority of males, it should be also noted that two of the highest DOR values recorded were scored by men — one a staff carrier and one a patient non-carrier.

On the whole, however, men were simply not interested in recounting day-to-day details of eating, cleaning and hygiene
problems. They were most vociferous when their freedom of action was limited as the result of HB positivity, i.e., as when they were refused dialysis in some other city. The younger male carriers (under 40) were interested in discussing techniques for protecting their families and lovers; and non-carriers in this age group, whether male staff or patients, were concerned about techniques for avoiding being infected, accounting for their slightly elevated scores.

Women, carriers or not, tended to express more anxiety about contamination in the dialysis environment. The three cases which led to secondary infections with hepatitis B were all women, so it seems there is some basis for their concern. All three had been counseled "not to worry" about infecting others, but to use good, basic hygiene and they would be fine. Unfortunately, there were serious problems resulting in all three cases: a divorce; a child custody scare (which resolved itself when the child became ill with HB and completely recovered without retaining the antigen and the mother converted to antibody-positive after about 1 1/2 years); and an aging spouse who was almost lost to the disease. In the case that led to the divorce, the spouse of the carrier infected at least six other known members of his family of origin before they reached the point that coping with health problems simply overwhelmed them. Due to equipment failure, one of these three individuals was also involved in an accident in which at least one staff member contracted HBV.

Four staff carriers, two men and two women, talked about
changing occupations. One woman left the unit for almost a year, but is now back, claiming she was subjected to prejudice at two other health-care institutions because of the stigma of HB. One of the men believes he was also discriminated against because of HB positivity in competing for a higher level supervisory job in his field at another institution. This experience led him to evaluate his future, with the result that he is back in college taking evening courses toward a degree. Another of the male staff carriers finds the constant worry of infecting others, at work as well as in his social network outside the dialysis unit, is a heavy burden. He, too, would like to change fields and switch to something requiring low physical contact with others. The other woman has, as yet, taken no active steps to change positions. It is to be expected that the availability of HB vaccine will lessen the number of these kinds of problems in the near future.

Male staff members, carriers or not, seem generally to have a more objectified response to the whole complex situation — dialysis, HB, et cetera. Most men (other than physicians and custodians) consider their job at the dialysis unit as temporary, something they will change as soon as they get the opportunity. Dialysis centers are true equal opportunity employers and men may recognize that those with seniority for position advancement are women with advanced degrees, greater skills and entrenched relationships, and they themselves are out of competition for the jobs because the women are quite young (mostly in their 30's), and
the chain of command is shallow.

Women staff consider the job as the end reward for continuing their education. Whether RN, LPN or technician, they plan to remain in their profession throughout their working careers although they may shift between units, occasionally. They exhibit a more personalized or involved response toward the patients and the situation than the males, although the physical care rendered by members of both sexes is judged by both patients and peers to be of the same quality level.

These are entry level positions to the middle class. As such, they are far more satisfactory to the women than the men, as careers. Men see the physician as the top of the medical profession, and a goal to which they, perhaps, should aspire, however unrealistically. In this type of career modeling, while some changes have taken place, there is relatively less flexibility among paraprofessional men than women.

**Age.** The data in Table 12 listing age versus mean degree of response shows the youngest group, under 40, to be the most reactive to carrierness. Carrier and non-carrier alike, the eldest group had

<table>
<thead>
<tr>
<th>DOR carriers</th>
<th>Non-Carriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 39</td>
<td>11.3</td>
</tr>
<tr>
<td>40 - 59</td>
<td>6.2</td>
</tr>
<tr>
<td>≥ 60</td>
<td>-3.0</td>
</tr>
</tbody>
</table>

Table 12. Age vs. mean DOR scores.

the lowest scores. Negative scores are the result of statements that they failed to do something they really thought they should have done, or that they did something they knew they should not have
done. (Not preventing a child from drinking from their glass, or sharing a cigarette with a spouse are typical negative responses.) Mental health counselors today are likely to have less impact on the elderly than on the young, all things being equal, when counselors encourage the expression of emotions or feelings, rather than repressing them, as a step toward mental health. When they were growing up, older people, particularly men, were not encouraged to express strong emotions or feelings (Rubin, 1982). During the interviews older respondents tended to speak with greater acceptance and resignation in their demeanor, while younger people were more excitable and vociferous. The elders were less likely to change and the younger more likely to be demanding change in the system of dealing with hepatitis carriership.

During the third and fourth decades of life in our society a person's social and occupational networks normally are expanding, and people are busy building careers and families. Frequently a high degree of mobility in neighborhood, occupation and even city is demanded of them, a requirement that would be severely limited by chronic health problems. Normal problems of this time of life—spouses and lovers, parenting, schooling, in-laws, employer-employee relations, etc.,—are overlaid with a serious health problem which exacerbates the more usual concerns.

The older groups, to whom things have happened at a more leisurely rate, and at a time of life when their expectations are different, may well be less concerned when they deny a similar
degree of concern as the youngest group of carriers. In this study, the older cohort was composed of a lower income group, and part of the difference may be accounted for by differing interests. When individual responses are examined some may be generalized, as above, and some are unique. For example, combining his reactions to dialysis and carriergship, one male in late middle age (over 60) said bluntly, "I think about this place 12 hours a week, 3 times a week for 4 hours while I'm here, and then I completely forget about it". Even though this statement is an obvious exaggeration, it conveys the effort this individual is expending to preserve in his mind an image of self-sufficiency, independence and health. He was also one of those who became (suicidally) noncompliant for several weeks when he was first informed he had become HBsAg+. Cases like this challenge the professionalism and humanitarianism of the staff and in turn aggravate their concern. They also challenge the investigator because the patients do not distinguish clearly between renal failure and hepatitis problems during the interview even under constant reminders. The ability to make this distinction is a salient issue in this study because how carriers perceive themselves (stigmatized or not) and what they do to cope with the resulting self-image are personal and social effects of carriergship. One respondent who lives alone has told no one about his dialysis, let alone his hepatitis carriergship. He bears two stigmata, in secret.

Education and understanding.

The complex variable sociologists call socioeconomic status, or SES, is compiled from simple variables listing an individual's
education, income and occupation. Of these variables, education produced the strongest associations with both degree of response and level of understanding. Tables 13 and 14 display an obvious

<table>
<thead>
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<td>0</td>
<td>3</td>
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<td>4</td>
</tr>
<tr>
<td>≥ 16</td>
<td>1</td>
<td>0</td>
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</table>

Table 13. Education by degree of response score. Frequencies, grouped.

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<th>non-carriers</th>
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<td>4</td>
</tr>
<tr>
<td>9 – 12</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>13 - 16</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>≥ 16</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 14. Education by level of understanding score. Frequencies, grouped.

associational trend in the positive direction more pronounced for carriers than non-carriers: the more years of education, the higher the response and the higher the level of understanding. On the strength of this sample size, I would hypothesize that a path analysis should show that education influences level of understanding, which in turn influences degree of response.

Tested, but unassociated, variables.

Race, marital status, network size, religiosity, occupation and
SES show no association with degree of response or degree of understanding. This agrees with a 1980 study by Poll and De-Nour on dialysis patients. They found no relationship between patient compliance and understanding, I.Q., or demographic variables. In a very large sample of thousands some secondary associations or influences might be expected to show up with these variables, but in the renal failure-plus-hepatitis carriehip context, there were only a limited number of ways reported for dealing with the dual problem. These will be discussed in the next chapter.

Summary

Kiernan and Powers (1982) in general report findings consistent with those in this section. Since they do not have a breakdown into sample categories, it is difficult to compare the study, but many of the same behaviors by carriers and members of their networks seem to be similar to those reported here. Their patients also under-rated personal contact of various sorts as being at lower risk than did the staff who counseled them. They reported renal disease as being less stigmatizing than HBV, and that HBV caused a lessening of emotional closeness.

Staff members in this study were also more responsive to the antigenemic condition than patients or non-carriers. Patient carriers, particularly males, are more aware than members of other respondent categories of things they are doing improperly or not doing at all to prevent infecting others.

Half of the carriers claimed they did not know how they contracted HB, but most staff members could enumerate several
possible situations when they might have been infected. Three carriers reported secondary cases of HB in their families after they had a positive blood test.

Patients are more reluctant to reveal their carriergship to others than are staff members. They seem to be more inclined to fear guilt or blame than staff, who see it as a matter of probability over time. Staff objectivity, however, does not dissipate their own concern. Staff members and non-carriers feel more strongly than patient carriers about carriers' responsibility to inform others who are close to them or who render personal care of some sort. Staff carriers' response to carriergship is more vehement than any other group. Their major concerns seem to be infecting mates and children, whether marriage and children should even be considered, and whether they should change occupations. Several years earlier, a main concern would have been lack of salary while on furlough, but this is no longer a problem. At the same time as they show concern over having become HBsAg+, there is a noticeable denial of problems, physical and other, resulting from the condition.

Women speak about carriergship with greater freedom and understanding than men. They also admitted to being concerned more often than men, that is, it was more in their awareness. The three carriers who reported secondary cases of hepatitis B in their social networks were women, although the exposure of several staff members to an in-unit accident involved a male patient.
Among carriers both staff and patient, the younger people tended to show higher concern and the elderly the least. The younger people reported more changes in behavior than the older as a result of carriergship. Many patients have only an unclear conception of the relationship of hepatitis B carriergship to dialysis — whether one is an integral part of the other like occasional changes in their blood level readings, or whether it is a separate disease or condition.

The variables of race, ethnicity, marital status, network size religiosity, occupation, and SES seem not to be associated with degree of response or level of understanding in this particular sample, although the sample is too small for a valid statistical test.
CHAPTER IV
PERSPECTIVES, SEMANTICS AND BEHAVIOR

Introduction

The questionnaire items and the additional spontaneous comments they elicited from the respondents produced some interesting staff-patient differences in definitions of disease in general and hepatitis B and kidney failure in particular. There are also differences between staff and patient understandings on the meaning and significance of these topics. Since it was stated as one of the purposes of this study to contribute to applied methods and theory, it is necessary to explain how the analytic results were derived and how they contribute to the understanding of carriers, their behavior, and carriership status.

Similarities and differences in understanding between staff and patients will be discussed under these headings:

3. Contagion and its effects on self and others: what they perceive as happening to themselves and how they observe others reacting to their condition or their degree of debilitation.
4. Information management: how they cope with their beliefs and observations, and the anxiety or fear they arouse.

Mauksch (1973) and Barker et al (1978) analyze goals, while
Gussow and Tracy (1972), Goffman (1963) and Poll and De-Nour (1980) use one or a combination of these four topics in their studies. None of these, however, combine all four within a single study where it might be possible to build layer on layer of understanding as the material undergoes sequential analysis. This is one of the ways that this study attempts to carry forward the subject instead of merely repeating or replicating results which have gone before.

There will necessarily be some overlap or repetition because categories derived by physicians, social scientists and computers do not coincide exactly with those of each individual respondent whose answers may address more than one topic or level of phenomena at a time. How not to "lead the witness", rather than the reverse, is a technique yet to be perfected, when it is necessary to elicit spontaneous responses but to get ones that are still generalizable under analysis.

1. Goals: staff versus patient

Rational behavior is goal-directed. Several goals or types of goals may be in effect at the same time, each of them contributing motivation to an interaction and attempting to control its outcome. The dual goals of medical professionals concerned with disease carriers are 1) the prevention or control of disease, and 2) having their intervention cause minimal interference in the lives of the carriers (Barker et al, 1978). On examination these goals are understood in different ways by staff and patients. Staff personnel see themselves as successful in their goals because the patients appear to behave more or less capably when they come in for
dialysis. The patients never report to the staff the many daily struggles within themselves that involve decisions and deprivations due to their infectiousness with hepatitis B. The hands-on caretaking staff rarely has the time to listen, and the patients seem not to think of requesting a talk with the social workers who are there for that purpose. To patients, prevention of disease and minimal interference in their lives are merely the lowest common denominator of that which they would like to happen, or had been led to believe would happen after they went on dialysis. Because they view their situation from inside out, subjectively or emically, it will look quite different from the framework within which they are viewed by the staff. Predictably, end-stage renal dialysis (esrd) is a greater patient concern than HB, and they tend to concentrate on it, as Bohnengel (1982) predicts.

Patients' goals may be listed as 1) survival (with esrd), 2) controlling fears of death and disease, 3) controlling death and disease, 4) controlling information on death and disease to enhance self-image to oneself and others so that: a) one can accept and live with one's imperfections, and b) others will accord some value to one's survival so that members of the society/culture will have a reason for sanctioning the support of one's continued existence.

Mauksch (1973) suggests the structural factors of cure, care and core (behavior oriented toward protecting and maintaining the institution) may be thought of as ideological processes involved in intra-institutional interactions or negotiations as well as in
Barker's terms as staff goals. "Every profession resorts to a priori assumptions and value orientations, many of which are shared with colleagues. These make up the body of professional tradition."¹ (The philosophical question of whether ideological processes are identical with goals is not relevant here. The different authors use them in similar ways to explain behavior.) Not being social scientists, the medical staff of any health care agency would probably recognize the first two of these as goals, but not classify them with the third. They recognize the reality of needing to protect their institutions in order to accomplish cure and care, but do not consider this with their health-care efforts as a goal. Rather, they seem to regard core more as a politically sound policy, or as vested self-interest that harms no one but benefits many. In any case, the processes oriented toward cure, toward care and toward institutional survival or core will be discussed in the context of how they affect and are affected by participants' interactions.

That "cure" as a goal of contemporary health care workers and their patients is a conservative concept has been noted (ibid.) and is documented here by interview materials. Younger as well as older physicians see it as too idealistic and simplistic for today. A resident commented: "75% of the problems dealt with in internal medicine are no better nor worse for the physician's intervention".

Be that as it may, a senior nephrologist stated: "Few physicians in any specialty can claim a 'cure' by today's standards, so the best we can hope for is to stop the route of infection by educating the patients about their fistulas and infection, as well as hepatitis and infection, and showing them by example that we care by being very careful with them." As far as the hands-on dialysis staff are concerned, cure has long since been supplanted by care in their priority system. Optimum rehabilitation with minimal interference in patients' lives is the way they see their services directed. There is a great effort to get the patients to take as much responsibility as possible for their lives in solving major problems as well as in plain, everyday coping.

Insofar as patients are concerned, some want to take some responsibility for themselves and some do not. These latter may not understand the subject, but it sounds bad, they don't want to hear it, and so they avoid it with euphemisms. The former are actively engaged in creating a positive self-image, both for themselves to live with as well as to project to others. Most patients, consciously or not, seek to create a positive self-image so that they will not appear to be decrepit. By doing this they expect (predict) that society members inside and outside their networks will not develop cultural-specific beliefs which devalue them, nor institute death-hastening behaviors (Glascock, 1983) against them.

The core function (or goal) of maintaining and protecting the institution gets carried out in staff-patient interaction when the
staff underplays how the patient has come to have hepatitis (see discussion of contagion, below), and in the visible precautions they take to avoid contamination. Fulfilling the core function is part of the basis of how the staff manages information with the patient and the family concerning the route of infection. Avoidance of embarrassment and blame on the part of the agency staff and avoidance of hostility on the part of the patient is not altogether successful, but the system remains operational and the core function is fulfilled. Further insight into this problem is given below under information management, section 4.

Patients are not especially concerned by the core goals of the staff. It is among the patients, however, that are found those who may still have subscribed to or believed in the cure goal, long since redefined by medical professionals. The ultimate realization that their kidney disease can be dealt with only by "end-stage renal dialysis" (esrd) can be devastating and it is often comprehended only over a period of time and in bits and pieces. The disparity in mutual understanding of the definition of goals, each group of the other's as thus demonstrated, causes effects that are difficult to deal with because they are so close to life-or-death level outcomes that objectivity is well-nigh impossible.

It is necessary to listen closely to the verbal component and keenly observe the nonverbal component of patients' communications for meanings in a chronic disease clinic. The close association between carriernesship and dialysis in patients' minds make it difficult to separate the effects of each condition as distinct from
one another. No two people will respond the same way, and on successive days the same individual may respond in a different manner to the same stimulus because their state-of-being changes rapidly. Among the variables that affect patients are their general physical condition, the weather, hunger, thirst, fatigue, time of day, month, or year, holidays, et cetera. Physical, cultural and environmental conditions all affect a patient's psychological state, which in turn influences how they respond to thinking about HB carri ership.

It is impossible to know how many patients might secretly hope for a miracle cure through their medical team and/or God because when facing the ultimate, or "end-stage", they must believe the medical team did or does their best, and it would be too threatening to blame God for not having come through for them. (They may have to face Him soon.) So most are outwardly resigned and accepting of their condition. The counselor tells them when they begin dialysis that if they comply with the necessary diet, medication and hygiene restrictions, the dialysis team will cooperate to attain the maximum rehabilitation possible with their condition. The shock of words such as "end-stage" and "forever" usually has patients agreeing to this goal, which is articulated for them by the dialysis team. It

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2. The terms, environment and environmental, are used throughout this paper in the psychological sense of not only the physical surroundings, but also includes the totality of persons, situations and circumstances that impinge on a patient's consciousness at a given moment.

is not difficult to imagine their distress, months or years later,
when informed they have yet another health problem — hepatitis B carriernship.

Because of their changing daily condition or situation, to a patient it may seem that the quality of their care varies widely. The dial settings on the dialysis machines which the patients negotiate with the technicians directly affects how much discomfort they undergo, and therefore how comfortable they feel; how trustful they are of the staff by extension colors their attitude toward the interviewer. The staff attempts to build patients' confidence both in themselves and in the staff so they can both be as truthful as possible with each other and thereby succeed in effecting maximum communication about the patient's condition. Staff and patients are expected eventually to develop at least a minimal loyalty to the agency or institution. This attitude is seen by the staff as enabling patients to cooperate in maintaining the institution so that life-giving services may continue to be provided. Most of this is, of course, outside the awareness of both most of the staff and the patients. When patients are greeted with, "You are doing so well! Dr. X will be so pleased when he sees you", the verbal reward encourages the patient to continue doing whatever it was that had been successful. From time to time the level of success they are achieving may need to be renegotiated to get back up to maximum effect.

Summary. A major difference between staff and patient goals concerns the struggle for control over the patients' behavior by the
staff and the staff's behavior by the patient. The staff believe that they have adequately instructed and cared for the patients. They are the professional care-takers and the patients should obey them by taking their advice. They are protecting the patients, themselves and the health-care institution. There is higher awareness of fulfilling the first of these goals than of the latter two.

The patients feel their instructions were incomplete and/or their care inadequate since they contracted HB and carriageship. They withhold a certain type of information from the staff which would more fully inform the care-takers of their condition. This is partly because patients are aware that the staff considers this "personal" information trivial or irrelevant to the business at hand and so may not pay attention to it. It is, further, a type of information that health-care professionals often avoid learning because it taps that emotional level of patient involvement which they were traditionally taught to avoid because it could cloud their decisions and pierce their carefully constructed overt emotional invulnerability. Foster and Anderson call this "detached concern". Social workers are aware of the significance of such information, and some medical schools have added courses in social and and behavioral science. (Foster and Anderson, 1980).

A significant block of patients' experience with respect to minor physical complaints, family problems, finances, etc., goes unknown, largely uncomprehended by the staff, and therefore non-influential in broadening their perspective. From those who do share these
"trivia" it is apparent they are at times quite significant.

Since the patients lack the training on which is built the "professional" care-taker perspective, it is improbable that their perspectives would be at all similar. Landy, (1977), Alland, (1964), and Kleinman, (1980) all comment that it is improbable (or at least most unlikely) patient and care-takers would share similar perspectives since the patients lack the training on which is built the "professional" care-taker perspective.

2. Disease and its associations

In order to show the variety of answers given to a very specific question, answers to question II-1 (Appendix A), edited only for readability, are reproduced below. Showing a small segment of staff, patient, carrier and non-carrier responses will demonstrate problems of semantics, focus of attention, and subjectivity. This question is better than most for this purpose because of the high informational content of the answers which contain myriad associations for the respondents. For further explanation and definitions of clinical details and terms relevant to hepatitis, consult Appendix D.

Interview responses to question II-1, Appendix A. What is hepatitis B?

   Staff carrier responses.

1. "A disease that makes you feel tired. I was afraid that the arthritis in my hands would keep me from working again."

2. "It's liver damage. The liver being taken over by the virus
causes lack of appetite."
3. "A disease that affects the liver, primarily. There is inflammation and the enzymes increase. I was tired and depressed, but I'm not sure this was due to hepatitis."
4. "An illness contracted from one who has hepatitis B. It can have catastrophic effects on the liver and endocrine system."
5. An infectious inflammation of the liver. You get jaundiced and tired. Also depression."
6. A systematic [probable meaning: systemic] disease that has a lot to do with liver damage and pain. It's highly dependent on a person's resistance. You get weak, lose weight, get depressed, nausea, bad taste in mouth, eyes sensitive to light, high blood pressure, no appetite, jaundice."
Staff non-carrier responses.
7. "Hepatitis is a very general term that means inflammation of the liver and can be caused by all kinds of things. There are serum and viral hepatitis."
8. "Well, say jaundice, lethargic, completely crained, general weight loss, anorexia, infection of the liver."
9. "An inflammation of the liver that produces enzymes that cause distortions in their blood."
10. "An inflammation of the liver. It may be contracted through the blood. There's a wide range in how people react to the disease."
11. "Hepatitis is a serious illness with a high mortality rate and you can get pretty knocked out for a couple of weeks."
Infectivity is high for gay males, dentists and people in blood contact occupations."

12. "It's an inflammation of the liver. I don't know that I'd call it a 'disease' — that's for things you or we must do. But it's an infection. Disease here at the unit is something never to be cured, as 'kidney disease'."

Patient carrier responses.


14. "A contagious disease. It scares you. I didn't have it bad. I was depressed for one month, and I stopped taking my medications."

15. "It makes you tired and drawn-out."


18. "An illness that makes you weak, itchy, sleepy, nervous, nauseous, jaundiced, light colored stool, diarrhea and depressed enough to see a psychiatrist. I tried nembutal to sleep, but valium helped with itching and sleeping."

19. "Dialysis and hepatitis go together. Hepatitis is part of it."

20. "An infection. Makes you weak, limp, short of breath, with loss of appetite and severe joint pain. I had a severe depression and was given medication by a psychiatrist. These symptoms lasted for a year."
21. "It's very dangerous. You can die from it."

22. "Hepatitis itches you. My problem is the kidneys, not hepatitis."

23. "A sickness that turns your eyes yellow."

24. "A liver disease with nausea, bile vomit, arthritis in joints, chills."

25. "A blood disease that affects the liver."

26. "I don't give it a name. To me it's just a reading in their blood chart."

27. "Hepatitis B is something not to get. They make you feel like a dog. Make you feel they [the staff] can get it just by talking to you. You get yellow, sick."

Patient non-carrier responses

28. "I wouldn't really know because I've never been around anyone who had it. Basically they [the staff] told me you might get nauseated, very sleepy; they said symptoms something like the flu."

29. "My daughter is a nurse and she told me all I know about it. Hepatitis is a disease of the blood. All I know is they used to go into rooms where they had 'em separate [isolation]. I don't know what it feels like or how it affects you."

30. "I've come across it in reading but not out in the world. Don't know much about it."

31. "It makes you very ill, very tired with a discoloration of the eyes. You shouldn't be around nobody, or eat or drink from the same [plate or] cup."
32. "Hepatitis B is a blood disease that's transmitted by human contact, or contact with various human body fluids."

Other responses.

33 - 42. Ten patients responded "Don't know": 9 carriers, 1 non-carrier.

43 - 45. Three staff members not asked direct question, but an excellent understanding of hepatitis B emerged during interview. (Top supervisory personnel were interviewed in a less formal, more open-ended context.)

The term disease is used in the broadest medical context in the dialysis units. On analysis there are at least two sub-categories of meaning: 1) debilitating conditions such as "liver disease", or "kidney disease", or "heart disease"; 2) contagious diseases such as hepatitis B, tuberculosis or measles are diseases labeled "infectious". A staff non-carrier decided for himself that HB should not be called a disease and invented his own semantic category (see response 12). He was quite adamant, for reasons he could not explain, that kidney disease resulting in esrd was the only proper type usage of the term. Other staff members did not share his limited meaning and usage of the word, and if they distinguished in either denotative (main or usual) meaning or connotative (implied, ancillary) meaning between "disease" and "illness" or "sickness", it was not apparent. (Twaddle, 1980)

Besides the physician and a supervising nurse, only one person, a technician from a blood laboratory, freely associated hepatitis B
with a virus. Whether staff or patient, well or poorly informed, the overwhelming response to the request for a definition of HB was a recitation of symptoms. Answers fell into four major categories (Table 15). The last two answers constitute categories of their own.

Table 15. Frequency of items mentioned in response to question "What is hepatitis?", and by whom.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>freq. N=45</th>
<th>staff n=15</th>
<th>patient n=30</th>
</tr>
</thead>
<tbody>
<tr>
<td>liver, inflammation or disease of jaundice</td>
<td>12</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>tired, sleepy</td>
<td>10</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>anorexia</td>
<td>8</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>nausea</td>
<td>4</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>arthritis</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>weakness</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>itching</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>liver enzymes elevated</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>chills</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>eyes light sensitive</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>nervous</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>HBP</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>sleeplessness</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>diarrhea</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>pain in liver</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>weight loss</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>completely drained</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>knocked out</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>drawn out</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

**Emotional reactions**

depression                     | 6          | 3          | 3            |
fear, scared                   | 3          | 1          | 2            |
disease                        | 11         | 4          | 7            |
contagion (idea of)            | 10         | 4          | 6            |
blood, association with virus (see note, responses 43-45) | 8          | 1          | 7            |
ilness                         | 4          | 2          | 1            |
mortality rate/death           | 2          | 1          | 1            |

HB subsumed under kidney failure as part-whole | 1 | 1 |
don't know                     | 9          | 9          |
Staff gave more informational answers than patients, and carriers' answers tended to be somewhat more subjective than the non-carriers'. More staff correctly associated hepatitis B with the liver and etiologically with a virus. Patients were more likely to associate HB with blood and a generalized concept of contagion inherent in the dialysis procedure. It is probable that more patients than merely the one listed above carry a cognitive category that contains the dialysis-hepatitis B relationship as whole-part. Etiologically, there is no causal relationship between the two, of course, but from their personal observations they use the idea of contagion to associate the two. Further questioning (below) illuminated these concepts more clearly. Almost all who reported depression or fear in this question had a moderate to high score on the DOR scale. Emotional responses will be discussed more fully later.

Interview responses from questions II-2,4.

Excepting the top supervisors, (MDs and nurses holding at least 4-year degrees), none of the respondents had a clear idea of hepatitis B surface antigen, HBsAg, (HAA or AA), or its role in the occurrence of hepatitis B. On the infrequent occasions when the core antigen (cAg) or the e antigen (eAg) were mentioned by staff members, the information was incorrect. Of particular concern was the fact that two staff carriers who tested positive for the e antigen thought that it made them somehow safer or less contagious, whereas in reality this antigen is associated with chronic, active hepatitis and may lead to cellular damage and progress to cirrhosis,
hepatic insufficiency or primary hepatic carcinoma (Appendix D; Blumberg et al, 1975). Admitting to a lack of knowledge, both staff and patients were rather defensive and many claimed they did not understand the technical explanation given them by the physicians or other informers. Others seemed to have forgotten so completely that they claimed they had never been informed, and 44% answered "don't know" to II-2. Hepatitis B was associated with HBsAg by 7 people, 5 more associated it with blood, and 3 people had a vague memory of having heard the term but no more than that.

Kiernan and Powers (1979) hypothesized that who informed patients about their carriernesship and how they were informed may have had an influence on their understanding, and II-4 was structured to explore this possibility. Whether a physician, nurse, technician or physician's assistant informed them of their antigenemia, there is no association with information on or comprehension of HB, its contagiousness or its persistence. But most patients were unsophisticated with respect to the concepts of medical science.

At one unit, patients contradicted each other as to what the same supervising physician of their unit told them about the source of their infection. One carrier reported that in 1977 the MD told him he was probably exposed to blood left on a station by a positive patient who was previously dialyzed in it. Another patient reported that in 1979 the same physician told her it was probably from a blood transfusion. Assuming the patients were reporting accurately, and the physician was not dissembling, this is difficult to explain.
Were the dates of these responses the other way around, it might be possible that the physician changed his mind about the source of contagion during the interval. The Red Cross and the CDC — Atlanta adopted more stringent controls on blood donations during this period of time that makes it virtually impossible for HBsAg+ blood to enter the donor system today.

One of the dialysis units studied provides a brief paper handout of dos and don'ts for the HB carrier that is mostly concerned with hygienic practices both personal and around the house. The remaining units rely on verbal transmission of information about what they should or should not do. Several carriers claimed that no one formally told them. Although all unit supervisors said carriers were informed of their antigenemia as soon as it was discovered, an oversight is possible. One who made the claim was an experienced, reputable worker who became very upset to hear others in the unit discussing her/his condition before she/he knew about it.

In any case, based on this study, who does the informing or how they are informed seem not to be as relevant to comprehension as the understandings produced during higher education. A series of brief illustrated conversations and lots of repetition of previous facts might improve the informational level. On the other hand, if the patient is determined to deny the whole situation, all the best efforts may prove futile.

**Question II-5.** How do you think you became a carrier?

While no one claimed to know the answer to this question with
absolute certainty, (reflecting physician and staff uncertainties), both staff and patient carriers had ready guesses about it. Among the five staff carriers who answered there were four who remembered at least one needle-stick and another who said she often had skin-breaks from the frequency of hand-washing and probably got it that way. The patients' answers differed markedly. Nine answered blood transfusions, five said from the machines or other equipment in the unit and one said he was in the same hospital room with a young man who was not known to have had HB until after he was admitted. One staff and ten patient carriers professed to having no idea how they contracted HB.

Matching staff-staff and patient-patient answers, all but two of the non-carriers' were similar to the carriers'. The staff and most patient non-carriers mentioned contamination in the unit, and two said transfusions. One pre-World War II immigrant with little formal education seemed to understand very little about anything that was happening to him and had no answer at all.

Staff responses showed a realistic appraisal of their contact with hepatitis B. Their 'guesses' were probably correct. Patients' statements about blood transfusions, however, probably were not. Some of them claim to have been told this by the physician or nurse who initially informed them, and others by friends or relatives. Paid donors were the main source of blood transfusion infections until the early 1970's, when it was realized that paid donors were the potential source of various diseases. The Red Cross and other blood banks ceased recruiting from this pool and began a program of
testing each unit of blood donated for several potentially hazardous factors. If any were found, the blood was not used for transfusions. Since most of these carriers were identified at dates later than the time when testing began, it is unlikely that transfusion was the source of the HB infection. Several possibilities for this answer remain. Perhaps someone on the staff in an effort to protect themselves and/or the institution (core goal) did deliberately misinform the patient. Alternative possibilities are that it is a spontaneously-occurring explanation in dialysis units because of the omnipresence of blood, or one patient gets the idea from someone who knows that years ago blood transfusions were found to be one source of hepatitis B.

Not being able to assign blame for a cause for the infection is a source of anxiety for the patients, and for some a reason to mistrust what certain staff members do or say. In no case was it mentioned that a patient had definitely been infected by a staff member, but since accidents in the unit frequently involve blood, several cases of HB among staff members were attributed to specific patients. This was done for reporting purposes only, but it did serve to make the several patients feel guilty about the contamination even if it was hardly their fault if the equipment failed. Patients become highly sensitive to any suggestion of contamination or failure on their part, because most of them are struggling mightily to keep up the appearance of health and/or productive activity.
Question II-6. What does being a carrier mean?

Eight patients disclaimed any knowledge of carriergship or its implications. An additional ten carriers did not know how long the condition might last. Six expected it to last "forever" and six said the period of carriergship could vary up to many years or forever. With respect to the possibility of infecting others through one's carriergship, there were two distinct ways of expressing it: fifteen said carriergship means the carrier can give the disease to someone else, while five, all patients, said someone else can catch it from you. Curiously, two people misunderstood something they were told, because they believed that if they didn't use precautions, they themselves could get it again. Attempting to explain this curious response, a senior staff member said they probably were told they could get Hepatitis A or nonA-nonB, and didn't listen closely enough to hear they could not get hepatitis B again, since having had it conferred immunity to that type.

All staff carriers expressed contagion as their responsibility, i.e., "You/I can pass it on", whereas in discussing it the non-carrier staff tended to speak of the infectiousness of the virus, and not express it in such personalized terms. The patient carriers seem, once again, to be attempting semantically to avoid responsibility of the contagiousness of the disease and the potential of infecting others by talking about how "others can get it from you". They are passive catalysts. One man discussed it quite coherently, but ended up saying, "But none of this applies to me. I was never sick with it, and no one knew I had it. I barbecue
for a lot of people, and no one's ever gotten it from me."

One of the more interesting observations in this study has been
to note that at times people really do pick and choose pieces of
objective data to fit in with their theoretical perspective of life,
in addition, at other times, to building their perspective on their
observations (Anderson, 1982). Perhaps it would be even more
accurate to say that one's perspective tends to be constantly
modified in the direction of protecting one's self-image, whether
the modification is congruent with the rest of their cognitive map,
or mazeway, or not. This "reintegration" is most likely to occur
where there is a subcultural group facing the same environmental
problems which make it necessary to modify the group perspective to
bring it more in line with observed reality. Each individual
contributes to the innovative process, and the new view is
constructed together, but not necessarily consciously (Wallace,
1970). In this way it is validated by the group as it is being
developed. Eventually, presumably, incongruities in the perspective
will be reinterpreted or conventionally ignored, so that the
perspective is once again a "whole" in the person's mind.
Question II-9. What did you know about HB before you became a carrier?

Table 16. Level of knowledge about HB before carrier ship.

<table>
<thead>
<tr>
<th>Information item</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>sick/run down/tired</td>
<td>5</td>
</tr>
<tr>
<td>infection (-ous) or contagion (-ous)</td>
<td>5</td>
</tr>
<tr>
<td>jaundice</td>
<td>4</td>
</tr>
<tr>
<td>disease</td>
<td>3</td>
</tr>
<tr>
<td>liver</td>
<td>2</td>
</tr>
<tr>
<td>virus or &quot;bug&quot; cause</td>
<td>2</td>
</tr>
<tr>
<td>restrict diet, no alcohol</td>
<td>2</td>
</tr>
<tr>
<td>2 kinds of hepatitis: serum and infectious (?)</td>
<td>1</td>
</tr>
<tr>
<td>risk in dialysis unit</td>
<td>1</td>
</tr>
<tr>
<td>needle-stick as source of HB</td>
<td>1</td>
</tr>
<tr>
<td>isolated from others in dial. unit</td>
<td>1</td>
</tr>
<tr>
<td>nothing - never heard of it</td>
<td>16</td>
</tr>
</tbody>
</table>

Despite the supervisors' assurance that all staff and patients were told about hepatitis when they began work or dialysis in the units, one staff and 15 patients claimed never to have heard of it before they became HBsAg+. Since this was an open-ended question and no choices or items were suggested by the interviewer, there are relatively few answers, but the staff agreed there is little knowledge before they become positive. Most of these answers, in fact were volunteered by the staff.
Question II-10. What have you learned since?

Table 17. Level of knowledge about HB since carriergship.

<table>
<thead>
<tr>
<th>Information item</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>use of separate dishes, linens</td>
<td>6</td>
</tr>
<tr>
<td>personal hygiene, esp. blood</td>
<td>5</td>
</tr>
<tr>
<td>danger of liver cancer</td>
<td>4</td>
</tr>
<tr>
<td>3 kinds of hepatitis</td>
<td>3</td>
</tr>
<tr>
<td>elevated liver enzymes</td>
<td>3</td>
</tr>
<tr>
<td>cause: dirty needles, blood transfusion</td>
<td>3</td>
</tr>
<tr>
<td>&quot;bad feeling&quot;</td>
<td>3</td>
</tr>
<tr>
<td>stop having sex</td>
<td>2</td>
</tr>
<tr>
<td>a blood disease</td>
<td>2</td>
</tr>
<tr>
<td>HBsAg, HBeAg</td>
<td>2</td>
</tr>
<tr>
<td>use separate dialysis station</td>
<td>2</td>
</tr>
<tr>
<td>organs, immune system involved</td>
<td>2</td>
</tr>
<tr>
<td>do not use &quot;the pill&quot; or other drugs if possible</td>
<td>1</td>
</tr>
<tr>
<td>nutrition for HB</td>
<td>1</td>
</tr>
<tr>
<td>jaundice</td>
<td>1</td>
</tr>
<tr>
<td>vaccine no help for</td>
<td>1</td>
</tr>
</tbody>
</table>

Seven of the above items are practical dos and don'ts and nine are general information about the disease. Considering that these are not repeats from question 9, above, a certain amount of information has been learned from all sources, mainly by staff efforts to inform. Eight claimed to have learned nothing more since they became carriers, but 2 showed some knowledge despite the disclaimer. Three who answered they had learned "not much" seemed to know less than the 2 who claimed nothing.

Although the units handled the educational process in a slightly different manner, there was little difference in amount or kind of knowledge retained by the carriers. Most staff (all nurses, most technicians and dieticians) were reasonably well informed, but whether they received a printed form or verbal instruction repeated over a longer period of time, most patient carriers seemed to have
the same level of detail. One or two highly educated patient carriers in each unit had a better grasp of the disease than many staff members, but they either were married to an MD, had in their close social network at least one MD to whom they could turn at any time, or were RN's themselves. Because of the minimal educational experience of about one-third of the patients, the number claiming little or no knowledge either before or after becoming a carrier checks out reasonably well. Interestingly enough, the three women mentioned in Chapter 3, from whom relatives and/or staff members contracted HB were not among the less-well-educated group. They blamed their secondary cases on having been poorly informed by their supervisors (when they were hired) or by the physicians or others when they were informed of carrier ship. These cases were especially poignant because in all cases spouses or children were involved (in addition to staff in 1 case). Two had been told "not to worry about it" by those who had informed them, but it seems the message, complete, was meant to be more like, "Take these precautions, then don't worry about it".

There is probably less satisfactory communication between staff and patients on the subject of hepatitis B than the staff realizes. Only 27% of the total respondents associated HB with an inflammation of the liver, and 83% of these were on the staff. With the exception of not wearing rubber gloves when dealing with carriers, (except during emergency equipment breakdowns when blood leakage occurred), the behavior of the staff was observed to be congruent
with their level of knowledge about HB and regard for its infectivity. According to the patients' assessments, their own compliance with hygienic precautions is often a sometime thing. There are, however, one or two members of all four sub-groups (carrier/non-carrier; patient/staff) who are much more conscious of contagion than the rest.

For some individuals the concept of contagion due to the germ theory of disease is held concurrently with the belief in Divine Providence as the cause or permittor of disease to occur. This seems to give rise to little or no dissonance in their minds, possibly because medical science and religion as cognitive categories do not overlap in their view, nor, therefore, in meaning, and thus do not consciously contradict each other. One staff member who held both ideas became conscious of it during an interview and apologized for the dissonance.

Because of the many possible opportunities for contagion, few staff or patients were certain when or how they were exposed to HBV. Staff tended to associate exposure with specific elements and accidents in their daily environment while patients tended to avoid blaming the agency or its staff and preferred to assign the responsibility to an outside agency such as the supplier of blood for transfusions. One blames neither God nor the care-takers for misfortunes theoretically under the control of either or both, but projects the ultimate responsibility onto unknown others. In a setting for the care of the chronically ill, it is expected that the powerless do not challenge the powerful, nor do the weak challenge
the strong (Katon and Kleinman, 1980). There were a few occasional exceptions to this general pattern.

The staff see themselves as being actively responsible for not transmitting HB to patients (and others). Patients see themselves as passive catalysts in the transmission of disease. The nature of their goals and their views of what their duties are correspond to these self-images. Staff members play a care-giving, nurturant role while patients, unable to care for themselves, have no choice but to passively accept the services of the staff. Patients whose behavior does not fit this passive mold but attempt to retain more control over their own lives either withdraw from the social interactions or "community" of dialysis or else are known as troublemakers. Thus the somewhat defensive, apologetic tone and demeanor of staff people when they discuss their antigenemia, as opposed to the lack of guilt and often confusion and annoyance of patients when they talk about it. Each sub-group has its own view of causal and contributing factors, and individuals, through time, accumulate and validate these shared beliefs and attitudes among themselves (Good and Good, 1980; Klenow, 1979; Lewis, 1980).

The higher degree of response (DOR), higher educational level, higher level of comprehension, and protectiveness toward the patients, all bespeak the staff's responsibility that they have learned to feel toward their charges. The personalities of some patients may be less lovable than others, but all were observed to receive the same level of care and frequency of prompt attention
when needed.

Of the staff who contracted HB, 20% reported suffering depression compared with 10% of the patients. Proportionately, more staff carriers suffered severe symptoms of HB than did patients, and mild to severe depression frequently accompanies other symptoms of the virus (Denes, 1978). This is mentioned briefly here because for a few respondents the unusual lassitude contributed to their anxiety, and was a highly salient part of their definition of carriership, whether objectively correct or not. There is further discussion of emotional effects below.

The practical dos and don'ts about HB contagion management are the kind of information remembered by patients, and abstract or theoretical ideas about the nature of the disease are more relevant for the staff. Level of education is associated with the number of "don't know" answers, but not with occurrence of secondary and tertiary cases of HB among carriers' social networks. These latter cases patients attribute to incomplete or incorrect data on the part of those informing the victims of HB, or an occasional risk-taking, e.g., "Once won't matter". Additionally, in two cases, the relative who became infected with HB did not take seriously the information given by the carrier or the staff.

Summary.

Some respondents defined hepatitis B as an infectious disease, some saw it as a liver condition of some sort, and some were unable to assign it to any meaningful category. Several people spoke of HB as though it were a stage in the progression of renal failure,
inevitably associated with it. The fact that it is a virus disease unconnected biologically with kidney function is difficult for them to comprehend. The fact that it could be spread much the same as a cold or the flu seemed not to be well understood initially by some staff and most patients. Because hepatitis B was in some way related to blood, cautions about contamination with blood were retained, but not the generalizing principle concerning blood as well as all other body fluids. It was not intuitively obvious to patients that it was other than one more factor in the blood, which was regularly monitored and nothing to fear. Some staff members thought it remarkable that so few secondary cases of HB occurred, considering the level of understanding and hygiene of some of the carriers.

One of the unintended and staff applauded results of this study was that at least everyone who became a respondent was much better informed about hepatitis B than they had been before. The supervisory staff felt that the information received by staff and patient carriers through the means of the interviews served to reinforce all that they had been saying, and there was among many of them a better appreciation that before of the seriousness of HB.

These topics were covered in the research well before the vaccine had become available, and no one was as yet aware that protection from HB was so close to being achieved. So the most frequent associations with hepatitis B, after liver damage, in respondents' minds was with various symptoms such as jaundice, and being tired,
depressed and scared. But these last three were also frequent accompaniments of the dialysis process, therefore it was difficult for respondents to differentiate whether they were effects of HB or hemodialysis. Since only a small fraction of the patients had had clinical or severe symptoms of HB, they were in no position to assign their malaise to hepatitis rather than to renal dysfunction.

One of the more disheartening occurrences for the supervisory staff that was reported by the patients was that no matter how carefully they were informed about HBV, or by whom, so many of the patients did not comprehend what they were being told. A very high percentage of them denied having been counseled about how to deal with the knowledge of their new HB contagion. Intimately associated with communicating health facts were also contests of will, power struggles between individual staff members and individual patients over responsibility, and the depression that follows feelings of hopelessness, powerlessness and lack of control over their own destinies. (see Alexander, 1980)

There is probably less adequate communication about HB between patients and staff than the staff realizes (De-Nour, 1971). Having discussed with patient carriers once or twice about the danger of contagion, they may feel patients are adequately informed and will comply with any necessary hygienic behavior. However, over time, the urgency of scrupulous cleanliness lessens and patients tend to relapse into the passive role of the chronically ill so that they do not have to constantly deal with the contradictions or double-bind injunctions they receive at the conscious level. It is impossible
to "be independent", "be normal", and "be grateful", which if not
verbal demands are at least nonverbal demands communicated to
dialysis patients (Alexander, 1980). It is impossible to be
independent if one is made dependent on the directive to be so.
Also paradoxical are the other two injunctions. Western
institutional medicine requires conformity to the sick role and
reserves for itself the responsibility of care for sick people. A
major barrier to medical care according to Katon and Kleinman (1980:
261-262) has its roots in the doctor-patient relationships
characterized by the authoritarian power structure of traditional
practitioner-patient interactions. Professional biomedical
relationships have always been hierarchical, and while "social class
and status of the patient influence how much influence he is
 accorded in the clinical encounter, ... the power differentiation
of the doctor-patient relationship is most impressively unequal."
Staff tend to override patients with respect to arbitrary
preferences in negotiating non-critical aspects of the procedure
such as which chair to use, this side of the room or that, a high or
low setting for dialysis, etc.

In this kind of double bind, there are no victims. All
participants may be caught in mutually destructive behavior.
Considering reports of staff negativism in other studies (De-Nour et
al, 1978; Alexander, 1980), staff behavior and their attitudes
toward patients in this study were remarkably benign, with very few
exceptions. There was the odd exceptional case here and there where
this was not true. There was general lack of sympathy for the woman who left dialysis to join a faith-healing group, but returned in a few weeks in serious distress. There was the illiterate, black woman in her 50s who also had a cardiac condition, but whose husband brought her in each time because she was dead drunk. But in general, staff attitude toward patients was warm and positive. The need to see normalcy in patient behavior as a practitioner need, not a patient need, was recognized by the administrative physician in one of the units. In order to conform with this staff need, dialysis must be perceived as a compartmentalized event that occurs just three days a week, and this is exactly what was observed in this study.

The third directive to patients that they should be grateful, or "at least act like they are being helped" (Alexander, 1980), was of particular interest, because in an occupation of low pay (compared with the higher pay of the supervisory staff and medical personnel), part of the technicians' compensation is seeing patients' health improve over time (Chrisman, 1982). (All health workers presumably share in this kind of satisfaction, but it seems to be of special importance to those not trained as MDs or RNs who never thought they could be actively involved in patient care.) If the patient does not behave as expected, there are accelerated attempts by the practitioner to help more or else to reject the patient, which is the ultimate paradox. As Alexander states, patients are not grateful for obvious reasons.
The "prestigious and financial functions of institutional medical service, and the personal and professional gains enjoyed by dominant practitioners, counter the [three-part] directive at one level. The horrendous problems resulting from the disease and treatment counter it on another level. The chronic failure of patients to comply with the directives that they be independent and normal leads to pessimism, not to gratitude." (Alexander, 1980, 320)

Patient carriers became highly sensitive to the possibility of being blamed as the source of contagion for others and tended to speak in the passive tense about how "others can get it from you [me]", whereas it was more common to hear a staff member speak of the "fear of contaminating others", clearly seeing themselves as active sources of potential infection. The patients' rejection of responsibility and the staff's acceptance of it are distinct differences demonstrated by these responses.

One might not agree with Eisenberg and Kleinman (1980) that "there is no common cosmology between healer and patient" in Western medical practice, but it could be agreed that "there is the presence of many contradictory belief systems" among the staff and patients of the esrd centers. The most frequently held dissonance is the simultaneous belief in the germ theory of disease and a concurrent belief in some version of a causal Divine Providence. For many people, even many with science training, medicine and science are not overlapping categories in their cosmology, and thus do not interfere with categorical compartmentalization, each exclusive of the other.

Further discussion of several of these topics summarized here will again appear below, because the information was elicited in a
different context and is also relevant there.

3. Carriership: effects on self and others

Hepatitis B carriersonship affects various categories of people in different ways. Carriers, non-carriers, staff, patients and members of social networks of patients view carriersonship from various points of view. There has already been discussion about the first four of these groups. In this section they will be reviewed and supplemented and the effects on relatives and friends will be introduced. Many of the symptoms of the disease carry medical or biochemical explanations. The behavior devolving from these symptoms influences everyone's view of the disease and its persistence in the body (which is only discovered months later after the victim has "recovered" from the symptoms).

Between 50 and 60% of all cases of HB in the U.S. "are subclinical, asymptomatic and usually undetected. Subclinical cases are most likely to develop chronic sequelae" (Hilleman et al, 1978). Victims may express surprise or shock when they are identified as carriers because they have had no symptomatic warnings of the disease. There is neither an effective treatment nor a cure for persistent HB antigenemia, or carriersonship (Merigan & Robinson, 1978; ACIP-CDC, 1982). Because of the cost of the vaccine (3 shots @ $125) we can expect no great rush for immunization among the general public. It is being offered, mostly under a federal or other general funding plan, to those health care agencies and institutions that deal with high-risk groups (pp 2-3). However, unless there is a widespread public demand for a general population immunization
program, which is unlikely because of the expense, we may expect a certain number of cases of HB to keep appearing. The reservoir of infection would be the "street culture" and others not living or working in total-care institutions (who would be immunized). Most citizens have little contact with these groups, so they are minimally affected by hepatitis (see Appendix C).

Question II-7. How did you feel when informed about HB carriernesship?

No answers to this question included reference to such physical symptoms as increased heart rate, elevated blood pressure or headaches. Table 18 lists responses and their frequencies spontaneously given by carriers to the open-ended question.

3. Each profession has its own definitional variation of this term. Here, it includes illicit parenterally injected drug-users, including pushers; prostitutes; chronic alcoholics or winos; bag ladies and other homeless wanderers. "Others" refers to the un inoculated male homosexual community, those who use self-injected legal materials, and tattoo parlor clientele.
Table 18. Responses to question II-7.

<table>
<thead>
<tr>
<th>response</th>
<th>staff</th>
<th>patient</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td>angry at others (supervisors, professors)</td>
<td>5</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>depressed</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>concern about infecting others</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>worried about health</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>concern about job, finances</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>scared, fear unknown outcome</td>
<td></td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>self-pity</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>surprised</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>angry or disgusted with self</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>worried about being avoided</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>unlucky</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>guilty</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>not concerned, forgot about it</td>
<td>8</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>resigned</td>
<td>3</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>accept it</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>more concerned with esrd than HB</td>
<td>3</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>lucky it took so long (9 yrs.)</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>don't know</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
</tbody>
</table>

Both staff and patients need a way to escape the fear and guilt of exposing others to HBV. Only 1 person listed guilt as an answer to this question, but it came up repeatedly in other contexts, especially when discussing the infection of others. For example, when answering the questions in section III, one woman vehemently declared, "They say I gave it to him, but I think he got it from ...", and again later, "They try to make you feel guilty, and they should stop." Such defensiveness is usually understood as a guilt reaction. Staff non-carriers were also concerned about contagion, but centered on avoiding infections in the unit. The patient non-carriers who were interviewed had little awareness or concern over hepatitis B except for one whose spouse was a physician. There was extremely high concern and awareness in this case, approaching the
highest response scores of the male staff carriers reported earlier (Chapter III).

All but 3 of those who reported anger when they were informed said they had gotten over it and now realized it was not deliberate and was really no one's fault. The three who still felt angry were all between 35 and 40 years old. Two were staff and one was a patient; all three were HBsAg+ for a year or more. The respondents seemed not to be the victims of generalized anxieties so much as they were aware of very specific kinds of feelings and their causes. The one that seemed to puzzle them the most was depression. Only 6 people reported a period of depression during or following their bout with hepatitis B, and they seemed to be unaware that this symptom frequently follows recovery from a virus disease. Listening to their comments raised the question whether more would have reported depression had the concept been in their cognitive repertoire. More on this in section 4, ff.

Those who expressed worry and concern focused primarily on two topics: infecting others and whether their health would jeopardize their jobs, and thereby undermine their financial security. Though not expressed always in answer to a specific question, even if they had said they were not especially concerned over HB, most of the respondents at one time or another admitted to fear of infecting others, and being blamed or avoided for it. Even though half of the carriers displayed lowered affective responses when discussing contagion, they would still indicate in some way they were aware of
and thought about exposing others. Several of the older men had unusual ideas about the contagion of carriersonship. One, for example, said, "They told me my blood was just 'technically positive', so it was O.K. I try to be careful with others, but my wife and I aren't scared of it. We share drinks, food, cigarettes, and she's never caught it. It's been years, now." The woman has never had a blood test for HB markers, so it is unknown whether she has antibodies or not. To him, the disease may be contagious for others, but not his wife.

Only 6 persons over all questions mentioned religious belief of some sort in association with or in explanation of their responses to carriersonship. One woman said that religion was of no help in cases like this, because it was the responsibility of the individuals to contain the infection as best they could. Several others commented on the futility of their efforts, once they became carriers. "Qué sera, sera." God permitted it to happen, so it was in His hands. A staff member suggested that personal hygiene was such a commonplace, daily routine that the concept of contagion was also part of the dialysis routine, not something to be prayed about, especially.

Those who reported being surprised or angry or disgusted with themselves recalled how proud they were of their sterile technique, and how they told themselves they would be so careful that they would never endanger a patient. Their self-images received quite a blow when informed they were HBsAg positive. One person (staff) reported a feeling of guilt because she hadn't taken her parents'
advice to "get more rest", and seemed to think this contributed to her having a fully symptomatic case of HB. Others were afraid of being considered guilty if they infected others.

Only 3 respondents were aware of themselves enough to state that the kidney failure was the greater of their problems, and therefore they were not highly concerned with hepatitis carrieryship. This was particularly the case if they had not had the usual symptoms.

**Question II-3.** Do you still feel the same way or have your feelings changed?

Half reported an attitudinal change from their first reaction to carrieryship, the other half reported no change. Of these latter, 10 reported they were never upset, then or now. Another 5 reported they were upset then, and they still are. Of those who reported change, all the change was in the same direction — from more to less concern. Three respondents "converted" to being antibody positive since they had first been interviewed, which left them no longer able to infect others. They were, however, still subject to discriminatory behavior by other staff members because they were expected to continue to care for antigen positive patients, or help clean up after spillage of a carrier's blood. Everyone who becomes HBsAB positive belongs to an exclusive club, all of whom are "safe" because they can no longer get the disease. This is less important, now, since the introduction of the vaccine because the main function of the vaccine is to produce antibodies to HBsAg.
Question III-1. What do you think is the probability of passing on HB?

Table 19. Carriers' judgements of probability of passing on HB to another (n=30).

<table>
<thead>
<tr>
<th></th>
<th>high</th>
<th>moderate</th>
<th>low/none</th>
<th>D.K.</th>
</tr>
</thead>
<tbody>
<tr>
<td>staff</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>patient</td>
<td>3</td>
<td>2</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>13%</td>
<td>13%</td>
<td>43%</td>
<td>30%</td>
</tr>
</tbody>
</table>

In order to test the consistency of their answers and the congruence of the elements of their overall perspective, the question of contagion was approached from the point of view of probability. This shifted interest from a subjective involvement of the question of contagion to a more objective-seeing question of personal opinion rather than subjective attitudes which the respondents could readily associate with the sanctioned "party line" of the units. Because only carriers are used for this analysis, the numbers become rather small. Asking non-carriers how do they think they would feel about contagion if they were carriers is informative, but not comparable to asking carriers how they feel about it. Carriers have a dual responsibility toward themselves as well as to significant others and the general public, of which one would not expect non-carriers to be aware. Thus the lack of comparability of this bit of semantic context disallows one thing but allows others.

A general attitudinal answer to this question of contagion is established by informal, rarely verbalized, institutional policy, and the staff are expected to abide by it. But the problem is that
the attitudinal policy toward contagion itself is contradictory, and may serve to confuse. When hygiene practices are important, the contagiousness of HB is stressed. When peace of mind is disturbed by anxiety or depression, as when a member of someone's network was inadvertently exposed and they are waiting out the incubation period, the low probability of contagion is stressed as a calming factor. They want it both ways. One way out of the dilemma is to avoid the issue except when brought face-to-face with it.

Then too, as predicted by interactionalism, answers change due to context (Good and Good, 1980; Goffman, 1974). Sometimes a person will feel contagion is high and at another time and in another context, such as when there have been no new cases of hepatitis for a while, the same individual will say the probability of contagion is low. For the 26% of carriers who believe the probability of exposing others is moderate to high, there is a conflict or breakdown between this belief stated or real, and the institutional policy. For example, accepting new patients who are HBsAg+ is a potential source of contagion in the unit. Nevertheless, a compassionate policy prevailed. None among staff or patients objected. This is in contrast to dialysis units in nearby or distant cities which were "clean" because they transferred all their HB+ patients to one of these units in Cleveland, claiming economic hardship in the scheduling and sharing of only a few machines. The directors of all units interviewed in this study answered in the same way, namely, that everyone who needed it had a right to be dialyzed. They declared they would accept them despite hepatitis B
or any other disease or condition they might have. So, just as the physicians, nurses and support staff of other kinds of facilities such as emergency or trauma units, drug rehabilitation units, etc., do, the eard staff accepts it as part of their responsibility to deal with HB or any other contagion or condition a patient may present. They learn not to deny frivolously their compassion, service and care. How firmly or deeply this attitude comes to be internalized is unknown. What is known is that with few exceptions, the health care workers express this attitude verbally, and congruent behavior establishes its validity non-verbally. This is totally in line with the humane principles they are now taught in many medical and nursing schools. (Bosk, 1979; Foster and Anderson, 1978)

With respect to attitudes on contagion, it has already been reported that with few exceptions many staff and patient carriers express low concern about it. Two-part answers were common, some denoting change over time and others describing varying contemporary situations. Some staff replies were: "Contagion is generally pretty low, but in my occupation it's moderate." "Usually high, but I take precautions, so with me it's low." Patient reply: "Low for others and zero for me because I'm careful." "I was upset in the beginning, but I'm not so concerned now." In line with denial of concern goes this low judgement of risk of infection. The answers support each other. But there are two kinds of answers; one contradicts the other. When asked directly, (III-9), there is
denial. This seems to be an attempt to project low concern to the public. However, when questioned indirectly about other items such as symptoms or behaviors that can transmit HB, (II-7; III-2), there is a high awareness of an association between concern-producing aspects of the disease (which causes others to be exposed and become ill) and behavior.

**Question III-9.** How great a concern has HB been in your life?

<table>
<thead>
<tr>
<th></th>
<th>staff</th>
<th>patient</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td>major</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>moderate</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>minor</td>
<td>1</td>
<td>21</td>
<td>22</td>
</tr>
</tbody>
</table>

Table 20. Self-assessed degree of concern about HB and carriership among carriers.

Only 8 carriers admit to a major to moderate concern over their carriership. Only one staff member reported HB was of minor concern now, after stating that in the beginning, for the first year or so, it was of major concern. Other responses from this same respondent, however, in their length, detail and the heightened affect they aroused, bespoke of more than little concern, even now. It seems fairly clear from this question that staff members consider HB carriership worthy of greater concern than patients do. (This was also true of non-carriers.) Two of those answering "moderate" said it had been major during the years when they were HBsAg+, but since they had recently "converted" to HBsAB+, their concern was downgraded to being only moderate. By this device, carriership also lost an element of personal involvement and took on more of an objective meaning, i.e., they spoke in the idiom of "we" and "us"
rather than "I" and "me".

Some patients who claimed minor or no concern about carriership in their present lives knew or understood very little about hepatitis B. Several commented they couldn't get too upset if a) they didn't understand it, and/or b) they couldn't do anything about it, and c) no one else had had it during all the time they were supposed to have been contagious. (Three cases that resulted in secondary infections are discussed in Chapter III.)

**Question III-2. What behaviors could pass on HB?**

As a further check on how much of their briefing by supervisors on HB was remembered, this question was asked. The answers could be more tightly grouped, but individual answers have been tallied in order to preserve their own cognitive categories. It is easy to see the overlap among categories and the difficulties of generalization.
Table 21. What behaviors can transmit HB?

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Staff</th>
<th>Patient</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>use of contaminated utensils</td>
<td>2</td>
<td>12</td>
<td>14</td>
</tr>
<tr>
<td>sexual intercourse</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>kissing</td>
<td>1</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>infection thru skin break</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>contaminated linens</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>direct contact</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>contamination by blood, urine</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>bandages, kleenex, menstruation</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>hygiene-wash hands after bathroom</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>needle-stick</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>sneezing, coughing</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>preparing food, eating contaminated food</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>using same bathroom, toilet</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>dirty machines</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>improperly labeled specimens</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>wash hands before eating</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>blood transfusions</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>dentists</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>don't know</td>
<td>10</td>
<td>10</td>
<td>10</td>
</tr>
</tbody>
</table>

Two thirds of the carriers had specific answers for this question. This indicates that their answers to II-9, 10 (what do you know about HB?) underrated much of their actual knowledge about HB contagion. Seventy responses for 20 people averages 3 1/2 items per person remembered about route of infection and transmission of the disease. Ten answered "don't know". The time interval between the first and second interviews offered carriers the opportunity to recall or discuss information that had slipped out of their awareness. Remembered most often were prohibitions about food and contaminated utensils, sexual intercourse and all kissing (babies to lovers). Various types of infections through skin breaks and from direct patient contact were specifically mentioned (Table 21). The director of nursing at one unit said that she thought the presence
of the research scientist in the unit, all by itself, functioned as a reminder to everyone, staff and patient alike, what they should and should not be doing vis-à-vis hepatitis B contagion. (This is an example of an unintended consequence — the presence of the researcher changes the situation.) Comparing these answers with those to II-7 (probability of contagion to others) seems to indicate they chose to underrate the infectiousness of the disease while simultaneously carrying an awareness of it at some level of consciousness.

Question III-3. Where in the body does HB occur?

Table 22. Carrier responses to III-3.

<table>
<thead>
<tr>
<th></th>
<th>staff</th>
<th>patient</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td>liver</td>
<td>5</td>
<td>10</td>
<td>15</td>
</tr>
<tr>
<td>blood</td>
<td>1</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>all over</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>eyes (jaundice)</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>joints (arthritis)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>skin (jaundice)</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>stomach</td>
<td></td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>saliva glands</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>kidney</td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>appetite loss</td>
<td></td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>itchy skin</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>muscles</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>depression (brain?)</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>weak, tired all over</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

Differing from earlier answers, 1/3 of the 45 respondents and 1/2 of the carriers were able to associate HB with the liver. Patients were not clear about liver function, but they had negative feeling or anxiety about its being damaged. They wanted no further organ impairment and 2/3 resisted thinking about it or else forgot about it.
Question III-5. Has HB affected your health? Did you have symptoms?

Table 23. Have HB/symptoms affected your health?

<table>
<thead>
<tr>
<th></th>
<th>staff</th>
<th>patient</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
<td>15</td>
<td>18</td>
</tr>
<tr>
<td>D.K.</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
</tbody>
</table>

Hoofnagle (1981) reports 50 to 60% of infections are subclinical, asymptomatic and usually undetected. Excluding those answering "don't know", 60% of all carriers interviewed in this study fit Hoofnagle's statement. If it is assumed those answering "don't know" would have known had they had any of the symptoms, 24 or 80% had asymptomatic cases. The supervising physician at one unit said it should be even higher, possibly as high as 90 or 95%.

"Subclinical cases are more likely to develop chronic sequelae. Prolonged biochemical, clinical and serologic abnormalities tend more frequently to follow anicteric hepatitis [see App. D], particularly cases with an insidious onset and very mild protracted symptoms." (Perillo & Aach, 1981)

Three carriers, 1 staff member and 2 patients, claim they believe they are still feeling the effects of the virus, but most staff members believe these effects are probably due to dialysis, not hepatitis or carriernesship. The kinds of symptoms reported as still occurring are tired (unusual need for sleep), aching joints, sclera unclear, depression/enervation, weak spells. Except for discolored sclera, all reported symptoms could be equally probably
due to esrd, as staff members believe. Still, those who attribute these symptoms to HB have added them to their beliefs about the effects of the disease, so are recorded as such. From this point of view, their perspective on both the disease and carriersonship are of they, themselves, being somewhat more dangerous than those who don't have persistent symptoms — or persistent antigenemia.

**Question III-7.** Has HB affected other areas of life?

<table>
<thead>
<tr>
<th></th>
<th>staff</th>
<th>patient</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td>yes, while acute</td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>some now</td>
<td>4</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>no</td>
<td></td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>don't know</td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
</tbody>
</table>

The staff reported both more immediate effects during acute symptoms (for those who had them) and continuing effects because of avoidance of others and precautions against contagion. Their lives at home and in the esrd unit reflected these effects. Non-carrier staff indicated they were conscious of the possibility of getting HB (before the vaccine) and would be extra cautious both in the esrd unit and at home. They felt that social, family and sex activities would all be affected. As they perceived their carrier colleagues, they felt they were heavily burdened by carriersonship. It is true that all six staff carriers reported far more problems than carrier patients with their careers, social lives, family lives and sexual activities. Four said they would have no more children, and an unmarried staff member wondered whether she/he should have any at all. All worried a lot about their jobs.
One technician's experience was particularly difficult. She expressed it that "my career was in shambles". The physician in charge didn't want her in the esrd unit, nor on the hospital dialysis floor. Rather than furlough her since she was able to work, the personnel department began a series of rotations for her between the emergency room, (internal) medicine and surgery until she was so discouraged that she quit and went to another hospital. After a few months she changed hospitals again. Finally a former nursing supervisor invited her back to the unit in which she contracted HB and is there at the present time. No secondary cases of HB have been charged to this technician, and she is certain that had she not been black she would not have been treated as she was. It is true that no other staff carrier or anyone any of the staff knew of, male or female, black, white or other, was ever treated in this way, and it is pleasant to report that she is once again productively caring for the HBsAg+ dialysis patients on a full-time basis.

A number of such stories from the earlier days of dialysis served to keep alive staff fears of unemployment and financial destitution when they initially learned they were carriers. It took one divorced mother with a child over six months to get her unemployment compensation because she was the first ever to claim it for "carriership". The compensation review board had no concept of an able-bodied person carrying contagion, or of how long it took some people to recover from this debilitating virus infection.

Most male patient carriers retired when they were diagnosed
with kidney failure because they were in their 50's or 60's, so they were not concerned about employment. Younger men and women continued their regular employment after dialysis and/or HB, several in health-care fields. Many of the women patients did not work outside the home and they, too, did not worry about compensation. The staff carriers were in an unusually vulnerable position, fearful of being cast aside from productive occupation forever, as the result of an accident which had a known probability of occurring, sooner or later, in their high risk occupation.

**Question III-8.** Any changes in your life since carrierness?

There were 42 conscious acknowledgements of changes in behavior for 16 carriers who answered "yes" to this question for an average of 2.6 per person.

**Table 25.** Any changes in life style since HB?

<table>
<thead>
<tr>
<th>behavior item</th>
<th>staff</th>
<th>patient</th>
<th>total</th>
</tr>
</thead>
<tbody>
<tr>
<td>better household hygiene</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>isolate utensils</td>
<td></td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>separate linens</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>separate bath room</td>
<td>3</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>at first yes, now no</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>goes to night school</td>
<td>3</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td>kissing, hugging, touching less</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>paper utensils at first</td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>&quot; &quot; still (especially as guest)</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>restrict social life, contacts</td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>do less, still weak</td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>better eating habits</td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>more sleep</td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>better personal hygiene</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>no alcohol, smoking</td>
<td>2</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>careful of blood contamination</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>never use public facilities</td>
<td></td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>no</td>
<td>1</td>
<td>12</td>
<td>13</td>
</tr>
<tr>
<td>D.K. (don't know)</td>
<td></td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>
Comparing Table 25 with Table 21 shows consistency in answers. The same kinds of things tend to show up more frequently, except that the numbers are lower in Table 25. When questioned about personal behavior or the effects (III-8) there was a reserve among patients as though they didn't care to reveal private matters, whereas the staff were much less reluctant. When speaking in general, however, or in the abstract (III-2), patients displayed more knowledge about both symptoms and contagion.

One of those who answered "at first, but not now", referring to her physician's injunction to avoid sexual intercourse, commented that during the acute and recovery stages of the disease, "you're so tired you don't care". Several others stopped sexual activity completely during the acute stage, but have resumed since with condoms. Older carriers, both male and female over 50 who addressed the subject at all, dismissed it by referring to their age as a usual cut-off point for "that kind of thing", anyway. For those who still restrict their body contact and social interaction with others (whether friends, family or lovers), carriernesship, by denying them the solace of closeness, could lead to depression, and has.

Staff members attending night school would probably attempt to change occupations if they are successful in their training and job-hunting. At the present time there is a general shortage of nurses and technicians to augment the staff to care for the continually increasing esrd clientele. Departure of experienced people would be a severe loss to the agency.
Question III-10. Anyone in network been tested for HBsAg?

Table 26. Results of HBsAg test in social network of carriers.

<table>
<thead>
<tr>
<th>relationship</th>
<th>n</th>
<th>staff</th>
<th>patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>wife</td>
<td>4</td>
<td>1 HBsAB+, 1 sAg-</td>
<td>4 HBsAg-</td>
</tr>
<tr>
<td>sons</td>
<td>3</td>
<td>1 sAg-</td>
<td>1 sAg-</td>
</tr>
<tr>
<td>husband</td>
<td>2</td>
<td>1 sAg-</td>
<td>2 AB+</td>
</tr>
<tr>
<td>friend</td>
<td>2</td>
<td>1 sAg-</td>
<td>1 AB+</td>
</tr>
<tr>
<td>fiance</td>
<td>1</td>
<td>1 sAg-</td>
<td></td>
</tr>
<tr>
<td>mother</td>
<td>1</td>
<td>1 non A-non B</td>
<td></td>
</tr>
<tr>
<td>nephew</td>
<td>1</td>
<td>1 sAg-</td>
<td></td>
</tr>
<tr>
<td>landlady</td>
<td>1</td>
<td>1 sAg-</td>
<td></td>
</tr>
</tbody>
</table>

When blood tests initially show an individual to be HBsAg+, the offer is made to have the blood of members of their family tested, if they so desire. Of this sample, 7 patients and 4 staff members accepted. The mother of a fifth staff member (a renal patient in Indiana) turned up with non-Anon B, and is totally unrelated to this study, but is reported for completeness. Among the rest of the staffs' networks tested, 1 person was AB+ and 4 were Ag- showing one had had HB in some form and 4 were never infected. Among the patients' networks, 3 were AB+ and 6 were Ag-. There was a total of 15 tested, of whom 4 were antibody positive (1 staff, 3 patient), 1 was an unrelated nonA-nonB, and 10 were antigen negative. The sample is too small for valid association tests. Unreported by the patient, but anecdotally recounted by staff members was one case in which the spouse caught HB while assisting in home dialysis, and died. This person had moved away before this study began.

Question IV-2. How did your network members react to your carrier ship?

It is a fundamental assumption of this study that humans'
behavior, knowledge, beliefs, etc., continually change as we accumulate life experiences. It is further assumed that most of the knowledge on which our behavior and beliefs are based comes from observing and evaluating other humans, most of whom are within the same sociocultural system. The reactions of others to one's own condition serve to communicate the essential acceptance or rejection of members of society to its consensual norms (Merton, 1949; Parsons, 1958; Goffman, 1963). Table 27 lists the responses of their network numbers as perceived by the carrier respondents.

Table 27. Responses of social network members to respondents' carriership.

<table>
<thead>
<tr>
<th>type of response</th>
<th># of network members</th>
<th># of respondents reporting</th>
</tr>
</thead>
<tbody>
<tr>
<td>calm, not concerned</td>
<td>28</td>
<td>9</td>
</tr>
<tr>
<td>worried, concern</td>
<td>27</td>
<td>12</td>
</tr>
<tr>
<td>avoidance</td>
<td>21</td>
<td>6</td>
</tr>
<tr>
<td>interest</td>
<td>20</td>
<td>8</td>
</tr>
<tr>
<td>no response</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>angry</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>amused, teasing</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>no one else knows</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>surprise</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>totals</td>
<td>113</td>
<td>51</td>
</tr>
</tbody>
</table>

These "emotional" responses will be discussed again in the following section on coping with the effects of HB carriership. In present context, they testify to carriers' perceptions of how members of their families, co-workers and friends responded to them when they were informed of the carriers' status. The first entry says the 28 network members of 9 carriers took the news calmly and showed no concern about it. An additional 8 reported no response at all among 10 relatives and friends, which leads to the speculation
that they had no idea what the carriers were trying to tell them. So a total of 17 carriers claim their families and friends responded with low or no affect to carriersonhip. However, their knowledge and behavior in other ways discredited the surface meaning of this type of response. Some of these same individuals were among the more agitated about infecting others. Several respondents assured me they were neither homosexuals nor "druggies", to make sure I did not take their having had hepatitis B the wrong way.

Summary.

The severity of symptoms may affect the attitude and behavior of carriers toward their assessment of how serious a disease is hepatitis. "The reactive component in illness has long been recognized as an important aspect not only in defining the condition but also in the patient's response to treatment and in the course of illness" (Mechanic, 1980). Parsons (1958) comments that a patient's attitude toward a disease may influence its severity, so that where there are few or no physical symptoms, there is less likelihood of a highly reactive response to hepatitis.

Since between 50 and 60% of all cases of hepatitis B are subclinical, there is a tendency for many carriers to deny its seriousness and its capacity for causing problems. This response also functions to alleviate fear and guilt over having been exposed to HB — for the time being. Sooner or later the facts will have to be faced. There is also the added factor of exposing others to a serious viral disease if it is ignored.
Despite overt refusal to admit concern over carrierness in one context but ready to admit it in another, over half of the carriers showed they were knowledgeable about the infectiousness of HB and how it was passed on. Individuals understood its contagiousness to different degrees as a result of different kinds of information and assumptions they held when they joined the dialysis units.

Religion seemed not to play an important role in the esrd unit. At least it was rarely discussed. It may be appropriate here to apply the "render unto Caesar" idea — Saturdays or Sundays are for God, and the rest of the week medicine gets the credit for assisting. No dialysis takes place on Sundays, and religion is out of the picture during the week. Only rarely was it mentioned spontaneously in the unit. There was also a kind of ambivalence among the staff concerning whether it was helpful for the patients to be overly concerned with religion in the hope of an impossible cure.

About half of all carriers interviewed reported that their initial concern and fearful responses to HBV had subsided to a much lower intensity. Some patients were very angry and others only somewhat annoyed at the staff for not informing them more fully about HB, even though in most cases the staff told them just about all they, themselves, knew. It was not very much, all too frequently. By and large, the staff shared this criticism about their superiors, in turn. Some of them even blamed themselves for getting HB despite the fact they had no idea how or when it actually occurred.
One significant worry of carriers was that others would stigmatize or discriminate them from healthy, normal people, and by doing so, lower their intrinsic (emotional) value among members of the network. That such a quasi-economic idea is relevant here is argued by Glascock (1983) very persuasively. In our culture and social system, the idea of death-hastening behavior is anathema, but there are at least two kinds of examples in recent history that make this idea seem less remote. 1. The fact that in the middle years of highest productivity and earning power a couple may be asked to choose between educating their young and adding to the chances of survival of an aging, ailing parent, when there is not enough money to cover both. 2. In the earliest years of dialysis little more than a decade ago, there were citizens' boards appointed to determine who would be the ones to live with the aid of the newly-invented dialysis machines. Who wants to be passed over?

This kind of consideration demeans the self-image of the carrier, and their self-assessment was already none too high. They recognized they needed the support of various segments of society in order to survive. It was difficult under the circumstances to deal with rejection or alienation when there was little of positive value they were able to see they could contribute any longer. Thinking in these terms, Glascock points out, is not characteristic of our society only, but widespread among many simple as well as more complex human social systems.

Early in the interviews about 75% of carriers said they believed
the chances of their passing the HB virus to others was low, none, or didn't consider it worth worrying about. Some respondents seem to view themselves as more dangerous to others than those who are not carriers, but denied it out loud. Staff, especially, were concerned lest they inadvertently, or (worse) carelessly expose others, especially patients, to infection. Denial of these types of concerns gradually lessened when the respondents came to realize that the research scientist was not a spy for some agency that was going to revoke any of their benefits. It was replaced by denial of concern over incapacitation (decrepitude) and by valiant efforts to behave as "normally" as possible. Later answers to questions which overlapped these in semantic content brought out evidence of contradictions, "breakdowns" or disjunctions of a sort that fits the model suggested in Chapter I.

Staff members expressed greater awareness of effects of antigenemia, both immediate and long-term, than did patients. They were all extra cautious when on duty, but non-carriers could relax their caution then they left the unit, and the carriers could not. Some staff carriers who were not married or parents, felt particularly burdened by considerations such as: should I marry, should I have children, better not to hug and kiss relatives and friends. This kind of rumination deprived them of needed support and security. When they were informed of their carrier ship, the two things of most concern to staff members were: 1. How badly will I be debilitated, and for how long? This includes worry over infecting others if and when they go back on the job. 2. Will I be
paid while on sick leave? No longer of concern, this latter was preeminent in the early days of dialysis. Today, the carrier patients, most of whom were permanently "furloughed" or retired when they were diagnosed in renal failure are covered by disability pensions or welfare. Hepatitis does not enter into their economic plans. Only when they travel does it become a problem.

There was also reported a drastic decline in sexual activity among staff and patient carriers, particularly (and not surprisingly) among those who had more severe symptoms. They knew what they did not want to pass on to others. Patients over 50 were less concerned about this factor than were younger respondents. Having their families and close friends vaccinated should remove this concern from younger carriers and allow them a more normal life, free of having to create a distance between themselves and intimate relationships. Young female carriers think about Caesarian deliveries to prevent infection during birth. Vaccinating neonates has just begun to be considered. Less than a third of the carriers reported accepting the offer of having members of their families tested for antigenemia. Only 4 of these reported a relative as antibody-positive, meaning they had had some form of hepatitis B. Because they continually sought to minimize the effects of their ill health, especially among their family and friends, almost all patients prefer to avail themselves of professional dialysis at esrd centers rather than learn home dialysis techniques. It offers them low-profile attention when outside the dialysis unit. The staff, for reasons of fewer infections, better dialyses, and fewer
hospitalizations also believe dialysis centers are the answer. The procedure is complex and demands careful, sterile technique for continued success.

In some cases, these attempts to protect their families and friends from the realities of dialysis and carriergship are rooted in bitter experience. The worry caused to members of their networks was of deep concern to some carriers, who quickly compared experiences with others. When relatives, friends and colleagues showed avoidance behavior toward them, or became angry, annoyed or were amused by carriergship, they tended to take it very personally and conclude that HB carriergship was stigmatizing. Clues to their beliefs about how the stigma was defined were contained in some of the justifications given to the author. Denial of being a "street person", using injectible drugs and being a homosexual were felt to be relevant. Separation from children and grandchildren were high on the list of predicted effects feared by older carriers. Burdening spouses and relatives, and escalating costs of being ill were also critical factors in the denial of concern and incapacitation by both working and retired carriers.

4. Coping with effects of carriergship: information management

In Chapter I McDermott and Roth (1978) were cited for their excellent statement of the interactional perspective in anthropology. They found that in reviewing the literature that there were three major "organizing metaphors" of interactional accounts used by field workers to gather and analyze data. These
are: 1. eliciting native knowledge; 2. search for communication codes; 3. information management. They acknowledge that all three may be useful in any given study, but one usually emerges as the main or central way by which the data are most productively analyzed and explained. This study uses all three, but since effects of carriergship include coping behavior, the third will now assume importance.

The original proposal for this study leaned heavily on producing an "ethnography of hepatitis B carriergship" through the utilization of the first of the above — eliciting native knowledge. While analyzing the interview data gathered over a period of time, the differences and misunderstandings that existed among the various groups in the study became apparent. Questioning both patients and staff about these differences showed where some of the problems originated. It was not so much a breakdown in the various communication codes\(^4\) being used by physicians, hands-on staff, patients and their relatives. The problem was that, partly due to low interaction in and outside the health-care agencies of the various groups, each individual and to some extent the group (carrier, non-carrier; staff, patient) had their own code and were oblivious to the others'. To those who are naive in the study of semantics, communication or the social sciences in general, everyone

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4. These include verbal and non-verbal behavior. The codes include vocabulary, style of delivery, manner of address, demeanor, clothing, gestures, affect, and any other element that sends a message to the person at whom the communication is directed. See Goffman, 1963.
thinks and should behave in the same way, e.g., the well-knownemark attributed to the late Lady Astor, "I find if I speak slowly,
loudly and distinctly enough, I am understood anywhere in the
world". Goffman, (1963), Watzlawick et al (1967) and Laing (1969
and others) give numerous examples of mis- or cross-communications,
given the basic assumption that universal norms are believed to
exist, and of how people try to make themselves and others fit those
norms. Knowing no other communication code than their own, to the
individual carrier all others were flawed, even though all
participants were properly carrying out their expected behavior as
each understood it. Autonomous judgements were made routinely about
what would be good or not good for the other groups to know about
the disease, carriernesship, dialysis, or whatever. From the
outsider's point of view, (research scientist and scientist's
audience) there was no consistent base of facts that could be taken
for granted, since each was interacting with every other person as
an individual. This was, of course, exactly what the staff was
being encouraged to do, but an unexpected result of it was the
disparity in fundamental factual knowledge on which to base their
everyday interactional behavior.

To cope with this problem, Goffman (1963) recognized that people
used information management as an important control. He described
how and when it was used, and the various techniques involved. This
section of the study analyzes the data for evidence of the following
proposed sequence of occurrences which also serves to further
operationalize the procedures utilized.

1. Carrier observes response of certain significant others to the idea of carriership.

2. Observed responses are processed through the unique cognitive system of the carrier.

3. Carriers' interpretation of response of others as avoidance or stigma produces anxiety.

4. Carrier develops fear of rejection by others, varying from little to mortal.

5. Carrier copes with fear and anxiety by attempting to control information acquired by others so that they do not respond negatively to the carrier. This may be done either by withholding knowledge from them, or by denying to self and others that any problem exists.

6. Expected result is little or no stigma, which is often achieved, and lowered anxiety over rejection. The latter is evidently achieved often enough that this strategy is used over and over by many victims.

The above sequence is derivative of the model, Figure 2, using Goffman's (1963:8-19) sequence of anticipatory behavior regarding stigma and his frame analysis idea (1974) with Agar's schema for strip resolution (1982:789-791) to arrive at an application for the data of this study. This section is an attempt to identify the above stages of the development of a behavioral interaction sequence so the model may be applied. Not all of the above steps may be
observed in each case, but may have been interpolated from the preceding and succeeding evidence contained within the interview responses.

Questions II-11, 12. Have you ever had or asked for hepatitis counseling?

The staff recognized that counseling for the esrd patient who has become antigen-positive could be quite useful. At various times, social workers, nurses, renal physicians, psychiatrists and psychologists were observed to be serving this function in the units. There were even times when the investigator was pressed into this type of duty by the staff because of the detailed knowledge of hepatitis she gained during the preparation for the study.

Patients understand that social workers may be assigned to ease them over difficult and energy-wasting confrontations with various bureaucracies. They rarely call on them in the role of psychological counselor, however. In fact, "counseling" is a somewhat mystifying word to them because they are not sure what it covers. Most seem to associate it with mental problems and do not realize that today its connotative meaning includes teaching, advice, and discussion about anything relevant to the individual patient or carrier. As a resource, counseling is under-utilized by patients, whatever area of expertise is needed on occasion. Every member of the technical and professional staff would respond promptly if a patient requested "counseling" about something. But they don't, or do only rarely.

Besides feeling no new answers will be forthcoming (as discussed
above), most patients seemed to have a need to keep a part of themselves and their lives separate from the esrd unit. A woman who had been on welfare for years said it was not good to have "them" know everything about you. They might use it against you. Men were even more reluctant to consider counseling. Several patients made a pointed comment to the effect that counseling could not help with their major problem(s), renal disease and carriership, so why take the effort.

Table 28. II-11. Have you ever been offered counseling?

<table>
<thead>
<tr>
<th>carrier responses</th>
<th>frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>no</td>
<td>19</td>
</tr>
<tr>
<td>minimal</td>
<td>4</td>
</tr>
<tr>
<td>adequate</td>
<td>4</td>
</tr>
<tr>
<td>full</td>
<td>1</td>
</tr>
<tr>
<td>contradictory</td>
<td>2</td>
</tr>
</tbody>
</table>

All supervising nurses and physicians stated that every carrier who tests HBsAg+ is immediately informed of their antigenicity, so why do 19 persons answer "no" to this question (Table 28)? It seems they do not perceive being informed of carriership and accompanying advice as a counseling situation, whereas staff members do. They are told "as much as they are able to understand" in one unit, and just "a little bit more than that" in another.

When asked if they had ever requested counseling (II-12), only 3 people gave an answer other than partly or wholly negative. Two of these people received their counseling from a family doctor and a private psychiatrist, and the third, whose case was complicated by several other serious health problems, said they told her in the
unit everything she asked about. This was rare; most were not so well satisfied. But because of the mini-epidemic in her family, she was encouraged to talk and ask about anything at all in an effort to ease her depression and help her make some kind of life for herself after her marital separation.

Because the responses from the staff so often were "We don't know the answer to that, yet", or something similar, most patients became discouraged about asking for information or help with HB problems from the staff.

**Question III-4.** Were risk to others or preventive measures ever discussed with you?

An unintended result of this question was the confirmation of information management on the part of the staff. Of those who answered "no", 4 were staff members whose physicians simply told them "You know what to do about it", and several felt guilty that they didn't. Only 2 staff and 7 patients at this time claimed to remember having these topics (risk and prevention) mentioned to them. Since all were told about these things, as well as being given some advice about preventive hygiene, why, again, the many denials in the responses?

Some staff members admitted to "watering down" the seriousness or importance of carriernesship when they discussed it with patients in an effort to lower their anxiety about HB. When the answer to a patient's question was considered to be beyond the comprehension of the questioner, the staff member's answer likely to be given was "I don't know". There was no new case discovered during the period of
active research in any unit, so no such interaction was observed. The research scientist was requested by the unit supervisors to answer any and all questions the patients might ask about hepatitis. The staff admitted to being tired of repeating "I don't know". After the last interview all respondents were asked if there were anything more they would like to know about hepatitis. Some asked questions, 2 or 3 ventilated, but most seemed to get as much information as they wanted during the course of the interviews.

**Question III-10.** Has anyone in your network been tested for HBsAg?

This question and its tally, Table 26, are discussed on p. 119, under the subject heading of Contagion. It is referred to here, also, as a type of coping — or information management.

Eleven people availed themselves of the offer made by the esrd unit to have members of their families tested for antigenicity, according to their responses. The staff thought it was a slightly higher number. Four staff members did, but the other 2 did not want to alarm others in their families, and a number of patients repeated this reason. Here was a fairly widespread example of information management being practiced at home. Patients tended to be quite reticent when discussing hepatitis in the context or presence of their families and friends, so the figures in Table 24 should probably be considered as conservative. Over 50% were not tested.

The next two questions continue the discussion of coping with network members and their responses other than physical in nature.

**Question IV-1.** Who knows you are a carrier?
Responses to this question varied from 0 to 15 people. Staff tended to report larger numbers if unmarried, smaller numbers if married. Married people live in a family setting whereas the younger unmarrieds do not and seem to gather more acquaintances, co-workers, et cetera. Three people claimed no one outside the esrd unit knew of their carriercship, but on closer examination, one admitted the spouse knew and the other had told a dermatologist. Many older patients (50 and over) reported a restricted network size and therefore smaller numbers of others who knew. A total of 309 network members were remembered by the carriers, and patients claimed to have informed only 131 or 42% of them about their carriercship.

Question IV-2. What were responses of network members to HB?

This is discussed in the preceding section and the results given in Table 27 as response of network members to carriercship information. Causing worry and concern to a total of 27 others, and being subjected to avoidance behavior by 21 members of the network, with anger and teasing in 4 more, seems sufficient evidence of types of responses that caused the carriers to feel they had a problem both of self-image and of the image they presented to others. As anxiety builds they initiate efforts to deal with it.

Either from observing others' coping strategies, or as one originated spontaneously many times over, denial of any response from others was perceived by 8 carriers, and 9 reported some of their loved ones were calm or not concerned, which may or may not have been true. The mean number of years of education of those
reporting no response was 11.8 — almost completed high school. This was surprising because it was expected that concern among network members (with an education probably similar to their carriers) would follow the same pattern as the carriers', i.e., the more education, the more concern. Many respondents said they imparted the information in a calm, low-key manner, as did those who informed them. Control of response affectivity began at the staff level, filtered through the patients and on to the patients' network. If this had been done successfully, those with more education might understand better what was being communicated. The network members with whom I talked briefly and informally denied concern, but then the situation was such that they had little reason to reveal their anxieties to a stranger. Carriers were not eager to have the author interview their families and their choice was respected, so again in this manner they exerted control over who learned what about hepatitis carrier status.

Six carriers stated frankly that they and their relatives did not really understand what the "hepatitis fuss" was all about, and 3 verbalized a version of this idea: "What I don't understand I don't worry about. I have enough to worry about that I do understand."

**Question IV-3.** What do you say if you tell others?

Nine patients tried to explain to others the idea of contagion while eating, drinking and using the bathroom. One woman in her 50's said "I tell them I have hepatitis then leave it to them to worry about". Subsequently, she admitted that her level of
understanding of the condition was zero. Three said they'd mention the hepatitis, but no more. Eleven said they would never talk about it. Two said they were told it was associated with blood or transfusions, 3 said they barely knew the word, and 6 responded "don't know". (See Table 29.)

Table 29. IV-3. What do you say when you tell others?

<table>
<thead>
<tr>
<th>answer</th>
<th>freq.</th>
</tr>
</thead>
<tbody>
<tr>
<td>I don't talk about it.</td>
<td>11</td>
</tr>
<tr>
<td>contagion: eating drinking, bathroom.</td>
<td>9</td>
</tr>
<tr>
<td>mention hepatitis but no more</td>
<td>3</td>
</tr>
<tr>
<td>blood, transfusions</td>
<td>2</td>
</tr>
<tr>
<td>don't know</td>
<td>6</td>
</tr>
</tbody>
</table>

The staff carriers give a lot of thought to telling others and gave the most complete answers. No staff members refused to discuss it with others, although one stated "I rarely use 'hepatitis' — mostly 'Australian antigen'. Hepatitis seems too bizarre, too out of the norm. A. A. is not so bad." This verbal obfuscation is clearly an attempt to control the response from the other. Staff members take carriergship more objectively when dealing with patients or their relatives, but more subjectively when discussing their own condition. A high degree of information management was clearly evident from responses to this question.

In this whole series of questions it was difficult for non-carriers to fantasize what they might do under carriergship circumstances, so they were not pressed to imagine themselves into a worse situation than they already were from kidney failure. One must retain a high degree of sensitivity to ethical limitations in a
health-care setting, frustrating as it may be for science.

**Question IV-4. Should others know you are a carrier?**

The only two staff members who felt it would serve no purpose to inform others were both black and were able to discuss openly the racial issue, (Table 30). They said there were enough problems being black, on dialysis and carriers, so they needed no more grief. One of these did qualify the No answer by saying "dentists and such should know, I guess". A substantial majority of all respondents felt others should know about it, but it was acceptable to use discretion about who was told. If they (the staff) were informed (as they already were), it enabled them to remember to be more careful around the carriers for their own protection, and to share the responsibility of the necessary hygienic practices. This question was phrased in a normative context ("Should others...") and stimulated many more of an objective type response at the level of

**Table 30. IV-4. Should others know?**

<table>
<thead>
<tr>
<th>response</th>
<th>carriers</th>
<th></th>
<th>non-carriers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>staff</td>
<td>patient</td>
<td>staff</td>
<td>patient</td>
</tr>
<tr>
<td>yes</td>
<td>2</td>
<td>6</td>
<td>9</td>
<td>3</td>
</tr>
<tr>
<td>yes qualified</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;need to know&quot;</td>
<td>2</td>
<td>5</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>no</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>qualified</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;need to know&quot;</td>
<td>1</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>no</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>don't know</td>
<td>1</td>
<td>6</td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

the general good than when they were asked things for which a subjective response was appropriate. Staff members were much better at being able to separate those occasions when different levels of response (subjective or objective) were being examined. Not
surprisingly, the staff and all non-carriers were in high agreement about others' being informed. Carrier patients were less certain others should be informed, or rather, were more certain others should not be informed.

**Question IV-6.** Should carriers be identified and told of their condition?

Only 2 disassociated patient carriers (one drunk, one uninterested and preoccupied) answered "don't know" to this question. All other 43 respondents gave a definite "yes". The most frequent answers/reasons were: "We have a right to know what's going on with our bodies", and "For the protection of others". This was one of 2 questions that stimulated a near-unanimous response. The "right to know" seems to have overcome the false security of not knowing. People who refuse to see or deal straightforwardly with a physician because they fear what they might tell them are incomprehensible to the trained staff and even most patients, today. Only an occasional person, perhaps with a minority or foreign background, may still be heard to make this comment, and they risk being considered as less than competent by the modern medical staff.

So we have, so far, a group of people who vehemently claim the right to know what is going on in their bodies. But they also claim the right to keep the information to themselves as a matter of personal choice, even if (in a few cases) it could be of danger to others. Most recognize the need for professionals to know and would not refrain from informing them — if they remembered it at an appropriate moment. They tend not to think about it outside the
esrd environment and sometimes forget to tell dentists or others who should know.

**Question IV-5.** Anyone you still intend to tell?

This set of responses showed pretty general agreement that they considered hepatitis B anything but a fit topic of general conversation. All of those yet to be told were in the "need to know" category, some no doubt stimulated by the interview. All but 2 respondents voiced the recognition of a responsibility on their part not to contribute to others' getting HB.

This degree of unanimity among all respondents tends to undermine answers to earlier questions which might have led one to conclude some informed carriers understood nothing about what they were told. Except for 2 consistent "don't know" carrier responses in these questions near the end of the protocol, they demonstrated some comprehension of contagion, virus transmission, body fluid involvement and responsibility to try to contain the disease. Unclear and incomprehensible as this knowledge may be, they are to a greater or lesser degree aware of its implications.

**Question IV-8.** Would you rather not know you are a carrier?

This evoked another near-unanimous response of "No", except for
the one (disassociated) "don't know". Consistent with IV-6 (should carriers be told — the objective form of the question) everyone felt they had a right to know, or should know in order to adopt correct behavior to protect others. Whether they would tell those whom they would protect with this knowledge is unknown for some, but at least the statement was made and shows recognition of the problem. Thus, the denials of knowledge about hepatitis B, and denials of concern over their carriernesship being a danger to those about them become less believable, although those statements at the time seem quite sincere. It is probable that this apparent contradiction is accounted for by the different contexts in which the questions were placed when they were discussed. Some undoubtedly aroused more anxiety than others, although a concerted attempt was made not to induce anxiety by the research.

Question IV-7. Can you suggest any improvements in the way you were informed about carriernesship?

It is unfortunate that during the period of greatest need, i.e., before the vaccine came into use, the least was known and understood about hepatitis B. Staff members' frustration when they were forced to tell patients "We don't know", their shock when yet another person tested positive, a patients's growing cynicism or lack of confidence in them, all contributed more pressures to a job that already contains many inherent strains.
Table 32. IV-7. Could you suggest improvements in the way you were informed about carriergship?

<table>
<thead>
<tr>
<th>suggested change</th>
<th>frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>better explanation/more information on HB</td>
<td>12</td>
</tr>
<tr>
<td>complimented staff on handling HB problem</td>
<td>3</td>
</tr>
<tr>
<td>inform promptly (before others find out)</td>
<td>2</td>
</tr>
<tr>
<td>mark every + sample going to the labs</td>
<td>1</td>
</tr>
<tr>
<td>test blood before they transfuse it</td>
<td>1</td>
</tr>
<tr>
<td>eliminate isolation units (they stigmatize)</td>
<td>1</td>
</tr>
<tr>
<td>don't imply it's our fault if staff gets it</td>
<td>1</td>
</tr>
<tr>
<td>salary continuation (now changed)</td>
<td>1</td>
</tr>
<tr>
<td>no/nothing</td>
<td>7</td>
</tr>
<tr>
<td>don't know</td>
<td>4</td>
</tr>
</tbody>
</table>

As happened in the leprosy study, (Gussow & Tracy, 1968, 1972), staff and patients together construct a kind of perspective on hepatitis, parts of which each can agree on, which allows them both to bury or ignore some of the more serious implications of the disease for most of the time.

Sometimes giving and sometimes withholding salient information from the staff is one of a number of constantly changing devices for getting attention from the staff. This differential leakage of information about oneself, or information control, is one of the major methods of coping with the problem of the presentation of one's imperfect self to the world in a bid for a recognized, acceptable status in which one can survive.

Since it cannot be surgically, medicinally or magically removed, the need to live with and cope with the problem must be faced. How to change for the better the process of informing about HB was considered at length by some and not at all by others. "What's there to say, if you can't do anything about it?" was the lament of an elderly immigrant. All suggestions for changes, whether by staff
or by patients, were for behavior or policy changes for others. The need for more and better information about hepatitis was obvious from the fact that it was mentioned many times more often than any other item. Three people, 1 staff and 2 patients, thought it had been handled well, and could offer no suggestions for improvement.

One patient and one staff member felt there had been too much of a time lapse between when the lab results came back positive and when they were informed. One staff member was extremely upset (and remains so today) by having overheard staff members from a totally unrelated agency at an area meeting discussing her/his carrier-ship when the individual had never been told he/she had tested positive. To use Goffman's (1963) term, the individual felt her/his professional image (renal tech) had been "discredited" far and wide, even beyond the walls of the employing institution, and seemed as upset by this as by the fact of carrier-ship. Because this person was a black working in a white professional world, strenuous efforts had been made to become highly proficient, and he/she had attained an excellent reputation as a renal technician. Whether or not the person's image was damaged, (and there was no indication of this from any other source), this individual, within her/his own mind, is stigmatized, and the carefully built up image has been badly damaged.

While three respondents had mentioned disliking the idea of special or isolation units for carriers, only one of them thought to bring it up when this question was asked. The other two were black
and may have believed that nothing could be done about it because they still harbored a suspicion it was done because of their race, although both claimed they had been told the "real" reason. At least 4 respondents listed in Table 30 may be assumed to be sensitive to potential stigma, and 11 to be coping by denial, ignoring or not thinking about it. But there were many more kinds of negativism and denial than just shown by these 11. They will be discussed in the next chapter on denial.

Question IV-9. Anything more you'd like to add or comment?

Only 6 people declined to respond to this question. Most had more to say at the end than they thought. As in the previous question, "more information" was at the top of the list — 50% of them mentioned it here. A technician put it this way: "Tell the doctors and nurses to have more specific information and explain it, i.e., how virus is transmitted through secretions, so we can make small decisions (rubber gloves or wash or both) on our own." Four retain the lingering suspicion that blood transfusions were the source of HB carrierness. This is emotionally such a safe explanation of how they became carriers that it seems difficult for them to give it up. This is despite the fact that by now they've long since been informed that all blood for transfusion has been checked at least twice for HBsAg. Refusal to give up this explanation is a denial of other, more anxiety-producing explanations and correlated responsibilities.

Four people pleaded in their own ways not to be stigmatized and 6 felt they could have been treated better. (These answers came from
the various units, not all from the same place.) "Treated better" seemed to mean several things: treated more individually or "specially", be more attentive when one asks questions, "act without revulsion" toward carriers, (several care-takers were observed to jump back from the patient when blood was in evidence), more understanding, "more could be done for the ease and comfort of the patient rather than the staff". Here, again, there seemed to be a collapsing of both problems into one for purposes of answering this question. Those giving these kinds of responses seemed demoralized by all the negative input about both their problems.

One of the patients who perceived the greatest potential for stigma in carriership and was most critical of the care and treatment received responded by coping in an activist manner. There was no recognition on the part of this person that most carriers as well as most other esrd patients and staff prefer to leave it all behind, once they finish treatment for the day. She spoke of a series of unsuccessful efforts to get carriers or anyone else at the unit who was interested to come to meetings to discuss changes they would like to have made. She expressed bitter disappointment at the failure of her efforts. "No one showed up."

Occasionally, a period of negativism may invade the whole dialysis unit, or a particular shift of patients at a unit. It is usually ignored until it reaches general awareness of both patient and staff, at which point various coping strategies may be tried. It may be denied by many participants. There may then be a
concerted effort to eliminate it by extra attentiveness and encouragement among both staff and patients. A small birthday celebration with diet cake, soda and coffee might be set up. The staff has attempted to organize softball games and picnics, which also resulted in poor attendance. All of the organizers, whether staff or patient, had some college training and there is some good presumed to result from these get-togethers. But as one man in his early 70's said, "I went to one of their picnics years ago, and all everyone did was sit around and gripe and act depressed. I don't need that, so I've never been since." It sounded as though he was describing the need for group therapy sessions, several small groups, to express all the negative feelings resulting from renal failure and HB carriership, where relevant, first, before any attempt is made to try for "happy" occasions like group picnics, et cetera. Motivation to attend such gatherings is lowered by the transportation problem for many patients, the fact they they cannot share their food or drink (which in most known cultures is an accompaniment to social occasions) without fear of contamination, and the fact that there is no "real point" to the occasion (e.g., meeting new people, getting new information, seeing a new setting, new or different anything). The attempts to organize softball games among the staff do not appeal to most patients because they cannot participate or are simply not interested in the first place. The organizers tend to interpret this as a personal rebuff rather than general disinterest and disability, and return to work on Monday just a little less positively motivated toward the patients than
before. It is definitely a negative communication, but it is possible it is being incorrectly or incompletely interpreted. Many of the older patients have lowered energy levels, (a fact not unknown to the staff), and are not interested in very taxing activities. Many have no means of transport, and public bus service is cut back on week-ends. Many do not like picnics or softball.

Several people felt there should be more media coverage on the general subject of hepatitis, sympathetic to the agency and patients, but one person cautioned against "off-the-wall statements that scare people". Med-alert tags for carriers was another suggestion. More recent, up-to-date information, however, was the most often mentioned.

Only one woman mentioned prayer in this final, summary question. "Look to a higher power and pray a lot. Do the best you can, then forget it." This woman sees herself as the ultimate pragmatist using all the resources she has, and is sorry others won't follow her advice because "it really works". A few other patient carriers both black and white, early in the interviews mentioned that the reason they could be so unconcerned or resigned about the totality of their situation was that they felt it was in God's hands (see Ch. III). Calling upon deity was sporadic, a fact explained by Bohnengel (1982). She found that when a patient's situation intensified and approached crisis, there was an increase in coping techniques put into use, with religion as one of these. Otherwise it was clear to patients that the staff was not in sympathy with
mystical explanations, so they pretty much kept all such coping to themselves. The staff did not so much discourage religion qua religion, but because they were afraid religious behavior would substitute for the physical self-responsibility they felt patients should take on themselves. The more autonomy patients gave up, the more responsibility for them the staff had to pick up themselves, and that was not perceived as being their job, vis-à-vis non-professional services such as checking up on dietary compliance, hygiene, getting prescriptions filled, et cetera.

Summary

This section begins with an explanation of the full operationalization of the processes suggested by Goffman (1968, 1974) and Agar (1982) for analysis of data in an ethnographic framework. To the author's knowledge, this is an original and unique synthesis as it is applied to the negotiated interactions that constitute the social milieu or environment of the hepatitis B carriers in the esrd units.

Bohnengel (1982) lists five major kinds of coping strategies used by kidney transplant patients who are also past (and often future) dialysis patients.

1. Psychologically removing self from threat.
2. Minimizing its importance.
3. Information control.
4. Relying on emotional support from others.
5. Finding an overriding order or divine purpose in life.

In the present study of hepatitis B carriersonship, finding a divine
purpose did not seem to assume great importance, although it was mentioned by a few people. Those who had large families or social networks used the emotional support they provided, but there were many who were averse to appearing overly dependent on the emotional or any other kind of nonreciprocal support of others. Both 1 and 2 above are seen in the context of this study as effects of 3, information control. The first is controlling information about carriernesship and its effects on oneself so that withdrawal from the threat may be effectively achieved. Minimizing the importance of carriernesship is another way of denying certain information about hepatitis B and attempting to fool both oneself and others regarding its seriousness and possible terminal outcome.

In-house counseling by medical staff or social workers was underutilized as a resource by esrd patients. Patients wanted more information, more answers about HB than the staff could give them, and the staff was frustrated that they did not know how to satisfy this desire or need. Yet there were occasions when information was managed both ways, by staff to patients and by patients to staff and their social networks. It was admitted by some responsible staff members that sometimes they hesitated to tell everything they knew about HB to the patients, but no one admitted they gave fabricated answers. There is always a thought lurking in their minds, admitted several higher level administrators, that a patient might sue if they felt they had a case. Two people mentioned that others had urged them to do so when they became antigen positive, but that they
didn't see any point in it. Two reasons given were first, because of lack of proof of malpractice, and second, whatever the outcome of the suit, they would still have to depend on the same dialysis staff.

Another type of incident external to the health care system from a higher level of the social structure that contributed to misunderstanding and mistrust between staff and patients occurred early in 1982. A flurry of publicity about "dialysis rip-offs" was highlighted by the media when a Federal overseer health agency made an attempt to lay groundwork for a reduction in dialysis funding, along with other health care reductions. (No more has been said about it since.) It served to upset many patients, not to mention staff, but since a fundamental tenet of the program was poorly understood by the media (patients did not pay for their treatment; a Federal grant did\textsuperscript{5}) the patients eventually came to realize it was an attempt to have them demand less costly care, but less costly only from the government's point of view. From the point of view of both patients and health care workers, it would end up being more costly financially, emotionally and medically, with the probability of higher morbidity and mortality as further effects. These were not Federal concerns because their analysis had not carried to that level, nor correlated it with any epidemiological data (if indeed any such data existed.

\textsuperscript{5} The government released cost figures that staff administrators felt were quite unrealistic concerning home dialysis, the cost and percent of success of transplants, and number of kidneys available.
Sometimes carriers would deny having been given specific information about dealing with HB carrier ship, and sometimes they showed a fair knowledge of what to do and what not to do about it. If they thought a question had overtones of guilt or responsibility on their part, they denied having been well-informed, or even at times, informed at all. Otherwise, they talked more freely about means they used for better hygiene and to avoid infecting others.

In a further effort to underplay the seriousness of carrier ship, almost 2/3 of the carriers chose not to have their families tested for the presence of HB antigen and antibody. Overall, 4 of the network members tested were antibody positive and 10 were negative for both antibody and antigen. Only 42% of all reported network members had been informed about carriers' ability to pass along hepatitis B under the right circumstances, according to the respondents. Even with efforts to minimize HB in their minds, 27 network members were reported by carriers as being worried or concerned, and 21 enough concerned to exhibit avoidance behavior toward them. There were just 13 of the total of network members (309) who showed no concern or worry or response of any kind to carrier ship information, including those who did not understand or know about carrier ship.

In another question, only 9 carriers said they informed others about the potential contagion inherent in sharing eating and drinking utensils, bathroom facilities, et cetera. There were 17 who did not talk about it or didn't know what to say about it.
There was unanimity when asked if they believed they should be
told about it, but 8 said no when asked if others should know about
it.6

Queried about anything not previously covered, many chose merely
to repeat what they'd already said earlier. Need for more
information topped the list. A lingering suspicion among a few
patients that transfusions caused HB infections showed up here, a
few people made a statement about stigmatization and a few felt they
had not been treated well. Several of these latter had had no
previous hospital illness experience prior to their kidney problem,
so they had little to use in comparing, and their expectations might
have been unrealistic — a TV image, perhaps. Several others had
had extensive hospitalization and seemed to be venting frustration.
If asked conversationally what was going well (an undirected
question), some patients could hardly focus on an answer. They
seemed more tuned to problems and coping.

Attempting to cope with depression, isolation and dependency, and
trying to foster a sense of community and brighten their spirits,
the staff attempted to organize a number of activities. Several
gatherings away from the dialysis unit were cancelled or failed
because of very low attendance and lack of mutual interests.

Some people felt there should be more sympathetic and expert
media coverage of hepatitis B and one cautioned against causing a

6. After some queries and refusals, the investigator ceased
requesting permission to interview network members. This was an
early clue to the importance of information control.
scare this way.

In this "last word", so to speak, one woman answered "prayer". Others were concerned more with matters having to do with people in daily, face-to-face contact. Anger at deity over their undeserved burden was difficult to acknowledge, and most preferred to pass on causation elsewhere.

Summary of Chapter IV

Goals

Although they come together three times a week and cooperate to accomplish successful dialyses, end-stage renal dialysis patients and esrd staff members differ in their goals and priorities. Patient care with minimum interference in their lives, and protecting the institutional structure that provides them with a setting for their job of patient care figure prominently as staff goals, this latter particularly at the higher levels of administration and responsibility. Patient goals in this system are predominantly concerned with survival and minimizing their apparent decrepitude by controlling the degree of stigmatization that surrounds their image, particularly as it is perceived by others.

Estroff discusses analyzing the cultural values that interact with professional ideology to produce the kind of health care system we have.

"Missing is a working recognition of the significant dependency needs of many community clients, and the anger, despair and frustration this invokes among their families, friends, and various social service and health care system personnel. Also lacking is proper acknowledgement of the proposals, programs, ideologies, and accomplishments of enlightened patients and professionals, who often work
together to create more culturally appropriate systems of care." (1983:4) (Emphasis in original.)

Staff members seem more conscious of working toward concrete goals than do the patients, who prefer to suppress thoughts of outcome of their condition. The general public (community) and the governmental funding agencies know almost nothing of this level of the problem. As far as carrier patients are concerned, their subjective assessment may be that they feel better or worse on a given day, but there is never a cure to anticipate at the end of the road, whether considering hepatitis B or dialysis. However, this prognosis is rarely mentioned and is treated somewhat like a taboo. The staff may objectively see it as a good day if only 3 or 4 patients had a difficult time among the dozens treated during a 10-hour shift. Patients have a lot of time for introspection on their own concerns during the 4 hours on the machines, whereas health care professionals are encouraged not to become involved on an emotional level with their chronic patients. Despite this, Lederman, a neurologist, explains, "It can be devastating for physicians...so we often either purposely or involuntarily set up some sort of wall which can be misinterpreted by patients and their families as coldness or uncaring. In my experience, physicians are actually seeking protection from a terrible feeling of frustration" (1983:13). At the same time, patients try to overcome or close this gap and become "an individual person" or personal friend to members of the staff because they need the psychological closeness of a warmer relationship than professional objectivity allows. The gap
between what the patients want or need and what the staff can give is largely uncomprehended, especially by the younger workers. Perhaps it might be better to say it is quietly ignored by both sides as a method of reaching a compromise and getting on with what needs to be done. This is a form of unverbalized, negotiated agreement.

Disease and its associations

For the most part, non-carrier responses to questions on disease correspond most closely to the more objective staff carrier responses but were little concerned with hepatitis. With 2 exceptions, non-carrier patients knew even less about HB than patient carriers (claimed they) did. Staff non-carriers were verbal in their concern with HB in degree about half-way in intensity between staff carriers and patient non-carriers. Generally, the staff carriers and non-carriers were fairly close in their responses. Not so the patients, where a large difference appeared in some responses between the carriers and non-carriers because of the anxiety or fear of stigma and rejection.

The lack of realization on the part of members of all major groups of respondents that each group and individual within a group had his or her own separate perspectives, expectations and coping patterns for disease often seemed to lead to miscommunication and hostility. That all members of a given group might not feel or believe or behave the same way about the same thing (such as an "appropriate" response to a worsening of one's condition) came as a surprise to some respondents when or if they discovered it at all.
When a physician requested that a social worker persuade and prepare a patient psychologically to enter the hospital for further needed surgery, the social worker refused to do so. Having talked at length with the elderly patient, she reported he was tired, the quality of his life and life itself were ebbing. He simply did not want to go through the pain, having to anticipate success or failure of the surgery, weakness, depression, etc., all over again after having been there many times before. He'd rather just "slip away", and she felt he had the right to so decide. She did not care to persuade him against his wishes. The physician, trained to attempt further, escalating methods to keep the patient alive was shocked and upset by both of them, but allowed the decision to stand for the time being, when he could easily have peremptorily ordered the patient into the hospital as an emergency case without consulting anyone, and let the surgeon worry about consent.

Staff and patients differ in their perspectives on hepatitis B as a disease and its degree of seriousness. Members of the staff differ somewhat with each other (physicians, nurses, social workers), and non-carrier patients differ from carriers in their beliefs, experiences and attitudes toward disease. These are the factors that comprise the elements on which one's view of the world and how to continue to survive in it are based. This leads to feelings of rejection and a degree of hostility on the part of a few patients and a few staff members toward each other, but the surprise is that these kinds of responses are not more pervasive or intense.
By and large, of those involved with dialysis and hepatitis B, the vast majority "play the game" of successful efforts, and to a large extent, they succeed.

**Effects of contagion on self and others**

Feeling responsible for having HB antigenemia and feeling anxious or fearful of its effects on themselves and others were major non-physical effects of being a carrier of hepatitis B. Because it affected everyone around them, its psychosocial effects reflected and focused on the carrier. Those, staff particularly, who were employed worried about their source of income during their recovery period. Others worried whether they would once again become employable and whether they had to inform others.

About 2/3 of the respondents reported negative feelings when initially informed about carriernesship. Over half of the carrier respondents claimed that members of their social networks responded with no or low affect, when told of the person's carriernesship status, but some of these same carriers gave clear evidence of feeling stigmatized. Though they may not have said so in so many words (although some did), defensively stating that they were not "drugies" or gay gave away the fact that they felt there was some stigma attached to hepatitis B and carriernesship.

Half reported a gradual change in how they felt about carriernesship as time passed. They became less concerned, but they also got better at dealing with their concern. Some who reported no change either had never been concerned at all, or were upset at first and still are. Mostly, their social network members reacted the same
way over time. In accounting for this gradual lessening, "Time heals all" may be appropriate, but this is also another way of denying, i.e., disallowing an unpleasant fact to remain in one's consciousness for very long.

One of the breakdowns or dissonances discovered, this time within the individuals themselves, was that although a degree of concern that they might be involved in infecting others with HB was felt by a majority of respondents, 43% claimed they believed there was low or no probability of passing on hepatitis B. The surprise is that half of these were staff members. They justified this contradiction by saying something to the effect of, "Maybe for others' but for me, because I'm so careful, the probability of passing it on is extremely low." Then how to justify their having been infected in the first place, they blamed it on the carelessness of others: needles improperly disposed of, poor hygiene, incomplete sterilization of equipment.

The other side of this contradiction is illustrated in Table 19. While denying the probability of passing HB to others, 2/3 were able to list one or more of 18 ways in which HB could infect another, and many of these were people who said chances were low or none that they, themselves could pass it on.

How responses to the same question, one version of it done open-ended and the other done ethnographically, can differ radically with the same respondents is demonstrated by III-7 and III-8. Over half answered "no" when asked if HB carriership had affected other
areas of their lives. But when asked did carrieschip cause changes in their behavior or their lives, almost half acknowledged changes in their lives ranging from minor to significant.

Refusal to embrace Federal efforts to "solve their problem" by the use of home dialysis or kidney transplants is a realistic denial of naive suggestions. More danger of contagion and a vast shortage of organs will serve to keep the dialysis setting separate from the home setting for some time to come. Staff disapproval of home dialysis coalesces with the patients', and it is difficult to predict long-term use of home dialysis.

The carriers by more than half reported members of their networks responded unremarkably to the information that their esrd patient was now also HBsAg positive. However, responses to other questions and other reported behavior discredit the apparent meaning of this type of response by so many respondents. Worry or concern and avoidance on the part of network members are the two highest frequency negative responses. Down-playing carrieschip among network members is discussed further below.

The belief by those who reported avoidance that there was a stigma attached to hepatitis B were in a sense correct. Their observations that some people physically withdrew from them were probably accurate, because people are sensitive to the affective content in the behavior of others. Fear of the ultimate rejection of their persons, and/or denial of their company and their support by relatives and friends is a powerful incentive to play down infirmity and decrepitude.
Coping: Information management as denial

Is information control a form of denial, or is denial a form of information control? The author sees it as the former, because in an interactional analysis, what is done (strategy) influences what happens (outcome). There are many kinds of denial of which, for this special problem, people have heavily used information control as a coping strategy. Of Bohnengel's kinds of coping strategies used by patients, all were observed in this study, but information control through denial is the one most frequently reported and observed.

Among other types of coping, in-house counseling was under-utilized by patients. The staff was willing, but hesitant to impose unwanted or unneeded advice and knowledge on patients.

The kind and degree of denial of having been given certain kinds of information varied with the context of the interview at the moment. The more abstract or generalized the discussion, often the more voluble was the respondent, because the subject under discussion was perceived as being removed from his/her own identifiable experience. If a question had overtones in the respondent's mind of guilt or responsibility on their part, they denied possession of that particular information.

Further denial of the importance of carriersonship status was demonstrated when 19 of 30 carriers chose not to have their network members tested for HB antigenicity. Among tested patient networks only 4 individuals were antibody positive and no one at all antigen
positive. These carriers, so far as is known, have not generated any further carriers. This would seem to justify the downplaying of hepatitis B talk within the networks of most carriers.

Whether because of curiosity or a feeling of "right to know", almost all (98%) carriers felt they should be told of their carrierness even though nothing could be done about it. Thus they demanded to be allowed to face the reality of physical facts, even though it gave them less control of their condition than they already had, and would in the near future deny most of their knowledge of it and try to forget it. Of course, they were alive due to dialysis, so they may be encouraged to believe that carrierness can do them no further harm, but is just another factor controllable by the staff and their technological hardware.

Other attempts at coping by trying to foster a sense of community through picnics, ball games, etc., were unsuccessful because the group addressed consisted of a wide variety of age/interest, SES and energy level individuals. It can be a strain to suspend "real" role behavior for a few hours to pretend "we're all just folks together".

Others (e.g., Bohnengel, 1982) have found a belief in deity a solace as a coping mechanism. Only 3 individuals spontaneously mentioned reliance on a belief system and deity, although there were probably more who do but did not think of mentioning it in the interview context because it was otherwise compartmentalized.

Denial, as the major coping mechanism of hepatitis B carriers and esrd patients, with many different manifestations for which there is a possible set of logical justifications, is discussed in some
detail in the next chapter.
CHAPTER V

DENIAL: A MAJOR COPING STRATEGY

Introduction

It may be that earlier studies which have identified denial as a coping strategy for severely or chronically ill persons, the senile, or the aged, have not recognized it in all its forms as a virtually universal human response to their condition and life's impending terminal outcome. It may be far more important than has heretofore been recognized. As the label of a category of behaviors all directed toward survival, this study considers denial as a major coping strategy found in many cultures (Glascock, 1983). This should not be taken to imply, however, that the specific findings or conclusions of this study should be freely applied to other groups, even within our own society.

In Bohnengel's 1982 study of coping behavior in a kidney transplant unit, she found 16 types of coping behavior among her sample of 17 patients, and all used more than one type in combination with others. It is difficult to classify and generalize about response behavior when observing individuals in more depth and detail. Her findings included the fact that the greater and more immediate the threat (such as the body's rejection of a transplanted kidney), the wider was the variety and the number of coping strategies used by the patients. She concluded that coping styles
depended on severity of threat (problem), types of strategies available, and the nature or personality of the individual. Although Bohnengel's theoretical perspective is somewhat different than that of the author of the present study, her work was useful in dealing with some of the data involved. Her study was done in a crisis context, full of suspense as to whether the transplant would be a "take" or a "reject", and the responses of the patients tended to build to a peak and then subside. Chrisman (1982) discusses the subject in a non-crisis context.

By way of contrast the hepatitis B carriership research was done after the emotional peaks or crises had occurred, i.e., after they had been told of their renal failure which necessitated dialysis for the rest of their lives (barring a successful transplant), and after they had been identified as HB carriers. Since the diagnoses of both the renal failure and the HB carriership were in the past and they had been living with the knowledge of the antigenemia problem for some time (range: 9 months to 12 years), coping strategies were by now fewer and more cohesive, and similar ones were more widespread. Some people proselytized for their own technique(s), but not very vigorously.

A typical, generalized, historical sequence of events might run as follows. Patients are diagnosed as having renal failure and are told they will have to go on renal dialysis for the rest of their lives. Patients begin early in the unit after preparatory surgery, and begin to settle down to a new life style. After a period of time, one day a staff member, either a nurse or a physician, comes
to their dialysis station and informs them they have contracted hepatitis B and their blood carries a factor that can infect others. They are instructed about special hygienic measures to protect others, and they go home and consider the problem. Depending on how much of what they were told they understood, and how they felt their families and friends would respond to this new knowledge, they did or did not mention it to others. If they did, they carefully observed the responses of their intimates to the knowledge and interpreted it as negative, positive or neutral. Since most of them had no symptoms and felt no different for having been informed of their carriernesship, it was difficult for them to remember all the strictures which had been placed on their behavior by the staff member who informed them. Some noticed subtle changes in behavior toward themselves by family members and friends but others did not.

Now and then, in the dialysis unit, someone on the staff would remind them of the precautions they should be taking, and now and then they heard of someone who caught hepatitis B from one of the carriers in the esrd unit. Anxiety over contaminating others, and the fear of being avoided or rejected by them caused the carriers to belittle or ignore or deny the potential effects of hepatitis B as well as its seriousness. They withheld information about the disease from their friends and families and tended to mention it rarely, if at all. By and by a few remembered the hepatitis as being distinct from renal failure, and if no one at home caught it, it was all but forgotten. Staff members had to remain more aware of
HB, especially if they were one of those who had contracted it, but once they recovered from the symptoms, most of them assured others that they were fine, or that they felt better every day.

By these devices, both patients and staff members lowered the visibility of the disease in the unit, whereas the professional nursing staff simultaneously attempted to keep some level of awareness of contagion present in their consciousness, particularly when they were in the dialysis unit.

Eight carriers reported HB antigenemia a moderate to major concern and 22 reported it to be of minor concern or none at all in response to a direct question on the subject. However, these answers, compared with other responses such as perceived degree of risk of contagion of others, how much their life-style had changed and in what direction as a result of their infectiousness, and how others reacted to them did not always show congruence. Being "cool" about it, understating or even denying any problem came so routinely that it seemed to be an institutionalized response, mostly, but not exclusively, given by patients. The same person would enumerate several ways he or she acted in order to avoid exposing others, and then deny concern over the infectiousness of hepatitis B. This type of dual response was consistent in other contexts, also.

In the context of this study the multi-level manifestations of the various types of denial may be grouped into three categories.

1. Denial of disease etiology information.
   a. Blaming their HB on blood transfusions. Refusal to give up the transfusion theory of how they acquired the infection denies
other, more anxiety-producing explanations such as being the fault of themselves, their care-takers, or God's allowing it to happen.

b. Denial of contagiousness. 43% said no or low probability of contagion.

c. Knowledge of the danger that others might infect someone, but denial of possibility that oneself might do so.

d. Resisted thinking about consequences of HB, i.e., liver damage, infectiousness, morbidity, mortality.

2. Denial of responsibility and other consequences of HB.

e. Collapsing hepatitis B and renal failure into one problem that the machine, the staff or God takes care of.

f. Sloughing off the responsibilities for certain kinds of hygienic practices, such as contact with others, and hygiene for dialysis.

g. Denial of stigma in the wider society, but behaving as though it just might exist and avoiding it.

h. "Time heals all" attitude. A gradual lessening of concern about carriage.

i. Did not inform or fully inform network members about consequences of HB or carriage.

j. Were rewarded by staff for unrealistic denial of physical or psychological problems. The power of positive thinking.

3. Denial considered realistic by both staff and patients.

k. Refusal to consider either machine or continuous home dialysis, or kidney transplants. Comparing the choices, they showed
little inclination toward an unknown outcome at the price of far more responsibility and the involvement of their families.

Denial as a coping strategy is not new. Freud discussed it as repression, a major defense mechanism, around the turn of the century. De-Nour (1971) summarizes a number of authors who report it in the medical context. Twaddle (1980) discusses it within the theory of social identity. Under learning theory rubric, Bohnengel (1982) considered it as a coping strategy based on the belief in an external (or environmental) locus of control. Goffman (1963) listed three kinds of coping mechanisms used to deal with stigma, two of which are of importance in this study. They are listed in the framework of this research.

1. A direct attempt to correct the objective basis for the failing (i.e., plastic surgery if you have no nose) is not applicable here. There is no drug or procedure in current use that rids the human system of the hepatitis B antigen (IPAC-CDC, 1983). The new vaccine protects only those who have never been exposed, who are both antigen and antibody negative.

2. By devoting much effort to mastery of areas of activity ordinarily closed to those with this stigma. A few younger carriers are staff workers, but most of those in this study are also dialysis patients, over 40, and many are subject to other ailments (cardiac, diabetic) which are debilitating in themselves and disallow much physical activity. Younger patients and staff are more inclined to use this strategy by continuing to work and lead a more or less normal life.
3. The third of Goffman's categories is the one of most relevance for this study. Carriers break with reality and attempt to employee unconventional interpretation of the character of the potentially spoiled or discredited social identity. Such techniques of information control are varied and widespread among carriers, but all have as their objective the denial of a problem. In the face of two threats, the more overwhelming one tends to set the dominant response pattern (Bohnengel, 1982). Dialysis patients have learned to deny problems resulting from dialysis, and now they use the same familiar strategy to deal with the lesser evil, hepatitis carriership.

Interviews established that most carriers are aware that the potential for infecting others with HB is a serious problem. Supervisory staff states they have all been informed about it, but some seem not to comprehend the full import of the information. Their responses as to how they think they contracted HB, what they should be doing to avoid giving it to others, and how long they expected to have to deal with the condition all indicate knowledge of some sort about HB carriership and its being any kind of a problem. Why do they deny what many of them know is a serious problem?

Denial is obviously a highly successful coping mechanism that must lower anxiety in some way. Goffman suggests some gains from information management (telling others there is no problem) such as protection from social reality, escape from competition and excuse
for lack of success. It also maintains a protective distance between the self and others. Additional kinds of patient gratifications are discussed further, below. Considering this behavior as a negotiated interaction, as far as the health-care staff are concerned, they may be viewed as gaining the reward of goal fulfillment. They are successfully teaching and caring for the patient with the minimum of interference ("no problems") in their lives.

Most of the studies that identify denial as a major coping mechanism are written from the point of view of the health-care worker or the research scientist after having scarcely spoken with the patients. Most of these studies are grounded in a psychoanalytical, conflict, locus of control-learning theory, or structural perspective. But as Mauksch (1973), Katon & Kleinman (1980), and many others by now have pointed out, the patient's perspective must also be included in order to obtain a fuller understanding and possibly to explain some of the earlier published contradictions. The patient is, after all, as much a participant in the interaction as is the staff or the audience (research scientist-observer). The health-care worker is as dependent on the patient's share of their interaction as is the patient dependent on medical staff to oversee that the care they have agreed on is being carried out. Patient noncompliance would frustrate the staffs' achieving their goal of care and rehabilitation.

The environmental situation (or phenomenological context) on a given day may influence everyone's responses and therefore may not
be overlooked or ignored. On more than one day the research scientist arrived at the dialysis unit to be met with some variant of a negative statement of all the things that had been going wrong. On these days everyone seemed to want to communicate, if only to use the interview as a welcome distraction.

Another level of interaction also to be considered is that within the family and any others who may be involved (from the patient's perspective) in their primary care, not as a hands-on medical professional or paraprofessional but in an institutionalized responsibility role. Spouses, offspring and other relatives, social workers and financial benefits overseers such as welfare or insurance agencies would comprise this category. From a patient's despairing cry (before anyone else can say it) "I'm a burden to everyone. Good for nothing anymore but to sit or lie around. Why can't I just die and get it over with?", to a relative's or bureaucrat's unvoiced agreement with this sentiment, a psychosocial-economic perspective is also to be recognized and entered into our considerations.

Another factor in the formation of a perspective (or belief system) about their physical condition that would lead to what De-Nour (1971) called "massive denial" is Goffman's societal norms, and their input as patient-perceived social sanctions. Gussow (1972) found that the attitude of the general public toward leprosy stigma was rather low in affect; in fact, little different from the response to any other contagious disease such as
colds, influenza, tuberculosis, et cetera. In order to discover whether this same attitude prevails today toward hepatitis B in the perception of the general public, a small pilot study was conducted. (See Appendix C).

The results were similar to Gussow's, i.e., almost 90% of the persons interviewed were not afraid of contagious diseases intruding their daily lives. Over 3/4 were not concerned with getting hepatitis B. In addition to the survey of the general public, a surgeon and an intern evidenced concern which later diminished rapidly in both cases after HB vaccine became available.1 Carriers say they tell few people about their carriership because they do not want to be blamed if someone in their social network becomes infected with HBV. While denying concern, they enumerate many ways in which they try to avoid exposing family members, especially young children. Off guard, their anxiety or fear is apparent; but questioned about it directly, it is denied. The social stigma of being blamed for others' contagion is an ever-present fear. The evidence for this is that 2/3 of the carriers report some kind of affective, negative response to their HB carriership when they informed their families, friends or colleagues, but which they mostly denied if directly asked, "Did others make you feel bad when you told them?". (If question IV-2 did not elicit an answer this was an alternative directed question sometimes used.) Along with

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1. One wonders whether these results from March, 1983, would be the same in late 1983 and 1984, since AIDS and herpes have received so much attention and brought contagious "new" diseases into the public awareness.
the statements of others' reactions, most carriers would end their statements by declaring that most responses of others to their condition were positive or neutral in character, thus reassuring themselves there was no stigma. However, question IV-2, Table 25, shows 55 network responses that carriers could consider negative were they so inclined, 48 positive and 10 neutral in spontaneously generated answers to an open-end question about network members' reactions to knowledge of HB carriernesship. This result may establish an argument for carriers' believing they perceive a social stigma, but not that one is in reality very widespread with respect to HB.

Examined case by case, the degree of consistency of carriers' replies depended on their individual personalities, the context in which the subject was introduced, how they felt that day, and their attitude as a cumulation of these factors. Other, subtler factors such as time of day, month or year, weather, hunger, thirst, degree and kind of medication also affected their attitude on a given day. But for some, denial, even refusal to discuss the actual or potential effects of HB, was their consistent way of coping with the problem, wherever it arose. Even the two carriers who refused staff members' requests to participate in the study did so by declaring they had experienced "no effects" from hepatitis and therefore could not contribute anything to the study.

Since denial of the importance or significance of their condition is widely reported for patients with various kinds of chronic illness (Gussow, 1968; Mechanic, 1968; Beard, 1969; De-Nour, 1971), a creditable explanation is needed for the process by which denial
is the coping strategy used spontaneously, widely, and presumably, successfully, by so many in disparate circumstances. When members of the dialysis staffs were asked to discuss the frequency and meaning of the denial of the effects of carriergship, they admitted that denial was a problem in dialysis, also, that sometimes led to noncompliance with diet, fluid and medication requirements. Their favored explanation was that patients were subject to "information overload" in coping with the problem when it arose. Patients in the early days of their dialysis fail to distinguish between renal failure and carriergship as separate conditions, but think of hepatitis antigen as one more impurity in the blood that is being eliminated by the treatment machine. Another explanation offered is that of simple forgetfulness.

It is here suggested, however, that two other factors, both interactional but at somewhat different levels of analysis, should also be considered:

1. How denial is generated or learned and retained as sanctioned behavior by the individual.

2. Glascock's recent (1983) insight into an aspect of sociocultural triage, which produces strong motivation for coping using denial strategy.

Learning denial as a negotiated interaction.

Mauksch (1973) reminded us that behavior in the presence of others is interactive; or as Watzlawick et al (1967) put it, one cannot not communicate when in the presence of others. Depending on
the nature of the expected outcome, an interaction may be intense or
down-key. With the expectation of a gain or reward the behavioral
negotiations can become spirited. For example, a patient is greeted
on arrival at the dialysis unit with smiles and verbal kudos, then
still feeling good a while later during the interview, they may
answer "I don't have any problems". When a staff member,
overhearing the exchange, turns and beams and nods or gives a
thumbs-up signal to the patient, they are non-verbally rewarded to
deny to outsiders any and all problems due to their overall
condition. The staff member, of course, is using "the power of
positive thinking" in the belief that it encourages the patient —
which it may well do. But an unintended consequence of this
behavior is to encourage the patient to view her/his situation
somewhat unrealistically, thus putting off mentioning a symptom or
occurrence that should have been reported to the physician.
However, the staff behavior described is consistent with their
professional goal, namely, medical intervention with maximum
retention of rehabilitative powers and minimum interference in
patients' daily lives (Barker et al, 1978).

Staff and patients together write the script and the scenario on
how they will agree to behave in both stereotypical and unique
interactions. Each time the situation has similar elements, they
embellish the low-key or denial response so that in time it becomes
the usual or socially expected response within that environment.
(At home the "party line" and role-playing style may be quite
different.) A supervising physician readily admitted to "malignant
underplaying" of problems with HB in an effort to get everyone to "think positive" for the promotion of the mental health of both the staff and the patients.

Sociocultural definition of the economic cost of life.

Whether due to lack of knowledge, lack of funding or lack of facilities, not everyone whose life could be extended by the application of state-of-the-art Western medicine is in fact able to be treated for their long-term survival. How each culture manages these triage decisions through social processes is of interest here. In a recent article in the American Anthropologist Glascook (1983) makes an important observation vis à vis this question. He discusses sociocultural definitions and rules for death-hastening behavior which are present in most societies, from the simplest to the most complex. He observes that such rules are not directed, for example, at all old or crippled people but only at the decrepit. This term contains much of the semantic content of Goffman's "discredited" people, those who have a disparity between their apparent social identity and their actual one. For example, carriernesship is not outwardly apparent. Glascook shows that this intact/decrepit distinction is present in many societies, but the idea has simply never been taken up and investigated since Simmons articulated it in 1945 and 1960. Decrepit refers to individuals who are incapacitated to the degree that they become living liabilities. In our society we agonize over "pulling the plug" or "benign neglect" while in other cultures there are withdrawal of food, water
or attention, things which are not sanctioned here, but occur only as accidents. Recently U. S. courts have begun to take a greater interest in requiring all possible efforts to be expended to keep alive those who want to die, or who in other countries would be allowed to die, if not hastened along their way.

It is intriguing to speculate about an economic sanction of this sort as a universal sociocultural phenomenon that reappears or remains functional generation after generation in small as well as large sociocultural systems. In the 1980s the U. S. courts (and the Federal Administration) seem to feel that the doctors and families of decrepit people are no longer competent to decide among themselves when is the proper moment to discontinue life-supporting devices and practices. Hubble reports that in the 1960s in Seattle, (known as "the home of dialysis"), an appointed committee composed of people from all walks of life had as its sole function to decide who among the dozens who suffered from kidney failure were going to be the ones favored by allowing them to be dialyzed on the few, prohibitively expensive machines which were than in existence. Articles in print and other types of press coverage of these committee members at the time were chilling. Some of the variables they had to consider were age (no one over 45), and no one with any other health problem. Such questions as who would be more productive for the future in society, a teacher, a doctor, a minister or a newborn baby, had to be asked and somehow answered. (Hubble, 1969) Knowledge of the necessity for such questions and decisions disseminated to the general public rapidly brought about
the demand for funds to develop better and cheaper machines and techniques for dialysis, as well as federal intervention to pay the costs for everyone needing the service. The federal government in 1983 "leaked" a press release purporting to cut back on the funding for this program, but has not as yet done anything about it. At least one local television station, getting their facts wrong, did a feature on the "dialysis rip-off" of patients, when the patients were not paying — the government was, which may have been the whole point to the propaganda. Hepatitis B vaccination for high-risk groups is also currently government funded.

Since they are already all too cognizant of the thin edge that dialysis gives them between being considered intact and decrepit, there is little wonder that the additional burden of hepatitis B antigenemia makes carriers fear decrepitude even more than when they faced only esrd, and declare unrealistically on many occasions, "I have no hepatitis problem. I'm just fine."

Summary

Deeper insights and broader understanding of stigma phenomena could be gained in several disciplines by modifying existing concepts considering why and how important coping strategies are learned. Twaddle (1980) suggests allowing patients to participate in decisions whenever possible.

A major conclusion of this study is that while some evidence for stigmatizing hepatitis B carriers seems to exist, primarily in the social networks of the carriers, the stigma is more important in
carriers' minds than it is a reality in our society. It is not
difficult to imagine, however, the terror felt by the chronically
ill and the aged, as well as the debilitat.
CHAPTER VI
SUMMARY AND CONCLUSIONS

Purpose

Carriership and its effects on those who harbor the disease has been largely unstudied. This research was undertaken in order to gather information on the perceptions, beliefs, knowledge and behavior of hepatitis B carriers and to use this information to extend the limits of knowledge about carriership. Whether HB carriers should in some way be restricted for the protection of the general public was a question that helped define the study. In 1980 the answer to this question was not as obvious as it became two years later at the end of 1982 when HB vaccine became available. People in high risk groups worry much less about contracting the disease now that they may choose to be vaccinated. There is still interest in those who are already HB carriers because there is no cure for them, nor for those who carry many other virus diseases, and this study will contribute to that literature.

There was also the intent to test hypotheses about certain demographic and derived variables against carriership suggested from other studies. The small sample, however, restricted the amount of information from this source.

Theoretical Approach.

There have been few studies on carriership and only two on hepatitis B which focused on its effects on the carrier, both of
which were very small samples. There is no conventional social theory that covers the subject.

The umbrella perspective for the research is the interactional approach as discussed in all its levels and interdigitations by McDermott and Roth (1978). In a less dense text, Bock (1980) explains how the levels of the theory interrelate. The interactional component of this perspective is discussed by Goffman (1963, 1974), Watzlawick et al (1967) and Agar (1982). Good and Good (1980), Eisenberg & Kleinman (1980), Mauksch (1973), and Mechanic (1980) all discuss related ideology and negotiated interaction in hospitals and Glascocks (1983) suggestion of a widespread human response to infirmity were valuable in clarifying the learning of and the meaning of certain behaviors.

Methodological Approach.

The strictures placed on this research by an accumulation of federal and local agency rules, as well as by anthropological ethics, played a role in reshaping the study into its final form. A mixed interview technique of directed, forced-choice and open-end questions, along with observation of the principals in interaction in the health-care agencies were utilized for gathering data. Means and frequency tests were used where they yielded understanding from the 30 carriers and 15 non-carriers interviewed. Much of the interpretation and understanding of the meaning and outcome of interactions, however, came from observation and informal discussions.
Results.

The greatest difference in attitude and perspective on hepatitis B carriership was shown to be between staff and patients. Carriership itself, as a variable, differentiated carrier patients clearly from both staff carriers and non-carriers, staff and patients, but other variables yielded less information and were not as predictive. Carrier patients exhibited less knowledge of hepatitis B and carriership than staff, ignored their condition more, and denied more often that it was of serious consequence. The staff carriers were concerned about it, but rather than deny it they tended to observe all reasonable precautions. Most staff carriers seemed to harbor some residual guilt for having contracted the infection.

Carriers used various kinds of coping mechanisms to deal with their carriership. The use of disposable utensils, separate linens and toilet articles, restricting social activities including sexual intercourse, avoiding the subject and the denial of any or all associated problems were typical. Staff members' coping took the additional form of worrying about and being extra careful of contamination of others, as well as strong reassurances that they, themselves, were of very little danger to others. Staff members had a somewhat clearer picture of how they contracted HB, and most had 2 or 3 guesses as to what kind of incident was responsible. Patient carriers were much less clear about the source of their infections and blamed it on transfusions and dirty equipment. The staff could give no specific instances of how patients were infected but assumed
it was a breakdown in sterile technique or hygienic preparations between successive patients. Members of 3 patients' families contracted the disease, and more cases were reported about patients no longer in dialysis but these latter were not included.

Before the availability of the vaccine, incidence of antibody positive staff and patients in esrd units (pooled) was about at the national average, although the incidence in the local general population at the time seemed to be well below the national average. When the vaccine came into use after which there were no new cases expected in the units, it was impressed on HB carriers that while nearly everyone in the esrd units was vaccinated, they still needed to be cautious about public facilities for the protection of the rest of the unvaccinated, vulnerable world.

Some evidence of stigmatization was reported, and the greatest anxiety about being stigmatized and ostracized was among those carriers who were employed (staff members), young singles and those parents and grandparents with young children in their social networks. Because of the interplay of many factors it is not possible only to characterize physical contact and contaminated equipment as predictors for contaminating others. In the esrd units, improper or careless disposal of contaminated equipment and equipment failure can hardly be blamed on the luckless individual, patient or staff member, who becomes victimized by a systems breakdown or someone else's momentary lapse of attention. And it could be unendurable to avoid intimate behavior for the rest of
one's life.

That fear, anxiety or concern over their condition was both expressed and denied, often by the same people in different contexts, is well documented. Several even tried (unsuccessfully) to change jobs. Before it could become overwhelming, the victims of carriership would begin a systematic approach to coping with the situation by using familiar techniques they learned to use when coping with renal failure, and they once again (mostly) proved successful in the short run. Controlling how much and what kind of information others knew allowed carriers to feel they were in control of the situation and were lowering the affect of any negative reactions that others might display toward them. It is difficult or impossible to assess how much of this behavior is at or below the threshold of awareness. Members of the staff disagree on this point, some declaring the patients know very well how they can "manipulate" certain people and not others, (Twaddle, 1980) while other staff members believe patients are more naive and behave spontaneously. Denial of difficulties of one sort or another was observed many times over. Learning to use the many forms of repression or denial, out of fear of being ignored or allowed to die by society (if federal esrd funds are cut, as was threatened early in 1983) are viewed as the major factors in the employment of denial as a coping strategy. A benign, negotiated conspiracy of silence at times seems to bind the tongues of those victims who carry this fear, which is also shared by many other chronically ill patients, particularly those with visibly degenerative diseases (Gussow and
Tracy, 1972). Only a few, elderly patients extremely limited in their activities were able to communicate some part of this thought of being given up or cast aside by society.

Contributions of the study.

1. This research continues the efforts of Goffman, Kleinman, Good and Good, Agar, Mauksch, McDermott and Roth, and many others to synthesize anticipatory behavior sequences. The concept of reaction to social stigma was used to arrive at a way of linking beliefs, behavior and outcomes for this study, and situating it in its sociocultural setting, Midwest U.S.A., 1980-1983.

2. Extensive ethnographic description, discussion and examples of those aspects of the "culture of carrierness" observable in a controlled environment, i.e., end stage renal dialysis centers, provided.

3. Several scales were developed for measuring degree of concern, response and level of understanding. The degree of response scale was the most useful, but it needs revision and to be tested on a much larger sample in order to assess its full efficacy.

4. A combination of factors was used to analyze and give meaning to the behavior observed: a. goals, b. coping behavior to achieve those goals, and c. the subjective meanings of terms (disease, contagion, hepatitis) relevant to carriers' problems and how they influenced victims' and care-takers coping behavior. Situating the study in a specific setting, dialysis centers, offers a framework for audience understanding of the coping strategies of a group of
people with a unique set of medical and social needs, and contributes to the medical and social science literature and knowledge of chronic illness.

5. Denial is suggested as a, if not the, major defense or coping strategy by the chronically ill because of fear of a fatal rejection by both their personal social network and by an unfeeling, uncaring society.

Applications of this study.

Insight into the patients' point of view have been operationalized in one of the large units. The following statement by Alexander (1980) brought to the attention of the care-taking staff contributed to broadening their perspectives about why the patients sometimes behaved as they did.

"Hypocrisy, sham, and the sustained discrepancy in our premises about cure and care are ultimately the most powerful of pathogens. One can live with a disease if its treatment does not require deceit or paradox. One may also live with failure to cure, if the objective is the maintenance of congruent, meaningful interpersonal communication. If both patients and practitioners maintain congruence as a communicational ethic, they share in the healthiest of objectives." (p.327)

Emphasis was placed on the importance of opening or broadening lines of communication between all levels of participants so that the patients felt reassured when they were having a bad day. Closer and more frequent contact during the course of dialysis sessions was encouraged. Down-playing authoritarian approaches with patients and increasing positive interactions encouraging autonomy were recommended.

At some time in the not-too-distant future, because of the
emergence of newer exotic diseases, hepatitis carriers may well begin to feel that time and medical technology have passed them by. Because they lived at a certain time in a certain place and were subjected to certain conditions, they carry a disease that no one need contract anymore. Whether present or future research will find a way to "decontaminate" HB carriers, fewer and fewer people will be interested in their problem as time passes, and they will become living anachronisms.

The humanitarian thing to do would be to honor their wishes and do as little as possible to remind them of their situation which is no longer so perilous for their associates. Yet they must be cared for, supported and counseled as needed, not in the "surveillance" manner described for the United Kingdom by the Edinburgh author, Sharpe (1966), but in the spirit more of the hospice, cherished and cared for by those responsible for their survival. Allowing the patients as much autonomy as possible in coping with their very serious health problems may be a more difficult approach to their care than a traditional, authoritarian approach for busy professionals. However, it has been shown to be the better one to elicit patients' compliance in cases in which their cooperation is indispensable for their survival (Kleinman, 1980). They need to be motivated by knowing that someone cares whether they live or die.

The more depressed or anxious carriers might be encouraged to attend conveniently scheduled small group sessions, at first to ventilate their feelings about their place in society, their fears
of dying, and the like. Later, they could evaluate various strategies for survival that could enhance their life style. The groups should remain small, be carefully constructed and have a leader or leaders sensitive to the concerns of that particular group. The leader could take the opportunity from time to time to encourage maintenance of good hygienic practices for the protection of those in their social environment who are unvaccinated. As with end-stage renal dialysis, hepatitis B carrieryship is also something they probably will have to deal with for the rest of their lives.

Questions and further research suggested by study.

1. The association between behavior and the spread of infectious diseases needs further exploration. How the world-view of patients and staff members, which includes beliefs, values, attitudes, and perceptions, influences behavior and outcome of disease is a critical area that needs further interdisciplinary examination. What kinds of information are most contributory to a positive outcome for a) staff and b) patients? When in the course of treatment is the most effective or salubrious time to impart such information for the most efficacious results? At what rate of speed should the various topics be covered? Who should do the informing and what methods should be employed for greatest understanding?

2. What motivating factors aid or inhibit putting knowledge of disease etiology to effective use by patients and staff, and what factors enhance it? Further research into specific, current goals of patients and health-care workers could examine in greater depth the disparity between the interpretation of the meaning of symptoms
as differentially viewed by care-takers and patients, extending the work of Good and Good. Gaining the confidence of both groups and using a minimum of authoritarian symbols (white coats, technical vocabulary, etc.) is essential so that respondents answer full and openly. Only with full cooperation can the results of such research be utilized for practical application of the results and an expected positive outcome.

3. A large sample of at least 500 people who were experiencing or who had experienced the long-term effects of incapacitating diseases should be chosen to participate. A forced-choice questionnaire that would elicit ratings by respondents on subjects such as demographic and perceptual variables could be combined with depth interviews of these individuals to ascertain their beliefs, attitudes and goals with respect to their disease experiences. After being coded the responses of the two parts of the questionnaire from each individual would be tested for association and the results evaluated for degree of explanatory power. These preliminary statistics could be further tested for clues to further questions to ask. Separate, large samples for victims of hepatitis B, AIDS, herpes, CMV, etc., should be used for comparison of significant factors across various diseases to investigate whether any of the factors are shared in common.

With the recent press announcement (April 23, 1984) by the National Cancer Institute and the Department of Health and Human Services of the association of a leukemia virus with AIDS infections
(Gallo, 1984), the study outlined above would have broad implications. Combining similar studies from other countries that are experiencing epidemics of other viral diseases (e.g. Lassa fever) could lead to important new insights not only for the biomedical control of such diseases, but also suggest more possibilities for studying and controlling these diseases, worldwide. The history of studies on kuru in the South Pacific and its association finally discovered with anthropophagy is one of the more spectacular, successful associations between infectious disease, medicine and ethnography.

4. Determining where to go and how to choose and get sample populations nowadays for broad-ranging studies would itself be a contribution to all the interrelated sciences which would participate in and benefit from the research. Techniques for gaining entrée into countries with difficult access would need to be explored.

5. Illumination of the issue of whether the stigma of infectious diseases which have lasting consequences is viewed in ways similar or different than the ways they are experienced in the United States, or indeed, if there is even a stigma attached to them, would be of interest to the various participating disciplines. Finally, the extent of stigma experienced by persons with other kinds of handicaps might also be considered cross-culturally together with coping strategies developed to deal with them.
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APPENDICES
APPENDIX A

OUTLINE OF INTERVIEW TOPICS (PROTOCOL)

I. Demographics

1. Date
2. Agency
3. Respondent #
4. Gender
5. Age
6. Race/Ethnicity
7. Birthplace
8. Years of education
9. # generations in U.S.
10. Occupational experience
11. Residence
12. Income
   1) up to 5000 2) 5-9999 3) 10-14999 4) 15-19999
   5) over 20000 6) unknown
13. Marital status
   1) never married 2) married/living together
   3) separated/divorced 4) spouse deceased
14. Social network
   a) household (list each separately)
   relationship age sex
   b) Family of origin (list each separately)
   relationship living/dead age residence major illness
   c) Other: friends, co-workers (list each separately)
   status to ego age sex
15. Kind of carrier: normal/healthy active/chronic
16. Major illnesses
17. Military service
   when where how long occupation

II. Elicitation of semantic domains: definitions, knowledge, state of mind, counseling

1. What is hepatitis?
2. Have you ever heard of HBsAg?
3.* How were you identified as a carrier? [All answered by blood test in health-care agency. Question not useful.]
4.* a) Date informed? b) By whom? c) What was said? [a and b not useful]
5. How do you believe you became a carrier?
6. What does being a carrier mean? How long will it last?
7. How did you feel when you were told you were a carrier?
8. Do you still feel this way or have your feelings changed since then?
9. What did you know about hepatitis before you became sAg+?
10. What have you learned since? Do you think you know enough?
APPENDIX A    Interview     Page 2 of 2

11. Have you been offered or given counseling about hepatitis?
12. Have you ever wanted or requested counseling?

III.  Contagiousness:  effects on self and others

1. How do you view the probability of passing on hepatitis?
   1) very high  2) high  3) moderate  4) low  5) none
2. Specifically, what kind of things can you do that might pass it on?
3. Where in the body does it occur? What parts are affected?
4. Were the topics  a) risk to others and  b) preventive measures ever discussed with you?
5. Do you think this has affected your health? Did you have HB symptoms?
6.* Date of most recent blood test.  [The agencies routinely run tests monthly, so this question was of no value.]
8. Have you changed personal habits, your interactions with others, or restricted your activities since you became a carrier?
9. Has being a carrier been a major, moderate or minor concern for you?
10. Has anyone you know been tested for HB?  Before or after you became +?

IV.  Information management:  how others responded and what was done about it.

1. Besides the dialysis staff, name the persons who know about your carriership.  (List separately.)
2. For each one listed:  What was their general reaction?  What did they say or do?
3. What do you say when you explain it to others?
4. Do you think other people should know about it?  Who?  Why?
5. Is there anyone you still intend to tell?
6. Do you think carriers should be identified and informed about their condition?
7. Is there any change, improvement you would like to suggest in the way your being informed about carriership was handled?
8. Would you rather not know that you are a carrier?
9. Is there anything about any of this you would like to add or comment on?

* Questions deleted after study begun because all answers are similar or identical due to routinized procedures, and are therefore non-variables.
APPENDIX B

DEGREE OF RESPONSE SCALE (DOR)

Each item counts as one response
The total number of positive responses (above the asterisks in each section) minus the total number of negative responses (below the asterisks) is the degree of response.

I. Social contacts restrictions.

1. Changes or quits job without being fired or suspended.
2. Does not have sexual intercourse because of HBsAg+.
3. Does not live with anyone else because of HBsAg.
4. Does not eat with anyone else.
5. Refrains from hugging, shaking hands, other bodily contacts.
6. Restricts social contacts.
7. Refrains from kissing.
8. Is selective of &/or limits number of sexual partners.

* * * * * * *

9. Is not selective or restrictive of sexual partners.
10. No restrictions on kissing others.
11. No restrictions on social contacts due to HBsAg+.
12. Engages in intimate physical contact such as hugging, holding children on lap, etc.
13. Visits overnight in homes, or travels with others, shares swimming pool.
14. Remains in job with high physical contact with others.

II. Hygiene.

1. Uses disposable utensils.
2. Washes hands a lot - more than others doing same job.
3. Does not share linens, toilet articles, utensils.
4. Avoids use of public facilities - toilets, drinking fountains, etc.
5. Uses separate sanitary facilities.
6. Cares for own cuts and sores.
8. Uses or requests use of condoms during intercourse because of fear of infecting others.
9. Uses rubber gloves when working with patients, or in lab with + samples.

* * * * * * *
II. Hygiene. - (Cont'd)

* * * * * * * *

10. Staff: never uses rubber gloves. Patients: rarely wash hands.
11. Does not use or request use of condoms during intercourse.
12. Does not clean own bathroom, do own laundry or wash own dishes.
13. Asks another to treat or dress cuts, sores, etc.
14. Frequently uses public facilities: rest rooms, drinking fountains.
15. No separate use of eating utensils, glasses, etc.
16. Shares linens, toilet articles, cigarettes with others.

III. Information management.

1. Informs potential employers of HB carrier status.
2. Informs others about HBsAg+ without real need to do so.
3. Informs those performing personal services about carrier- ship.
4. Informs sex partner of carrier- ship.

* * * * * * * *

5. Tells no one about carrier status, even those (outside dialysis unit) who perform personal services or health care.
6. Does not inform sexual partner of carrier status.

IV. Fears, anxieties.

1. Reports being avoided or stigmatized by others or feeling guilty.
2. Expresses fear of being shunned, isolated, stigmatized, but does not report actual fact of having had it happen.
3. States fear of being blamed by others for spreading HB.
4. Expresses fear of lingering physical consequences of HB or carrier- ship.
5. States fear of infecting others.
6. Worried about losing job, source of income.
7. Gives evidence of being avoided or stigmatized; mentions isolation on dialysis machine.

* * * * * * * *
IV. Fears, anxieties - (Cont'd.)

* * * * * * * * * * *

8. Denies HB is/has been any kind of problem.
9. Denies ever having been avoided or stigmatized over HB.
10. Expresses no concern about isolation or stigmatization.
11. Denies (or expresses no) concern over possibility of infecting others.
APPENDIX C
RESPONSE OF GENERAL PUBLIC TO HEPATITIS B CONTAGION

Thirty persons (every third person emerging from 3 different shopping mall pharmacies) were asked:
1. Are there any contagious diseases you are afraid of getting simply by going about your daily activities? If yes, what?
2. Do you know anyone who ever had hepatitis B?
3. Have you ever been afraid of getting hepatitis B?

<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response</td>
<td>n</td>
<td>%</td>
<td>n</td>
</tr>
<tr>
<td>Yes</td>
<td>4</td>
<td>13</td>
<td>8</td>
</tr>
<tr>
<td>No</td>
<td>26</td>
<td>87</td>
<td>22</td>
</tr>
<tr>
<td>Mildly</td>
<td>1</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

Table 33 Public response to infectiousness of hepatitis B.

Table 33 shows the results of this brief, informal survey. Since it was meant merely to check whether public reaction was similar to that reported for the leprosy study and not to become a study in itself, thirty responses were considered sufficient. (Hospital staff and patients other than those dealing with dialysis who were available to the writer during this period were also asked, with essentially the same results. This even more informal survey elicited one surgeon and one intern who evidenced concern about HB, which concern rapidly diminished after the production of the vaccine.) Had the results been other than corroborative of the Gussow and Tracy results, more might have been done, but it was not possible or necessary to repeat their study at this time.

Almost 90% of the general public were not afraid of contagious
diseases intruding their daily lives. Hepatitis was not spontaneously mentioned by any respondent, although colds, influenza, pneumonia and herpes were listed by Yes responders. AIDS was not yet in the news. Three-fourths were uninformed about and unaffected by hepatitis B. A finding of this study agrees with that of the leprosy study of Gussow and Tracy — that there is little reason for carriers to be concerned about hepatitis stigmatization from the general public. Low awareness should mean low stigmatization. Even among those who admitted to worry about it said it with a deprecatory shrug or some modifying statement ("Well, mildly, I guess"), that drastically lessened the import of their Yes answer. All who answered Yes to #3 also answered Yes to #2. So far as any of these people knew, none of those they knew who had HB had remained carriers. One who had it himself during World War II while in military service has been tested at the V.A. and said he showed negative antigenicity.

The author believes that the general public, at the present time, is not as concerned about hepatitis in the United States as they have been reported to be in other countries. Blumberg and others who cautioned patience in setting up stringent restrictive policy recommendations for the behavior of carriers seem to be vindicated, particularly with the advent of the vaccine.
APPENDIX D

Information supplied by:
Infectious Diseases Unit
University Hospitals
C. W. R. U.
May, 1982

Hepatitis

Hepatitis is an inflammation of the liver. It may be caused by infection, alcohol abuse, drug intoxication, reactions to anesthesia, etc. Viral hepatitis may be caused by hepatitis viruses A, B, and Non-A Non-B, as well as yellow fever, rubella, CMV, and Herpes simplex.

There are about 60,000 cases of viral hepatitis per year in the United States. Hepatitis A, B, and Non-A Non-B cause identical histopathologic lesions in the liver, and may be distinguishable only by serologic diagnosis and epidemiological differences often. Infection with A, B, or Non-A Non-B probably confers lifelong immunity to that type but none to either of the other 2 types.

Preicteric phase -- begins with fever, anorexia, weakness, headache, myalgia, loss of taste for cigarettes. The patient may have right upper quadrant pain, joint pains, rash, hepatomegaly, and bilirubin in the urine.

Icteric phase -- nausea and vomiting and right upper quadrant pain are increased, and there is an onset of jaundice (often only in the solera). The spleen may become palpable.

Convalescent period -- may be weeks or months before malaise and hepatic tenderness are gone.

Subacute hepatic necrosis -- develops in less than 1% of young icteric patients and in 10% of elderly icteric patients. The patient still has fever, abdominal pain and vomiting after the first week of jaundice. Hepatic encephalopathy, mucosal bleeding, and ascites may be present. It may be fatal in 2 to 12 weeks after the onset of the icteric phase. The patient may enter an asymptomatic phase and develop cirrhosis years later.
Fulminant hepatitis -- develops in less than 1% of icteric patients. It begins as typical viral hepatitis but progresses to severe liver decompensation with coagulation defects, bleeding, fever, hyperventilation, occasionally renal failure, and hepatic encephalopathy within 2 to 3 weeks. 80% of these patients die.

Chronic persistent hepatitis -- this is a chronic viral hepatitis with a benign course and good prognosis. There may be mild symptoms and transaminase elevations, and the patient may remain HBsAg+ for an extended period, but hepatocellular damage is minimal or absent and globulins and prothrombin time return to normal.

Chronic active hepatitis -- this is a chronic inflammatory and fibrosing liver disease, which is also caused by non-viral conditions. The patient remains HBsAg+ and HBeAg+ without evidence of Anti-HB. The patient may remain jaundiced with malaise, elevated transaminases, prolonged prothrombin time and low albumin for months or years. It leads to cellular damage and may progress to cirrhosis and hepatic insufficiency.

Asymptomatic carrier -- the patient remains HBsAg+ for months or years but shows no evidence of continued disease.
## APPENDIX D- COMPLICATIONS OF HEPATITIS B OR NON-A NON-B

### VIRAL HEPATITIS

<table>
<thead>
<tr>
<th></th>
<th>A</th>
<th>B</th>
<th>Non-A Non-B</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of cases of viral</td>
<td>55%</td>
<td>30%</td>
<td>15%</td>
</tr>
<tr>
<td>type of onset</td>
<td>acute</td>
<td>insidious</td>
<td>insidious</td>
</tr>
<tr>
<td>fever</td>
<td>common, precedes jaundice</td>
<td>less common</td>
<td>less common</td>
</tr>
<tr>
<td>age group affected</td>
<td>usually children &amp; young adults</td>
<td>all ages</td>
<td>all ages</td>
</tr>
<tr>
<td>arthritis and rash</td>
<td>not present</td>
<td>may be present</td>
<td>unknown</td>
</tr>
<tr>
<td>jaundice</td>
<td>rare in kids more common in adults</td>
<td>Same as A</td>
<td>Same as A</td>
</tr>
<tr>
<td>transmission</td>
<td>fecal-oral route</td>
<td>contact with blood or blood contaminated objects parenterally or with mucous membranes or breaks in skin, sexual contact, delivery at birth, ? biting insects.</td>
<td>Probably same as B</td>
</tr>
<tr>
<td>incubation period</td>
<td>15-45 days (average 25-30)</td>
<td>50-180 days (average 70 days)</td>
<td>15-180 days may be 2 types. one virus: 2-4 wks. Other virus 8-12 wks.</td>
</tr>
<tr>
<td></td>
<td>A</td>
<td>B</td>
<td>Non-A Non-B</td>
</tr>
<tr>
<td>----------------------</td>
<td>----------------------------------------</td>
<td>----------------------------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td><strong>period of infectivity</strong></td>
<td>late incubation period (last 2 weeks) &amp; early prodromal phase</td>
<td>late incubation period &amp; acute phase, often persists for months or years.</td>
<td>late incubation period &amp; early acute phase</td>
</tr>
<tr>
<td><strong>carrier state</strong></td>
<td>no</td>
<td>yes (5-10% of cases)</td>
<td>probably-up to 1/3 of cases.</td>
</tr>
<tr>
<td><strong>serologic markers</strong></td>
<td>anti-HAV (IgM or IgG)</td>
<td>HBsAg Anti-HBs</td>
<td>none</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HBsAg Anti-HBc</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>HBeAg Anti-HBe</td>
<td></td>
</tr>
<tr>
<td><strong>vaccine</strong></td>
<td>none</td>
<td>available soon [now available-MF]</td>
<td>none</td>
</tr>
<tr>
<td><strong>mortality rate</strong></td>
<td>0.5%</td>
<td>up to 3%</td>
<td>rarely</td>
</tr>
<tr>
<td><strong>recover in . . .</strong></td>
<td>2-4 wks.</td>
<td>4-8 wks.</td>
<td>--</td>
</tr>
<tr>
<td><strong>prophylaxis</strong></td>
<td>ISG</td>
<td>HBig or ISG</td>
<td>--</td>
</tr>
<tr>
<td></td>
<td></td>
<td>HBIG-1 shot plus</td>
<td>Vaccine (experimental)</td>
</tr>
</tbody>
</table>