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INTEGRATING THE EXPERIENCES OF BEING OLD AND DISABLED IN AMERICA: FOUR LIVES

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INTEGRATING THE EXPERIENCES OF
BEING OLD AND DISABLED IN AMERICA:
FOUR LIVES

A DISSERTATION SUBMITTED TO THE GRADUATE DIVISION OF THE
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ABSTRACT

In American society disability during old age changes the older person's relationship with the medical establishment, the family and the community. Four cases are offered with details of individual experiences, reactions and perceptions of the reaction of others, particularly physicians, families and friends.

Chapters about American medicine set forth the historical basis for the authoritarian attitude of physicians which the subjects report. A literature review of selected medical journals offers an explanation as to why this attitude continues.

Differences between the marital and the parent-child bond are described; recent literature suggests that there is significant difficulty in the parent-child dyad when parental disability occurs. Exaggerated expectations regarding the care-giving and affectional abilities of the adult child may contribute to the dissatisfaction reported.

Finally, a homeostatic quality is observed in the subjects, and this seems to prevail in conflicts with American social expectations. At the same time the subject's expectations are more often compatible with current roles assigned to the aged handicapped.
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Chapter 1

Introduction

Purpose and Methodology

The four cases presented within this dissertation became known to me in my work as a geriatric social worker for a community-funded, medically-based social service agency, The Honolulu Gerontology Program. The four participate in a free health maintenance program of exercise, socialization and social services for the frail aged in hopes of delaying or preventing institutionalization. They voluntarily come to the Honolulu Medical Group for one and one-half to seven and one-half hours weekly. The social service agency is separate from the Honolulu Medical Group, and patients do not necessarily or usually have doctors from the Group.

I chose these four people from the hundred or so Program participants who have had a stroke because they had been attending for one to three years. I had had a good chance to know them and their situations and found them to be as ethnically and socio-economically diverse as the larger society. Despite diversity, they were all United States born and not so steeped in any subculture that emphasizing their "Americaness" in this dissertation would be inappropriate. They also had been handicapped long enough to have had experience living with the stroke and
developed attitudes and opinions about themselves and others. In addition, their strokes had left them with moderate to severe impairment; this was important because I wanted visibly handicapped subjects. Finally, the four people I chose struck me as having interesting stories to tell characteristic of those confronted with what 18th century physicians called the "half dead disease."¹

The collection of material involved conducting several hours of unstructured, tape-recorded interviews, obtaining information from their case files including responses to an Older Adults Resource and Services questionnaire (OARS)² and taking notes on conversations they had with me or fellow workers in our professional capacities. Home visits were made to all but Nobuo's and Norman's homes. Norman was interviewed at his University of Hawaii office, Nobuo at the Honolulu Medical Group and subsequently at an acute care hospital and the Rehabilitation Hospital of the Pacific. Marge was interviewed at home, in a hospital and later at her foster care home. Claire was interviewed at home and later at a care home after placement.

Of what value are the experiences of four handicapped and chronically ill old people to a student of American Studies? Their experiences are very important to me personally and to each person who knows them because they offer examples of responses to the kind of disorganization
and threat any one of us could face. As a social worker who meets over 300 frail aged people a year, I knew that while each person's response to disease is individual and unique, certain behaviors and attitudes seem typical. Fear or courage, dependency or struggle for independence, decay or growth are battling within us all. And, of importance to a study of American culture, these personal battles are not waged wholly within. They take place in a milieu of values and expectations which can be either hostile or supportive. What is even less appreciated by those who give little thought to the sick and handicapped, is that each of these personal battles has a quiet impact on the American social landscape. Further, collectively, the handicapped like other minorities have significantly changed this landscape. Each wheelchair bound person we see in the grocery store, each aphasic ahead of us in line at McDonald's, and each grandparent who becomes a silent, blanketed, expressionless grey shell is integrated into our reality of America and its people.

Robert Sklar has suggested that American Studies "belongs at the forefront of the effort to study the social and cultural circumstances of the non-elites" and ought to "transform an individual story into a cultural narrative." This is my aim in using case presentations. This is especially important in the chapter on American
medicine because, for all that has been written about the patient and his diseases, little has been written about his expression of his own needs and desires of the health care system.

The stories and words of the four people will be counterbalanced with a presentation of the prevailing medical, familial and societal attitudes toward the aged and/or handicapped as described in the literature. I decided to focus upon their relationship with American medicine, the family and the larger society after the interviews were completed because these seemed to be the most profoundly altered for these people and the most often talked about. In this sense, the subjects served to direct my interests.

For the chapter on American medicine and the stroke patient I made a systematic review of two highly regarded medical journals (Geriatrics: For the Primary Care Physician and Geriatric Consultant) as well as a selection of medical journals and texts for clues to the attitudes of doctors toward disabled and old patients. I then looked for parallels in the voiced concerns of my subjects.

Unlike physicians, families do not have literature by and for them covering their roles, standards and practices with reference to the aged handicapped. Instead I relied on a sampling of sociological and psychological writings
in an effort to discern the prevailing thoughts on the attitudes of families toward their aged handicapped members. Again, I counterbalanced this with the experiences of my four cases. The social context of being frail and aged was similarly approached.

Finally, because these four had lived a long time and had a stroke, they had some qualities or characteristics which made them feel whole and special, at least sometimes. In the last chapter I shall attempt to report on how they integrated their illness, themselves, and their position in American society in a unique way. I do this because their purpose for consenting to being interviewed was to offer instruction and advice on how it was and how they had survived.

To understand some of the difficulties and concerns of interviewing a stroke patient and in order to understand just what types of handicaps occur in this sweeping, diverse and catastrophic disease, I refer the reader to Appendix A.

This dissertation, then, is a contribution to those few works written on the subject of the lives of the handicapped aged, rather than their pathologies. These subjects were American and this dissertation belongs in the domain of American Studies because their illness had cultural consequences. I have tried to give their views
about being handicapped a certain equality with the professional judgments about them. Studying American culture from the viewpoint of the non-elite is part of the American Studies discipline, and the handicapped aged are a seldom heard group of non-elite.

A process of restructuring reality began for these people at the moment of cardiovascular insult. This process continued long after the acute danger of death subsided, after the long stay in hospitals, relearning how to function more or less independently, after the patient, once again a person, reentered the home left months before, and through a reintroduction to the world. Discovering the newness of their America, especially American medicine, their families and society, is my purpose.
An Overview of the Issues of Being Old and Handicapped

Aging is a biological, psychological and cultural process of life for which the alternative is death. In America aging is generally regarded as a negative experience in the abstract yet personally experienced as positive. The literature (both professional and popular) abounds in criticisms about the disregard for the elderly by American families, but studies based on surveys indicate that children generally do care about and are in contact with their aging parents. The elderly generally regard their own aging experience as satisfying, yet there is a preponderance of literature about the "plight" of the elderly. The discrepancy between personal experience and American stereotypes about aging in general is one indication of the ambivalence Americans feel about the process of aging and the ambiguity of expectations the elderly must confront.

Why old age is negatively stereotyped is not easily answerable, but several possibilities exist. Historically there was a shift in public opinion after the Civil War which is attributed to the medical community's growing negativity to aging, the efforts of large corporations to manipulate the work force by retiring the elderly, and later a growing preference by the media and the public for
youthfulness over aging. This will be further explored in the next chapter.

There are also psychological explanations for the American dislike of aging. At the core is the confrontation with mortality to which aging inevitably leads. In addition, the aging process, with the complications of deteriorating health, threatens independence so coveted by Americans. For these reasons, gerontophobia goes beyond a psychiatric illness to a social disease that Robert Butler has labeled "ageism."  

Negativism is perpetuated and disseminated by social institutions. It is possible that the public has been persuaded to think of aging in problematic terms by media presentations of it as well as by professional literature. Most popular works have focused on the downtrodden elderly. Who are used as comic relief, and the message is that they have no deeper qualities. Even the recent movies which have highlighted the qualities of the aged have described them in the bleakest terms, as persons raging against both their own failings and their society. The professional literature is even more neglectful in presenting realistic views of old age. Until recently, most professional literature was about the 5% who resided in nursing homes. By its very nature, professional literature focuses on the most desperate and the most
Those who live on such a literary diet about aging must surely be repulsed and afraid.

A discrepancy between fact and opinion is evident. The major longitudinal studies of aging in America and the works of Robert Butler, Bernice Neugarten, Robert Atchley and the earlier works of Charlotte Buhler and Erik Erikson attest to a psycho-social process which, while having the potential for despair, depression and low morale, is generally and largely satisfying, rewarding and engaging. A realistic perception of the situation of the elderly is needed. It must not assume that being old necessarily means being senile and yet it must not neglect the 15% of the elderly who are affected by dementia and the 5% who are severely disabled by it. It must now assume that the elderly are all poverty stricken and yet it must not ignore the 14-25% who are indeed poor. It must take into account that for some people old age means dependency and yet it must recognize the 81% of the aged who despite chronic disease live completely independent lives. Aging is a necessary and reasonable public concern when a mere 5% of our older population totals one million people. Still, irrationally and fatalistically to assume that tragedy is the destiny of all of the elderly is detrimental to their potential and ultimately to us all.
The detrimental effects of living in a society which fears or disdains old age exist because individual experience with old age is determined not so much by circumstance as by perception of circumstance. One of the most important factors in the prediction of life satisfaction in old age is the older person's perception of his own well being.\textsuperscript{16,17} This is most likely the consequence of actual conditions, neurotisism and the messages and reinforcement one receives from others. One of the major themes of the Pulitzer Prize winning book, \textit{Why Survive? Being Old in America}, is that ageism is largely determining the circumstances of the old and the perceptions the elderly have of themselves.

In the literature on stigmatization and handicaps, the case for self perception's being shaped by cultural values is clear. The definition of "normal" itself is culturally determined and the first experience of being stigmatized sets in motion a psychological process which forever alters the self.\textsuperscript{18}

One reality of old age that is consistent with stereotypic attitudes about the subject is that the elderly are not a healthy population. Health deterioration and chronic disease do increase markedly in advanced years. The incidence of chronic disease in the general population is about 50\% compared to 85\% of the old.\textsuperscript{19} Interestingly,
while the incidence of acute illness declines in old age, the duration of disease and the subsequent recuperation time triples. These facts show that health is a major determinant of the lifestyle of the old, and American values regarding illness are bound to be controlling factors in the perception of self. While great care has been taken in professional literature of late to distinguish aging from disease, there is no disputing the vulnerability of the old to disease and all its social ramifications.

Aged individuals with chronic conditions experience stigmatization for being both old and sick. A study by Tringo details a hierarchy of stigmatization of various handicaps by the public (he used a sample of college students) which puts old age eleventh of 21 chronic conditions. Twelve of the other chronic conditions occur significantly more often in the elderly as well.

Stigmatization is a reactionary process which psychologically alters both the "normal" and the stigmatized. It has been suggested that the labeling and differentiating of the handicapped from others serves the larger group's needs for security, protection, superiority and lessens its discomfort when confronted with deviance by regarding the afflicted as "less than human."
The cost of emotional and physical isolation affects all concerned. Avoiding unpleasantness, raising self esteem at the expense of others, and segregation are not admirable American attributes, and guilt must surely follow such behaviors. Furthermore, cruelty or indifference toward others must leave thoughtful people with the uneasy assurance of similar treatment if misfortune should someday strike them. Finally, simply being deprived of associations with others because of characteristics they hold is obviously self-limiting.

Nevertheless, the cost to the stigmatized individual is much higher. Besides whatever pain, suffering and denied experiences an affliction costs, there is also the psychological harm of being abnormal in a normal world. It is that world which sets the standards by which the handicapped judge themselves, and the "normal" environment is often hostile, degrading, pitying, voyeuristic and sadistic. Worse, for some, is their dehumanization, their nonexistence in a normal world.

Marge, one of the cases presented herein, was limited by her aphasic speech even before she spoke; and she described this difficulty in harsh terms. She chose to isolate herself as much to spare others as herself. Heads of state often have "advance parties" to pave the way before journeying to foreign places; Marge felt she needed
that assistance too. She and I talked about what a trip to McDonalds (a block away) would be like, and she described an emotionally trying experience for her as well as the clerks despite the fact that her language skills at the time were more than adequate to order a hamburger. She knew that people wondered what happened to her and wanted an explanation she could not provide easily. She knew they would not ask and that they would think all kinds of unacceptable things about her.

Marge was capable of leaving her apartment in her wheelchair, riding the elevator, braking her chair down the parking garage ramp, maneuvering the busy Waikiki block to the street light, crossing the ramped street, opening the door to the restaurant herself, ordering and eating her meal with her one good arm, chewing on the one feeling side of her mouth. She admitted that she enjoyed a challenge such as that; it was the dozens of contacts with people along the way that kept her in her room so much of the time.

Marge, after eleven months in a rehabilitation hospital, was a product of the "rehabilitation model" of medical care, which, in the essay "The Disabled Face a Schizophrenic Society", is shown as forcing the chronically ill and disabled into confused roles. The model assumes that life is made up of separate functions to be
mastered and the ultimate goal is independent ADL (activities of daily living). The author, Cynthia Griggens, asks, "what makes function so all important?" For Marge, the failure of the model is evident in the above example for several reasons. First, although she was masterful in her ADL, the trip to the restaurant failed to satisfy her because neither she nor those around her had been prepared for the emotions her appearance and speech evoked. Secondly, while Marge had mastered her ADL, she was slow, her eating was aesthetically displeasing and her speech was laborious, all of which she recognized. Carrying out her ADL in a normal spontaneous fashion was the impossible goal she held for herself. She often felt in competition with her handicap, dissatisfied with just "being." Griggens calls this dissatisfaction with just "being" typically American and a large source of dissatisfaction among the disabled. Marge was also dissatisfied because she was alone, lonely and mostly unloved. The promise of satisfaction with life if she worked hard at rehabilitating herself was an obvious falsehood. Clearly in her case "function" was not all-important. Emphasis on "doing" by rehabilitation left her even more dissatisfied with the person she was--someone who stayed home and "did" very little.

Griggens believes that the handicapped share most "normal" Americans' admiration of health, independence and
denial of mortality. Since these qualities are obviously not possible for the handicapped, the rehabilitation model offers them a method to be almost all right—-to be continuously working on overcoming weaknesses. She claims that the values of the health care system are merely an extension of the values of society at large. For society to forgive the disabled, they must be working on becoming something they cannot be. The assumption that being handicapped is the antithesis of being truly American is not exclusive to Griggens. Albrecht traces a fifteen year dialogue in social science literature regarding the unAmerican quality of being disabled.

Older people, even the healthy ones, share a fate similar to that of the handicapped. They spend a great deal of time "rehabilitating" themselves by trying to look younger, act younger, think younger and deny their aging. Ironically, Marge acknowledged her paralysis and aphasia but denied her age. The futile denial of the aging process is something Butler claims deprives many aged of the chance for psychological soundness and satisfaction in their final years.

A major hypothesis of this dissertation, to be tested in the chapter on integrating the stroke and subsequent experiences into a definition of self, is that the disabled older adult who doubts the values of the larger
society, who questions the medical model, rejects the burdens of stereotyping, and seeks to define him or herself with more personal values expresses greater life satisfaction. It is here that the differences in the four subjects will be illustrative. Marge's description of various aspects of her life showed what it was like for a woman who still believed in American values no longer attainable and who somehow blamed herself for failing. She said, about not working, that she resented "the miles and miles of non-returnables" (referring to the unemployed) and the horror she felt in now being one of them. She described the "punishment" of medical treatment and how she must "take what was coming to me." In the course of the interviews, glimmers of realization that she did not have to live by the values of others were also evident. She described her affliction not as a mark or punishment, but a random event of which she was undeserving. She resented others for changing toward her, for, by their treatment of her, altering her life beyond what the stroke demanded.

I can't help but feel that they resent the fact that I am a cripple and have to be cared for ... They avoid me and very often will remark that, uh, I'm leaving something to be desired ... If I just stay away, I don't have to make excuses for my manners.

As the dissertation developed, a different conclusion was reached, however. While Marge did resent others for
their reactions to her, and while she did feel that America devalued her, I came to see these conclusions more as a product of Marge's personality than of reality.

Becoming handicapped in America requires previously "normal" people to become accustomed to new roles. Because they were also old, my subjects had additional burdens. The experience of having a stroke required these people to enter into a new and intense relationship with many health care professionals. It was assumed, because of their age, that they would not return to work. Going home after hospitalization was a result of recent trends in long-term care in America. During rehabilitation the preference of complete independence even if it meant a task was completed less satisfactorily was cultural. The expectations and disappointments their children later faced regarding their care and the extreme commitment of those with spouses were all the result of Western influences on the family.

The cultural influences of America on these four people's lives is the subject of my dissertation, one finding is that they accepted these for the most part with little questioning. Within the bounds of social acceptability they sought to recreate their old selves. Without employment, sexual activity, independence, health or mobility, they tried through substitution and adaptation
to remake lifestyles which suited their personalities. Their conflicts with a society which dictated social boundaries were few when compared to the many instances in which they accepted social roles assigned to them. Still the desire to return to previous lifestyles did occasionally create conflict.

In conclusion, Marge and the others reveal much about their own adjustment to their altered lives and much about American society from a seldom heard perspective. This seldom heard from group, harmed by society's (and their own) attitudes, suffer under the burden of expectations of and assumptions about the old and the sickly. Its existence is directly counter to the "young and vital" standard Americans hold for themselves. I believe that in not seeing these people, hearing them, noticing and affirming their individuality; in not recognizing our social process of casting them out, we lose as much as they.
Notes

1 Eric Pfeiffer, OARS Multifunctional Assessment Questionnaire (Tampa, Fla.: University of South Florida College of Medicine) March, 1980. The OARS interview was developed by psychiatrist Eric Pfeiffer and used since 1975 for diagnostic and survey purposes by medical and social service agencies. It is a lengthy questionnaire about functioning in five areas: social, economic, health, mental health and activities of daily living.


6 Atchley, p. 30.


8 Andrew Achenbaum, Old Age in the New Land (Baltimore: John Hopkins Univ. Press, 1978) passim.


11 Butler, p. 12.

12 Examples in the last few years include Harry and Tonto, The Sunshine Boys, Going in Style, The Over the Hill Gang and On Golden Pond.

14Butler, p. 107.

15Ibid., p. 17.


19Atchley, p. 107.

20Ibid., p. 106.


22Eisenberg, p. 5.


24The short story by Flannery O'Connor, "Good Country People" in A Good Man's Hard to Find (New York: Image Books, 1970) pp. 159-184, in which a female amputee is seduced in a barn loft and her wood leg stolen by a "boy who collects oddities ... the thing that makes people different." brings out many of the baser feelings the handicapped arouse in "normals."

25Lee Myerson, "Physical Disability as a Social Psychological Problem" in Edward Sagarin, ed., The Other

2"Kriegel, p. 176.

2"Cynthia Griggens, "The Disabled Face a Schizophrenic Society," in Myron Eisenberg, et al., Disabled People As Second Class Citizens.


2"Butler, p. 74.
Chapter 2
Four Vignettes

MARGE

Marge was unable to reveal much of her early history because of difficulty with speech and memory due to her stroke. It was known that she was one of four children and had grown up in California. She attended but did not complete college. She worked for a large part of her life in set and costume design for a successful television variety show. She was married, had a son and a daughter and divorced her husband during her children's youth. After retirement from television she came to Hawaii and worked in fashion merchandising, finally starting her own fashion boutique in the late 1970's.

In 1978 Marge had a massive CVA which resulted in almost one year of hospitalization. Residual damage included a global aphasia (inability to speak) which gradually improved (it peaked at about the time of these interviews). She was confined to a wheelchair with enough weight-bearing ability to permit transferring. Her arm and hand were not functional. Her medical history also included stomach ulcers, arthritis and high blood pressure.

In 1984, after the interviews were completed, she suffered a second stroke and was moved from her Waikiki home to a foster home. Her speech was again affected and at last contact was limited to two words, yes and no.

Years ago, Marge divorced an alcoholic husband. Among his transgressions was an affair with a mutual friend, a nurse. After the divorce, Marge continued in a successful career in a technical aspect of television production and reared her two children alone.
She was bitterly estranged from one child, a daughter with a son of her own, because of a "drug problem". Nevertheless she continued to keep photographs of daughter and grandson prominently displayed. Her son lived on the mainland with his family but occasionally he came to Hawaii on business and to see his mother.

Marge's first stroke occurred when she was embarking on a new career as a boutique owner in a Waikiki hotel. While she never expected to have a stroke, she had had high blood pressure and transient ischemic attacks (TIA's) for over a year and these are considered warnings of or precursors to a completed stroke. She ignored them. Her business was beginning to succeed and she was considering marriage when, in a doctor's office while undergoing a physical examination, she began to have a severe cardiovascular accident damaging the left hemisphere of her brain.

After eleven months in __________ Hospital and the Rehabilitation Hospital of the Pacific and with painstaking attention by the Rehabilitation staff to every detail of her former home, daily needs and wardrobe, she was discharged to her own apartment in a Waikiki hotel. She could not speak except to say yes, no and hello, but she had been taught to answer the phone and receive messages. Other speech was occasional and unreliable. She also had
slight receptive aphasia—she could not understand entirely what was told to her.

Besides speech loss, she was severely paralyzed on her right side, so much so that she would never walk. Her right arm had no functional use except as a weight to hold items stationary as her left hand worked. She learned to use her left hand to assist her right.

In her own apartment Marge could transfer from bed to chair, chair to toilet and back. This required learning as much about the useless side of her body as the functional. It also required laying aside her sense of safety in favor of trust in various therapists who regularly demanded physical maneuvers that seemed to defy gravity. She could eventually reheat food in her microwave oven, make her bed and retrieve items from a range of heights below and above her. She could also dress herself in a modified muumuu (a loose-fitting tent dress with large arm-holes) without a bra or underpants.

The social services arranged for her to receive included a Handivan Pass so that (provided she could get from curb to destination on both sides of her journey) she could have public transportation for $1.00 each way. She was also provided with a Senior Companion for a few hours twice a week. This elderly woman, paid a stipend of $2.00 an hour under a federal ACTION program, would do errands
for Marge, cook a little and, most important, be in the
apartment while Marge showered. This free service was
supplemented by a paid housekeeper once or twice a week.
This young Vietnamese woman with "boyfriend problems" was
a source of much enjoyment to Marge. Marge also received
daily home delivered lunches. All of the above ended in
1984 when she was placed in a foster care home, but an
accountant friend continued to manage her money and
bill-paying, and she still came once a week to a health
maintenance exercise program. Program staff there also
provided case management to see that the myriad of home
services continued without critical interruption and that
her new placement remained appropriate.

If Marge's boyfriend visited in the weeks after her
first stroke, Marge did not remember. She did not recall
any visits from him and no closure to their courtship.
She never saw him again. Also, because she thought they
felt sorry for her, Marge ended all of the friendships
from her pre-stroke days except with her accountant.

For three years Marge went out once weekly to her
exercise program and occasionally to a physician. Rarely,
in the beginning, she tried shopping or dining out with a
companion but quit because it was not satisfactory. Her
brother came over once in the first year. Of the visit
she said, "He was nervous and I could sense a change on
his part as well as mine, because I couldn't talk or carry on a conversation."

Her son also flew out a few times and although she felt closest to him, she declined an offer to live with his family a few years prior to the interviews. Holidays were spent alone, as were all evenings and most days before placement. Staff from her exercise program stopped by on Christmas for several years because they knew she was alone and her accountant stopped by with a festive meal. Marge's son visited her at the care home recently. The incredulous care home operator reported he was on his way to the airport, returning home after business. Another time he told the foster home operator that he never felt close to his mother because of being sent to boarding schools. Despite this, Marge felt most comfortable with him.

When still living alone, Marge gave up the old wheelchair which The Rehabilitation Hospital had issued her and replaced it with an electric model. During the first interview she was awaiting its arrival and was discouraged and depressed by the fear that she had been swindled because she had not heard from the company. She said this depression was as bad as the one she felt when she had first suffered the stroke. The old chair required her to walk herself along with her one good leg, pushing and
correcting her course with her one good hand. The sight
of Marge inching up the parking garage ramp after the
Handivan dropped her off was anguishing enough that a
passing motorist might wonder if he should stop and help
or pretend not to see.

Until the second stroke in 1984, Marge's speech had
improved significantly (speech can be returning for sev­
eral years after a CVA whereas maximum physical restora­
tion occurs within the first year). She could speak
haltingly, often substituting words for lost ones but
could, more than half the time, get her point across. A
few months after the interviews for this dissertation,
Marge was found on the floor and taken to the hospital
with apparent stomach flu. Over the next week her speech
disappeared; she became incontinent of bowel and bladder
and unable to transfer herself. Her receptive aphasia
worsened so that she could not grasp more than two simple
commands during a neurological examination. After two
weeks at _________ Hospital and another two at the
Rehabilitation Hospital, she was discharged into a "foster
family home" in Aiea. Marge could no longer live indepen­
dently and so lived with a Filipino family whom she paid
about $1,000 monthly for her care.

She continued to come to the exercise program
with a Kotex pad or diaper although control of bowel and
bladder was returning. Speech was very limited, it took her about 15 minutes to communicate to staff that the noise of children in her new home was disturbing. There were several extended pauses in her speech during which she was either groping for words or had been distracted from her thoughts.

Marge's appearance and demeanor were noteworthy. She had a figure much like Dolly Parton and a blonde permed afro. She was jovial and she had a contagious belly laugh. Partially the result of the brain injury, she had a cheerful facade and a seeming lack of worry. This did not, however, soften her critique of society in its regard for "a cripple." Nor was she soft on herself. She admitted that her self-imposed isolation was an easy way of avoiding embarrassment and rejection and that she thought striving for acceptance the more admirable course to follow.

Marge acknowledged that she had had only part of a life since her first stroke. Her career, every friend but one, her lover and her family were "out of reach" since the stroke. Sadly, even a simple phone call to relatives on the mainland was not possible. She described sexuality as a "closed door." Her life, up until the last move, consisted of practicing reading the newspaper and watching the tennis players on the parking garage roof below her lanai. Even television was unsatisfactory; her
deficiencies made it difficult to follow the action and plot of most shows.

After the second stroke, Marge could barely speak. The staff at her exercise program found it difficult to know what she was thinking or wanting. Sensitive as they were after four years, they found the only way to treat her was as if they were in her position. This, they knew, denied the reality of her, made her a projection of their own fears and resentments.

Because she was speech impaired, in these interviews I, too, had the problem of avoiding "creating" her by leading and directing our conversations. In retrospect, there was some of that because I found speaking with an aphasic a guessing game in which I tried to help her find words when none came. I was aware that this would be a problem I could never entirely solve, but I felt strongly committed to trying to interview an aphasic person to try to explain what life was like for her.
NOBUO

Nobuo was born on Kauai in 1917, the only boy of four children. He quit school before beginning high school and worked in the construction trades all of his adult life. He married young and was divorced in his early thirties after producing one daughter and two sons. He had custody of his two sons but most of the responsibility of raising them fell to a sister because Nobuo was frequently working away from Hawaii.

Nobuo stated that he was an alcoholic during his working years and claimed to have resented the child support payments he made "because they cut in on my liquor money." When he was 61 years of age, angina attacks caused him to take a medical retirement and he had a stroke a short time later. After the stroke he quit drinking heavily, limiting himself to a beer or two a week.

The exact number of strokes Nobuo had in the years since retirement was undocumentable because some were apparently small enough to have been untreated. He had at least three significant strokes, the most major in 1979. His impairments included hemiplegia (one-sided paralysis) with walking requiring a leg brace and cane. His hand was contracted and his arm was paralyzed. Stroke damage to his voice caused him to speak in a loud, abrasive tone. Nobuo's judgment was also affected, causing him to not always act cautiously. Examples would include such things as trying to hurry down stairs or assuming he could walk much further than he could. Nobuo also had a long history of high blood pressure and prostate enlargement resulting in past surgery. After each hospitalization Nobuo was successful in returning to his ground floor apartment in Kalihi.

Nobuo found being an ironworker in construction immensely satisfying because he enjoyed both solitary pursuits and the camaraderie of an all male profession with physical challenges. First to "keep company" and
then later from habit, Nobuo drank heavily so that in
later years "I couldn't wait til I was through working to
get to the liquor bottle." It was not drunkeness but
heart disease which forced him into an early retirement.
It became impossible to hide; while several hundred feet
in the air, the angina attacks from which he was taking up
to an hour to recover.

Retirement brought more drinking, all day drinking,
drinking without buddies. His thoughts of gardening never
materialized. Of these years he said, "I was happily
drunk, with a glow to go to bed."

One morning, about two years ago, Nobuo awoke and
found he could not move. He was able to call an ambulance
from his bed but spent the next half hour crawling to his
door to unlatch the bolt. He spent the next several
months in Hospital and then at Rehabilitation
Hospital.

Nobuo's divorced wife had reared his daughter in
Hawaii while his sons shuttled between him and a sister.
Some years he spent working in California and then they
would come here for visits. He regarded parenting as his
biggest failure.

When he had his big stroke, his family rallied. Even
his ex-wife was attentive, he said with a chuckle. During
the long months in the hospital they all visited and even
got along, but that good will waned as he recovered and old family resentments returned.

Nobuo acknowledged that he was not easy to get along with and he was especially poor at being grateful. For a long while after his discharge, one son came once a week or so to see if Nobuo needed anything, but they often fought. Nobuo described it this way,

"I called him last night and told him, 'Don't come here just cause I want you to pick an item for me. Come because, after all, see how your old man is getting along.' There's no one for me to tell my problems except my boy. Because staying in a hotel [apartment] and I haven't asked my neighbors for help ever."

The conversation with his son ended with Nobuo hanging up on his son.

His other son was more aloof, contact was just a few times a year. He rarely saw his daughter. Despite the lack of family support, Nobuo shunned public programs or the help of the neighbors. He did this to avoid indebtedness. For a few years after his stroke Nobuo opted for costly taxi service over Handivan because he saw the Handivan as charity. When he finally chose to use it because of the expense of taxis, he saw that his van drivers were often tipped with gifts. Although eligible for chore, shopping and meal services, he refused this kind of help. Nobuo refused to allow me to come to his home, preferring that the interviews be conducted elsewhere "because of the
From my experience in visiting homes of single male stroke patients, I can surmise that the house would have had a urine smell and be cluttered because putting things away only meant difficulty in finding them again. Also spills would not be cleaned up because it was very difficult to reach the floor, and the major housekeeping chores of sheet changing, sweeping and mopping were practically impossible. Nobuo did have a "Hawaiian-Chinese woman" friend who cleaned or did errands occasionally for him.

Nobuo also developed a close friendship with Paul, a middle aged Caucasian man who had had a stroke about the same time and for a while had a global aphasia. Gradually Paul's speech improved and he and Nobuo often ate lunch out. Those outings were curtailed when Nobuo could not manage his toilet needs in restaurants anymore; the signal of need to urinate occurred too close to the actual event. Then, Paul and his family moved to the mainland, and a few months after the interview Nobuo received word that Paul had killed himself.

After Paul's death Nobuo confided, "I've thought of it [suicide] too, you know. I could do it and sometimes I think I will. I know it is something I could do if it got too hard." To Nobuo, suicide was not just a response to
sadness or depression but a way to reestablish control over his life.

Nobuo was quite complex in his attitudes toward all other people. Besides his generosity toward service providers, he also gave anonymously to group members in his exercise program and the Stroke Club. In the years after his stroke he visited the hospitalized and sent cards or flowers on behalf of the group without recognition or payment. At the same time, he was proud that all of his life he had never said "hello" first to anyone. He described his cynicism this way:

"I'm not too friendly, neither am I the worse guy. Sometimes a stranger comes up and makes some kind of remark, I'm kind of cynical about what remark he make. He looks so stupid to me. I'm getting wet and he's getting wet and he comes and tells me it's raining. [Laughter] Oh well, we're all getting old."

He felt secure enough to regard people who avoided him as the "losers." And he claimed this had insulated him from feeling the stigma of his handicap. He said he did not think or care about how strangers regarded him. But staff at the Honolulu Gerontology Program noted that he could be angered or hurt. As an example, when a companion to a handicapped group member nearly knocked Nobuo over in an effort to save his own client from falling, Nobuo came angrily to the staff and said, "Tell that guy we're all handicapped here."
In a humorous exchange with me which showed how much he shielded himself from the unfamiliar, he was asked if he had given much thought to the handicapped prior to his stroke. He first said no, then he described the only handicapped person he knew as a construction worker in California who became a marriage counselor. In probing for the nature of the handicap it became clear that his only handicap was becoming a marriage counselor.

Interviewer: Was he in a wheel chair?

Nobuo: No, he wanted to be a marriage counselor and he was not young, he was about 50 years old. And he was telling us guys that. And I thought he was a nut just because I didn't know a darn thing about it. I thought that he was off his rocker to do something like that. Because the ironworkers don't get the best pay but in L.A. it is over $17.00 an hour and a few benefits besides.

Nobuo was also quite tenacious and he described his philosophy in terms of the work he did for forty years.

I worked on the beams, for forty years. It does help. I think the reason I keep exercising is because when you're [doing] structural [work] and you have two holes and you're trying to get a bolt through it; you think you've expended all of your strength, you can't get the bolt through it. So you give it another try. Hardly any more strength come out but you make the hole so you can put the bolt through there.

Nobuo's left-sided weakness of arm and leg necessitated a leg brace and cane. His arm was used only as a weight when assisted into place by his right arm. His hand was contracted. His life consisted of attending exercise class, buying take-out meals at little restaurants in his
neighborhood and making casual conversation with acquaintances along his daily route.

The generous, quiet acts of friendship to group members and his deep reaction to Paul's death evidenced a softer side of Nobuo than he at first revealed.

Nobuo had a near brush with institutionalization just prior to the end of writing this dissertation when he had another stroke which made him temporarily incontinent and unable to walk. He improved at the Rehabilitation Hospital sufficiently to return home although the hospital staff had made plans to place him in a care home. Demonstrating the extent of his difficulty in family relationships, he refused to call his children about his hospitalization, leaving them to find this out many days later. Nobuo confided in me that he was too stubborn and longed for them to come by, but he also refused my offer to call them on his behalf.
CLAIRE

Claire was a lifetime resident of Honolulu who was born to Chinese immigrants in 1907. She was 78 at the time of this writing. She lived above a family-owned store with her parents and three brothers. She considered herself "well-to-do" during her childhood.

She married Robert shortly after high school graduation and they both worked for much of their early marriage. She worked for 22 years with the federal government; he worked for 35 years with a large Hawaii corporation. Real estate investments over the years provided them with additional security in retirement. They raised four children, one of whom died of disease in adulthood. Their oldest living son and his family lived in a cottage on his parent's property.

In 1980, when she was 72, Claire suffered her only CVA. Her medical history also included a number of prior surgeries for a variety of ailments. The stroke's residual damage included impaired memory and severe hemiplegia (paralysis) so that she could not walk. She could bear weight sufficiently to transfer from her wheelchair independently.

In 1983, her husband died and a major depression with two suicide attempts followed. After approximately one year of depression and crises Claire moved from her home into a care home where she made fair adjustment and her depressive state partly improved.

Claire wanted to back out of our interviews because the anticipation was making her "nervous." In fact, she tried to cancel, but a friend urged her to go ahead and try them as they might be enjoyable. While she cooperated fully and spoke at length about her life, I can hardly characterize the interviews as "enjoyable" because she cried often and freely.
Also, Claire's recall of her life after her stroke but prior to her husband's death differed from the recollections of those around her. She described herself as satisfied and emotionally unaffected by her physical deficits until Robert's death and then suddenly and dramatically transformed. But the staff at the Honolulu Gerontology Program had long been worried about her depression and apathy as well as about Robert and his ability to meet her needs. Her son had expressed similar concern, so much so that while he grieved for his father, he also saw his death as an opportunity for his mother to shake some of her passivity, dependence and apathy.

Claire's stroke occurred as she lay in bed with her husband, Robert. She awakened early in the morning with a strange feeling in her eyes, "like my eyeballs wanting to come out of the sockets." Robert urged her to go back to sleep, but in a short while she discovered she was paralyzed. She said, "Daddy, there is something wrong with me," and Robert awakened his son and daughter-in-law, who shared their home, and called the ambulance.

Claire entered the hospital with an old and familiar dread. She had had seven major surgical procedures in her lifetime (she named hysterectomy, thyroid removal, gall stone removals, colon surgery and surgery to a goiter), and each time she entered the hospital she pessimistically
assumed that she would die there. While at the hospital for the stroke, she described the pining for her own home. For the four months she stayed at _______ Hospital and at the Rehabilitation Hospital she felt like a prisoner because even on weekends, "they wouldn't let me go home." If she lived, there was no question that it was her own home and family that would receive her—not an institution.

To Claire, nothing seemed more important than family. As the stroke progressed that morning in 1980, she lost her speech for a few days. She described her family's bedside vigil when she was unable to speak. When she first spoke the pet name of her granddaughter, everyone was deeply moved.

Claire's speech returned rapidly, but her left leg and arm were so weak that she could only take a step or two and could not use her hand. She relied mostly on her wheelchair. In addition, she could not recall her alphabet, the days of the week, and had much trouble with numbers. For example, she could not recall how old her eldest son was when he died. Her guesses ranged anywhere from 50 to nearly 70 and his wife's age at the time from 20 to 40. She could compose and write. What was most important to her, her appearance had not altered; her face did not drag and her speech was not slurred.
It would be hard to describe Claire's 57 year marriage in clear-cut dependency/independency terms. She never learned to cook or drive; her husband discouraged driving and willingly cooked evening meals since she was working. On the other hand, she did work outside the home for many years, and she always had a separate social life with Chinese women consisting of club activities. She described herself not as dependent but pampered or even spoiled. Ever since Robert died unexpectedly in 1983, she had hated the position in which she found herself. According to her, her son Henry was well-meaning and devoted as were her other children. Nevertheless, she felt guilty for the demands her daily needs made on her family. Bathing, cooking, cleaning and companionship all had to be provided. Henry complained that it was not the time involved that was causing tension, but the feeling of inadequacy she evoked in her children—no matter how much they did.

Family tensions, along with profound grief for Robert, a sister-in-law and a brother who had all died within that same year, led to two suicide attempts (by aspirin overdose) and finally her voluntary and permanent move into an institutional care home.

She described the depth of her anguish in this way,

The first month that Robert died, I didn't feel anything. I just can't believe that he went. Just like he's still around; I see him all around the place. The second month, when everything
died down, then it dawned on me, "oh, Robert isn't here, Robert isn't coming back." [crying] My sister-in-law, when she died, I wanted to crawl into the coffin with her. I felt so bad.... It's just like there is nothing for me. Me in the big wide world. Just like, I don't know where I belong. That's how I feel.

As this dissertation neared completion, Claire was living in a Chinese care home, giving up her house of 32 years to her son (physically, not legally). She shared what looked like a college dormitory room with a very old Chinese woman who babbled and puttered about the room—a victim of a dementing disease. Claire still came to the Honolulu Gerontology Program several times a week and boasted that she had adjusted to the move that no one encouraged her to make. She especially liked the easy access to company and the idea that her personal needs were met without the guilt of imposing on family. Her women friends and family were still in frequent contact and she often would spend an afternoon in her house sorting through her possessions. Despite the good adjustment she claimed to have made, I was (in my social work role) alarmed to find her in bed and in nightclothes when I visited one afternoon.
NORMAN

Norman, born in 1913, was 72 at the time of this writing. He was the oldest son of five children. His Jewish family lived in Chicago in well-to-do luxury. His father died when Norman was five years old and his mother soon married Norman’s uncle. In his teenage years, during the Depression, his family lost their fortune and never regained it. He said of his remaining youth that they “just scraped by.”

During a span of twenty years Norman worked as an accountant and earned three degrees. The last, at forty years of age, was a doctoral degree from Columbia. The awarding of the degree shortly preceded a serious myocardial infarction (heart attack) from which he recovered uneventfully.

Norman married Rachael, six years older than himself, when he was 34. They had known each other for three days when he proposed and they were married in a few weeks time. She worked throughout the marriage as a government planner, he as a college professor.

At the age of 64 Norman suffered a CVA antecedent to an eye infection, herpes zoster. The damage from the stroke included significant memory impairment, mild emotional lability (mood swings), paralysis of his left hand and an awkward gait. In addition, the herpes zoster and cataracts caused vision deterioration to near blindness. In 1984, following eye surgery, his vision improved temporarily. In 1985 he was judged to be a poor risk for carotid artery surgery although this was the suspected cause of increasing dizziness.

Seven years ago, flying home from a London vacation, Norman suffered a cardio-vascular accident which left him unconscious and gravely ill for about ten days. His stroke was unusual in that it was probably related to an attack of herpes zoster, an eye infection. Until this
illness, Norman was a college professor who had published a number of books and articles. After the acute phase of his stroke and recovery, he was transferred to the Rehabilitation Hospital. He hated it and one day his wife Rachael gathered him up and brought him home, where she began the process of rehabilitation in their own way. Their marriage changed dramatically and, according to Norman, for the better. While he was very dependent on her for most daily needs and most social and emotional needs, he grew to know her more intimately than ever before. His admiration for her was very deep and his trust astounding.

As an illustration of this, one day a speaker on the subject of sexuality came to the Honolulu Gerontology program. Afterward, Norman, who could be very garrulous and flighty after his stroke, cornered the speaker and began a discussion about sexuality and aging. Rachael moved in and broke it up fairly soon, saying that the speaker undoubtedly had to be leaving and probably had heard all this before. The speaker, a social worker, then took one of the program student social workers aside and insisted that this woman was evil and castrating and for poor Norman's sake they ought to get counseling.

At the student's urging, I called both Norman and Rachael into my office, something I often did with couples
anyway. We had a long talk about their marriage and Norman brought up the subject of Rachael's controlling his contacts with others. He said that being social was new to him. He had always been a loner, but his stroke made him crave social contact. He knew that he was prone to be and look foolish at times, and he needed Rachael to come in and quiet him down and cut things off. In short, he knew what she did, and he did not mind it because he thought it was Rachael's way of protecting him and helping him to look good in public. He likened himself to an absent-minded professor, who was still a child when it came to social graces.

During the interviews Norman explained to me that Rachael and he knew they could not have children from the start of their marriage. Since his stroke in some ways they had slipped into a parent-child relationship but he made it clear to me that it fulfilled Rachael to care for him and it served his needs as well. Whenever she would grow too protective, he simply refused to play anymore. This happened when she wanted to keep him from going back to the University, especially by public bus. He insisted and that was that. She could have been more adamant; there is little doubt that she could have prevailed as hers was the more powerful position. Was she being overly protective? In retrospect one could say that his daily
forays to the University were beneficial to his sense of completeness and self esteem. They were productive in that he very slowly finished a manuscript begun before his stroke. They stimulated much growth because he saw people every day and was proud that he could do this without anyone's assistance. But I saw him at the University. He was chronically dizzy and sometimes could barely make it from the bus stop to his office. Some days he turned right around to go home. Sometimes his efforts at friendliness were construed as intrusive. And he reported getting so angry at people on occasion that he would like to "punch them out."

After his stroke, Norman surrendered his freedom to Rachael because he trusted her more than himself. Through negotiation she gave it back because she loved him.

The stroke changed Norman's day dramatically. For several years he did nothing each day except tag along with Rachael. Then he seized an opportunity to get an office at the University and begin work anew on a book. It changed his outlook immeasurably, but even before that he and Rachael tried to take charge of his illness. He exercised regularly; he joined a support group for stroke patients, he tried non-traditional medical therapies and began taking large doses of vitamin C because he believed it helped.
While this might look like an active and assertive lifestyle, he also slept or rested for all but a few hours each day. He had difficulty with reading or watching television and his immediate recall was so bad that he forgot the first part of a sentence while editing the next. His hemiplegia was mild; while his hand was somewhat contracted, it was still functional and he was able to walk but with a disturbing gait. His most troublesome symptoms were in the areas of intellect, affect and equilibrium. He complained of worsening dizziness; he recognized profound personality change from quiet and insecure to garrulous and friendly; and he attributed occasional fits of rage to the damage of his stroke.

Norman talked of his life in terms of his isolation. He insisted with regret that his mother, and his whole family taking the lead from her, never were affectionate. His mother never kissed him as far as he knew. His siblings did not express the deep love he reported they felt for each other but they would gladly share their money with each other. Of his years as a professor, he said he was "self absorbed" and other than golfing with colleagues he rarely socialized. Only in his writing and his marriage did he find expressive fulfillment. He talked also of insecurity. He was tremendously self-critical and only since his stroke, when he began to mix with others, did he
see that in his life he had many proud accomplishments. Sadly, he measured the best as past. When I asked him how he saw himself now, he responded, "I think I was the best writer in the college of ________." And I pressed, "but what about now" and he said, "Well, I think less of myself because I'm handicapped. I'm 75% handicapped."

He felt his future was closely connected to Rachael's. They shared a suicide pact should one of them die. He worried about how he could care for her should her heart disease worsen. While he believed he loved her at least as deeply as she loved him, he feared he would be an inadequate care-giver.

Of death he admitted increasing fear. It used to be something far off and unreal, increasingly he saw it as something in his near future. Intellectually, death was nothingness but emotionally it was an unknown. Of another stroke or increased disability he said he'd unhesitatingly choose death.

Norman was a complicated man. On some subjects he was dogmatic, on others incredibly receptive. He had many admiring acquaintances yet few friends. Despite a refreshing openness about his own feelings and needs he seemed to lack a sustaining quality in friendships aside from his marriage and family.
Chapter 3
Roots of the Authority of American Medicine

While the history of aging in America and elsewhere may be varied and often encouraging, the history of the frail aged in most cultures is often bleak. Their social destiny seems more harsh than their damaged bodies.

David Fischer, in Growing Old in America, notes that most cultures have distinguished between the old and the old and sick and that many of the benefits of aging disappeared with health.1 To some extent Achenbaum attributes the overall decline in regard for the aged in America to an increasing preoccupation with the infirm aged by American medicine, industry and public opinion.2 The assumption that being old is equivalent to being impaired has allowed for the denial of roles, power and potential to the aged. Early gerontology's first efforts were at dispelling the myths and stereotypes about old age limitations.3 While being ill may certainly be a personal tragedy, the social costs seem disproportionate, so much so that the aged do not want to be put into that category.

The infirm aged are a vulnerable class of people. In pre-modern cultures the aged without family and even some with family have been neglected, scorned or even harmed. This is often tied to socio-economic factors and the harshness of daily life.4,5 While no generalization about
such cultures can be made because many cared deeply for their aged, certainly the frail have been in a weaker position than the healthy aged. 6

In the 18th and 19th centuries in America, the aged generally enjoyed high status as exemplars of healthful and good living, because of having the expertise of experience, and in some cases because of property and position. Nonetheless, the frail aged were uncertain of their future, according to Achenbaum. This led them to provide for their care as a stipulation of transferring property to family members, to live in dread of being dependent on their families or to fear the possibility of the almshouse. While the almshouse, unlike the modern nursing home, did not specifically house the infirm, the pervasive fear of being one of the abandoned 2% of the aged in almshouses in the 19th century or the 5% of the aged in institutions today is similar. 7

From colonial times to the present day, the status of the aged seems to have waxed and waned but generally to have declined. Achenbaum particularly identifies the post-Civil War period as a watershed. 8 However, he also claims that the infirm aged have always been dependent on the obligation or affection of family or the charity of others and that these were not always given freely, with respect or given at all. The factors which have affected the
status of all aged for the most part have had a more negative impact on the aged of poor health.

With less than 2% of the American population aged until 1810, those few who lived to old age were measured more by longevity than infirmity. This longevity, admired by all as an indication of a good life in a spiritual as well as practical sense, won them the admiration of even medical science. In the latter half of the 19th century as America changed dramatically, so too did the status of the elderly. An increasing focus on science and technology in industry caused the elderly worker who was presumed inefficient, inflexible and old-fashioned to fall from favor. Regarding science and the aged, Achenbaum concludes:

New scientific theories and economic realities convinced Americans that individuals declined in old age as human existence marched on. Because they perceived the elderly to be afflicted with pathological disorders and no longer able to keep up with the pace, it is not surprising that writers claimed old people had lost their grasp on the meaning and nature of societal development.... Americans gradually discounted the value of old people's insights and claimed that young people were in the best position to understand the meaning of life.

Accommodating scientific theory and observation into the social, economic, and cultural needs and values of a particular time can often be observed. Farrel, in *Inventing the American Way of Death* suggests that this was
certainly so in the latter half of the nineteenth century. Toward the terminally ill and the elderly, the science of that period was hardly impartial. The aged's lack of reproductive ability made them nonessential to the species; their inevitable dying made them diseased and the hope of science was to one day solve the "problem" of aging.\textsuperscript{11, 12} The persistence of the belief that aging is a "problem" to be cured and that dying represents a medical, social and personal failing can be seen in such popular books as \textit{Life Extensions} or \textit{Prolongevity}.\textsuperscript{13, 14}

In the same fifty years, retirement became more acceptable to both worker and employer. More and more states created old age benefits and more and more large employers began pension plans to foster retirement.\textsuperscript{15} This trend culminated in the 1930's when the federal government, in response to the high unemployment of the Depression, began Social Security to reward the older worker who chose to leave the work force. While this change from employment to retirement for the older worker was by no means sudden or without some protest, Rooke and Wingrove, as well as Graebner, point out in that it is not clear whether retirement was regarded as a gift to reward the aged for hard work or just a new method of dismissal.\textsuperscript{16, 17} What is clear is that the loss of wages created a poorer old population, especially with inadequate financial
resources in time of sickness (except as provided by the government). This is particularly important because it was in this same period that medical costs began escalating. Also in a society which values work, the old became "useless" and less valued.

Demographic patterns also affected the status of the elderly. From being a relative rarity prior to 1830, increased longevity, decreased fertility and immigration brought about a significant increase in numbers. At the same time urbanization, with employment outside the home, decreased the family's ability to care for the sick aged (or any sick person) adequately in the home.

The practice of medicine altered radically after the Civil War. The changes within this profession, coupled with the changes in the larger society, almost seemed to conspire against the aged.

First, the practice of medicine became more scientific and empirical, and the good example of the elderly, once so instructive, was less valued. At the same time, the diseases associated with aging were subject to scientific study. Achenbaum states,

By the first decade of the twentieth century, therefore, specialists had not only superseded the elderly as experts in health matters but had also convinced the general public that old people suffered incurable pathological disorders. The ultimate result was often more deleterious than useful.
Secondly, the authority of the medical community in society at large steadily increased in America. While beginning in the 19th century, the full impact of this authority was not felt by the aged, as well as many other segments of society, until later into this century. Paul Starr, in *The Social Transformation of American Medicine*, traces the history of American medical practice from an initial period of being regarded as craftsmanship (with questionable usefulness at times). It assisted the family (primarily the women) in the care of the sick whenever conveniently available. Even this unremarkable status was threatened from the 1830's through the late 1800's by such populistic practices as homeopathic medicine, herbalism and Christian Science. While these alternatives gained some acceptance because they were more accessible and easily followed, physicians were also losing ground because of disunity and disorganization within their ranks, according to Starr. The professional isolation of rural practices along with medical schools without common standards and a general spirit of competitive noncooperation weakened the medical profession from within.

While medical schools proliferated in the early and mid-1800's according to Starr, the divisiveness of competition and self-servingness did not subside and unification and strength develop until the latter half of the
19th century. The AMA increased in numbers and it successfully lobbied for strict licensing of trained practitioners and exclusion of other kinds of medical practice in the hospitals that were springing up in large cities. Thus hospitals, and later long-term care, dominated by the medical establishment, arose at a time when the American family was finding the care of its sick and dependent an increasing difficulty.

Public surrender of authority to medical science also occurred because medicine became a more respected science. At a time when scientific rationalization, technology and specialization were being widely stressed in industry, these same developments in medicine made it seem more effective and respected. The social costs of this are summarized by Starr:

Science shares with the democratic temper an antagonism to all that is obscure, vague, occult and inaccessible, but it also gives rise to complexity and specialization, which then removed knowledge from the reach of lay understanding. For a time in the first half of the nineteenth century, the democratic claim of accessibility and universality prevailed in medicine. But the public, through its legislators and its own private decisions, gradually relinquished that claim as it became more convinced of the growing complexity of medical science and the limits of lay competence.

This surrender of authority occurred not just on a social level where public health and medical care were turned over to the medical community. On an individual
level as well, the relationship between patient and doctor changed dramatically at this time. Eliot Krause, in *Power and Illness*, characterizes this relationship as one of inferiority-superiority.\(^{17}\) Starr would agree with this because he notes that Talcott Parson's earlier work in describing the "sick role" did not adequately encompass the ambivalence and the unbalanced power in the doctor-patient relationship.\(^{28}\) All agree that displaying passivity and deference to the authority of expertise had become the societal expectation of the patient. This has begun to change in the last decade.

Parsons describes the rights of the sick to exemption from normal social responsibilities and allowed helplessness and dependency. The patient's obligations, however, are to desire health and seek competent medical care. Assuming the sick role, to Parsons, places the physician rightfully in a position of high authority.\(^{29}\) Other observers of this same doctor-patient relationship dispute this judgment. While the doctor may presume that he has vast authority, the patient may indirectly assert his own control. In fact, some have characterized the basic doctor-patient relationship as one of conflict.\(^{10}\) Consumerism is especially eroding any notion of supreme authority the medical profession might have assumed. Even the authority granted because of technical expertise, which has been
hard gained in this century, is threatened by the latest self-care trends.

A young doctor, Mark Rosenberg, in the notes accompanying a pictorial essay about patients, describes the control issue this way:

Physicians can use their social status, training or education to intimidate patients. They have the advantage of ... greater knowledge ... can further intimidate .... by resorting to jargon ... can label something an "emergency" thereby unilaterally assigning priority.... Physicians keep their clothes on, while patients take theirs off. Physicians stand up while patients lie down. Physicians control the appointment schedule and have the power to keep patients waiting. Physicians also control referrals and access to medical resources. Finally, the physician has the power to certify who is ill.

At the same time he elucidates the patients' tools of control, less numerous though they may be:

They need not seek medical care. They can refuse to pay, seek second opinions or shop around for a doctor they do like. They can minimize or exaggerate symptoms or give misinformation. They can refuse to comply with the doctor's orders. And they can intimidate through threats of malpractice litigation."

Notice that Rosenberg's examples do not usually allow for direct, verbal confrontation. I suspect that doctors and patients are not directly confrontive because they fear their relationship is too tenuous to withstand such confrontation. Putting the matter of degree of authority aside, this is clearly not the same contractual or business relationship with the patient as in former times.
This inequality in the treatment of the disabled today is analyzed by Griggens in her essay, "The Disabled Face a Schizophrenic Society." She complains that the authoritarianism of doctors is "racked with problems in control over decision making, the use of technology and lack of concern for the quality of life." She feels that doctors are the people who today carry out our wishes and "embody our moral confusions." Her fear is that in entrusting our mortality to medicine both individually and collectively we subjugate our responsibility to a warped institution.

Whether medicine's authority is absolute or not, the literature (and simple observation) suggests that medicine in the past 100 years has insinuated itself into more and more aspects of daily American life. It is often an ultimate authority for our legal system in adjudicating "competency," which is a legal not a medical term. Its authority extends into the educational process in the labeling, assignment and teaching of children. As a gatekeeper of public entitlements, the medical system determines who is able-bodied and mentally sound to work. Observation and common sense on the part of trained workers in the field are not sufficient. In the case of children the instincts of a parent are suspect without confirmation by medical authorities.
The reliance on hospitalization to treat illness as well as to house the sick and recuperating has also given authority to physicians who, as mentioned previously, early gained control of the hospital. Margaret Read poignantly describes the perspective of a new hospital patient in a primitive, rural society in which modern medicine has been introduced. The patient expresses concern for the separation, sense of loss of the wholeness of his world. We can assume that in the early days of American hospitals, patients and their families felt a similar sorrow and dread, especially given the record of early hospitals when infection, hopelessness and death were the norm.

Nevertheless, individuals continued to seek hospital care until the practice gained wide acceptance. Several factors can explain the increasing acceptance of hospitalization to treat illness. First, death in the year 1900, for example, was more often attributable to acute diseases of short duration. Without antibiotics there was little to be done by a practitioner. By 1970, deaths more often occurred due to chronic diseases with long and uneven courses. Hospitals can practically handle acute phases of certain chronic diseases. As chronic and debilitating diseases most taxes the family resources, their relative rarity compared to today made the support of hospitals in family health care less needed. As the cure rate for
certain diseases improved, the hospital became a more hopeful place to send a family member. Secondly, as stated previously, urban life with employment outside the home, smaller households, as well as accessibility to medical centers made hospital care more customary. Thirdly, changes within the family—its encapsulation and withdrawal from the community—fostered, according to Stannard, a more institutional approach to the care of the elderly. In fact, urbanization and the treatment of the sick in hospitals Talcott Parsons and Renee Fox speculate that the modern family lost not only practical means to care for the sick but their emotional ability as well. Stannard, speaking of death and the isolation of old age, attributes the unbearable trauma to lack of "an ego-supportive community."

The superordinate position of the physician can be seen in all areas of life. The leading baby care books are written by physicians, not parents. The final authorities on normal and abnormal feelings are psychiatrists. The previously normal and healthy state of pregnancy is now a major medical and financial concern of physicians and hospitals. Life itself is referred to in what Illich calls "medicalese" by such words as neonatal, newborn, pubescent, menopausal, geriatric. Doctors are regularly consulted throughout a lifetime, even for untreatable or
questionable problems. In the course of many chronic conditions the office visit affords nothing more than reassurance to the patient and little if any intervention. Perhaps the anxiety which necessitates these frequent visits and preoccupation about health comes from feelings of loss of control, lack of understanding of one's body and submission to medical science.

This is nowhere more true than in the care of the aged when doctors are asked and routinely answer questions about the future which logically one knows cannot be predicted. Consider the family who asks whether a parent is strong enough to stand sad news or a trip to visit a loved one. Consider the decision to place a parent in a nursing home, which, for medical insurance purposes, is never arrived at by the family but by the "doctor's order". No particular training is given to physicians to answer these and many additional life decisions for others. It is arguable that their instincts and experiences no more qualify them than those of the family or individual concerned.

As a result of the changes within society, the family, the work place and the medical community, the care of the frail aged has become more the responsibility of medicine and its ancillary services, less the responsibility of the family and the community at large. The adequacy of care
for the frail in earlier times (if it is judged by kindness freely given) was variable and related to the resources of the family, the status of the aged and the economy. It is possible that the American family has been relieved of the seeming burden of care for the frail without anyone's clearly realizing the social and personal costs of segregating the infirm from daily life. The literature suggests that the care of the infirm that has been relinquished to the medical establishment varies and perhaps has deteriorated.

Ironically, once medicine and government had created the policies and procedures of care for the aged, they then turned to advocating less involvement and responsibility. The major institutions for long-term care of the frail--Medicare, Medicaid, the hospital and extended care facilities--are at odds with one another over who can bear more of the economic burden. In the face of the ever increasing demands of a larger aged population, the latest trend is to encourage a return to family/home based care.

Marge, Nobuo, Claire and Norman were all living within their private residences as the interviews began. Two eventually moved to extended care facilities, one following a subsequent stroke and the other after finding the dependency on family too degrading and dissatisfying. The treatment for the CVA's these four experienced has varied
in past years. Prior to the 1950's each would have been treated in an Emergency Room, sent home with or without a naso-gastric tube depending on their ability to swallow. Increasingly in the 1960's they would have been sent to rehabilitation hospitals, provided they met the criteria for rehabilitation, or to long-term care facilities. These criteria for rehabilitation were based on current scientific thinking and were quite age biased. More often, the aged stroke patient eventually ended up in custodial care. In the past decade and a half, the aged's rehabilitation potential has been discovered and, they now are given help more often than previously. Most recent is the trend to more independence or dependence on family living rather than long-term care. All along, what has been most significant is that the medical establishment has determined the disposition of these people, who more and more have become "patients" and less and less individuals. Their ambivalently dependent relationship with American medicine is of primary significance for the four people who are the subjects of this dissertation. Likewise, the confusion and rolelessness of their family relationships (other than with spouses) and their isolation from the community in all its forms, from friends to neighbors to encountered strangers, is at least as
disturbing to them as their relationship with the medical establishment.

It seems that the anxiety of being old and sickly persists on account of its social consequences as much as its physical costs although the social structure of care has been destroyed and refashioned.

In this chapter, I have attempted to trace the rise in authority of American medicine, the subjugation of the family in health care and the general vulnerability of the ill aged to these trends. In the introduction, the separate and negative status of the handicapped with its social ramifications was described. These chapters set the stage for the heart of this work, which is a dialogue between the frail and us as professionals, as family members and as citizens.
Notes


3Ibid., p. 153.

4Simone de Beauvoir, The Coming of Age (New York: Putnam, 1972), p. 79.

5David Fischer, pp. 8-10.


7Achenbaum, p. 29 and p. 80.

8Ibid., p. 39, p. 52, p. 54, p. 57.

9Fischer, pp. 27, 29, 30.

10Achenbaum, p. 51.


13Albert Rosenfeld, Prolongevity (N.Y.: Alfred Knopf, 1976).


15Fischer, p. 165.


2. Fischer, p. 162.

3. Ibid., p. 114.


6. Achenbaum, p. 45.

7. Starr, p. 47.

8. Ibid., p. 102, p. 127 and p. 223.


10. Ibid., p. 59.


3"Starr, p. 5.


3"M. DiMatteo and D. DiNicola, p. 4.


4"Stannard, p. 12.

Chapter 4
The Disabled Aged's Relationship to Medicine

When asked what being hospitalized was like, Marge angrily said, "They expected me to behave myself and take what was coming to me!" In a word, she found the treatment "despicable." For Claire, entering a hospital signified her death although she had been hospitalized countless times throughout her life. When interviewed, she believed that doctor error had cost her the lives of her eldest son and her husband. Nobuo was also very angry, not so much at hospitals as with physicians. His most serious stroke occurred a day or so after his doctor refused to take his blood pressure during a regular visit despite Nobuo's history of high blood pressure and strokes. He thought Nobuo was trying to tell him what to do and so he haughtily refused. Norman was most angry and resentful toward the whole medical system—from the physicians in England who minimized his condition and sent his wife off touring Europe without him to the next seven doctors who in his mind failed adequately to support, educate or treat him. He came to believe they had awakened in him the need to preserve himself against the treatment of doctors.

Despite the incredible amount of anger, disappointment and bitterness these interviews revealed, all four of the individuals remained the regular patients of traditional
physicians. All acknowledged their own significant limitations in healing themselves, and so the medical community retained its hold on them.

Their anger seemed not so much directed at the medical establishment as at individual physicians, not at the hospital but its staff, not at society in general but its members. It was deeply personal—a private matter between themselves and another human being. Only rarely however was there any attempt to resolve their grievances by direct confrontation or negotiation and never to their satisfaction.

Nobuo reported three times in which he tried to confront the person causing his anger directly. The first time was described in the opening paragraph and of that instance he says:

Well, I had a doctor, but my doctor is Caucasian and he retired before I got the stroke and he gave me to the heart specialist at Clinic and I had a stroke, slightly, still able to walk. But I went, they had changed the procedure where the nurse doesn't take your high blood pressure, they turned it to the doctor. And I told the doctor, "Since I had my last stroke you haven't taken a reading of my high blood pressure." I don't know, he's the type of guy because I told him, he wouldn't take it. And I got this stroke a few days later.

Well I held it against him 'til now, then I thought oh well, let bygones be bygones.

....

Well he met me at Hospital on Saturday, and I guess they rotate and take all the other doctors'
patients. And when he came, he apologized. I guess it's a bit late. He did apologize and that's the first time they all apologized to me. They all gods you know.

He also angrily complained about a cafeteria worker who consistently avoided him rather than help him with his tray despite his obvious paralysis. Finally, he appealed to his insurance carrier not to pay for a doctor's visit when the equipment was not functioning and he did not receive the electrical stimulation to his paralyzed hand for which he was scheduled. Instead, the doctor used the time for health education, a worthless session for Nobuo, who has been in the stroke health care system for several intense years.

Norman also tried his hand at complaining directly. When his Health Maintenance Organization (HMO) physician told him that his records indicated that cataract surgery had been recommended previously, Norman bitterly pointed out that he had no recollection that this was discussed with him. Merely writing things in the record was insufficient—information had to be communicated to the patient, he insisted. The resolution? Norman rarely used the HMO his employer paid into and instead turned to private physicians largely at his own expense.

Neither Claire nor Marge reported any direct confrontation or effort at negotiation with their physicians or health care providers. Both have changed doctors
because they were dissatisfied, but they never communicated this to their previous physicians. Except for the bittersweet and belated apology to Nobuo, no one reported satisfaction from complaining. Norman, however, was sent to a psychiatrist because of his generalized anger, and he reported immense satisfaction at using the sessions to dump on the various doctors who were then treating him! This is in sharp contrast to the kinds of patient-doctor conflicts described in the standard medical journals. Except for a few examples of physicians who criticize their peers in popular literature, doctors' self-criticism focuses on:

1. Inadequate time spent with patients (noted 3\(^{-1}\) times in search).

2. Failure to communicate satisfactorily (noted 4\(^{-7}\) times in search).

3. Diagnostic or treatment error (noted 4\(^{-1}\) times in search but, every technical article by virtue of it being written implies, "a better way").

4. Dangers of stereotyping patients or imposing personal values on them (noted 5\(^{12^{-10}}\) times in search).

Many medical texts focus upon the patient; these vary from discussions of psycho-social needs to "managing" the patient through behavioral techniques. Doctors who have written books critical of their profession confirm that the inherent and fundamental problems and flaws of the
doctor-patient relationship are missed in the traditional literature. In advocating a new relationship between doctors and patients, Belsky admonishes the consumer to be assertive when he says, "It's not enough for the doctor to stop playing God. You've got to get off your knees." Lipp, a psychiatrist who views his colleagues as victims of the failed relationship between the public and the physician, claims that,

I would like to help you understand the quandary of the reasonably conscientious practitioners who care about patients as human beings but whose performance nonetheless fails to not only live up to their patients' expectations, but also to their own personal expectations ... there is a growing morale problem ...

Many of these physician-authors suggest that the current practice of medicine, especially the doctor-patient relationship is so flawed that only radical change will do. These concerns are barely alluded to in the journals of medical practice.

While the journals may not report it, the AMA is aware that serious problems in the relationship exist and are evidenced of it in escalating malpractice claims. The AMA, according to the New York Times believes that the image of the physician and medical treatment as always successful has led to high patient expectations and frequent disappointments leading in turn to lawsuits. Medical schools and practicing physicians have reinforced
those expectations with their "reassuring and self-confi­dent air." The AMA plans a 1985 campaign to encourage doctors to be more candid and hopes for a "massive change in public attitude."

Let us return to what the journals did report as problems. The time constraints of a busy practice which interfere with a sufficiently personal doctor-patient relationship or adequate medical history-taking were not mentioned by my four subjects. Marge complained about communication failure because, ironically, she with her profound, global aphasia, had been assigned a Chinese-born and poor English-speaking doctor. Norman complained, of course, that by and large certain doctors were unwilling to communicate with their patients. The journals cite class, age, race, economic and language barriers as communication problems, not the deliberate withholding of information Norman insisted upon. As for Marge's concern, while about 20% of newly licensed physicians are foreign born, the implication in the articles on communica­tion is that the patients have trouble with the English language! These articles suggest that the failure to communicate is related to conveying an adequate sense of caring and compassion. What no work ever states, not even the most critical of books (except Illich's, and he is not a physician), is that doctors do not care about patients.
Yet this was exactly what Norman, Nobuo and Marge suspected. Norman summed it up this way, "I generally have no use for doctors and don't want to relate to them. . . . If they listen, if they care about people then I like them. If they don't, I don't." Elsewhere, he lamented that it took seven attempts to find a doctor that would listen and care for him.

Consider the following as an example of what is not said about the doctor-patient relationship in the journals. An article entitled, "Pituitary-gonadal Function in the Aging Male: The Male Climacteric" introduces the subject of male impotence by noting that scientific advancement is ever-increasing the known organic causes of impotence. Once, 95% of male impotence was attributed to psychological causes; now more and more has been found to have an organic etiology. There is no professional acknowledgment of the harm and hurt that might have been inflicted on the countless men who were wrongly told their impotence "was all in their heads." Nor is there a professional warning for the future not to diagnose men in terms of current knowledge without recognizing its incompleteness. This speaks to an important issue which I believe the four subjects of this dissertation were trying to articulate. Physicians believe they know now what is correct and complete and that the patient has no
grounds for believing in the possibility of error or ignorance.

Other journals items reveal that 20% of deaths attributed to heart disease have been incorrectly diagnosed. That while patients at risk for stroke have good diagnosis and initial treatment, 42% have gravely inadequate follow-up. The ever-increasing popularity of pacemaker surgery fails adequately to acknowledge that somewhere between 5% and 25% of the patients have postsurgical emotional trouble of a severe and debilitating nature. The point of these revelations, according to the authors, is that doctors need to be ever vigilant concerning their fallibility and continually strive to improve their practices. A more realistic and humane message is entirely overlooked. Patients, consumers if you will, should be warned and educated about the inevitability of some failure in treatment. I believe that had such warnings been given to the four subjects I interviewed, it would have lessened their anger. They could not tell, because of the doctor's aura of confidence, what was fact or theory. As they were unsure of their doctors' affection for them (as stated in previous paragraphs) and as they each (except Marge) beheld examples of failed treatment, they grew suspicious and bitter.

Consider Claire, whose husband died during the recovery period from gall bladder surgery. Claire's personal
experience with gall bladder trouble made her doubt the initial diagnosis. Then, as he grew tired and weak instead of improving in the period following surgery, she and her husband appealed to various doctors for help. She bitterly described how one doctor offered to repair his congenitally defective nose as if that might help. They were not told why he was failing or that no one knew the reason. Yet she blamed herself—after a lifetime of experience with medicine, she should have gotten a second opinion about the operation to begin with.

The critical moment of disillusionment came when for all of the doctor's confidence, the treatment failed. Of this, Norman said,

... my stroke really changed my opinion of medicine. It made me realize that, maybe 50% of the doctors are not really qualified. ... I really respected doctors [before] I liked doctors. But I got this feeling [now] they don't know anything. It is terrible but it's true. ... At _____ Hospital if I could only tell you the manner in which they would stand up here and you down there and tell you this and that. I just couldn't stand it. And their problem was they would not listen to me. Never listen. He would examine something on me and say, "This is my diagnosis," and I would think to myself, "What the hell? I don't feel that way at all!"

The disillusionment occurred again and again, like a lesson not completely learned. At the time of the interviews, Nobuo was changing medications after three years. As he understood matters, he had been taking a medication
poorly suited for him all of that time and it had resulted in some recent stroke-like symptoms which had put him in a wheelchair. Ironically, Nobuo felt confident that his medication regimen was now correct despite his ominous sounding words.

Then the doctors told me that I was taking the wrong type of pill for three years. And I guess it all accumulated. Now I'm taking an alternate pill and I get dizzy on it but they had medicine for that; I'm all right now ... 

In reference to his urinary urgency problems he went on:

From now, but I don't know if I can make it because I have that problem of going to the restroom getting faster and faster. I can't control that. I think my insides are getting weaker and weaker with all the pills I'm taking.

Though these subjects said little about it, it appears that for all their anger and disillusionment they wanted to continue to have faith. A discussion of this will follow later in this chapter.

Nobuo said, of his increasing bladder difficulties, that while he kept telling his doctor, the answer was always that there was nothing he could do. An interview of mine with a local neurologist, Dr. Stanley Batkin, regarded as quite sympathetic to the patient's problems in getting good medical care, spoke to this point. He lamented that telling a patient there is nothing to be done about a condition is an all too common failing of
medical practice. First, it is often an outright error because specialists can often diagnose and treat specific conditions that an internist cannot. In Nobuo's case, he had not been referred to a urologist. Secondly, this kind of statement is a fundamentally erroneous statement regarding medicine, according to Dr. Batkin. Medicine, it seems, is forgetting its task of providing comfort and reassurance which he believes are as important as treatment. A doctor's message, when he says, "there is nothing I can do," is "don't come back to me with this same complaint." Yet it is the nature of chronic illness that the same complaints and symptoms continue. I would add that it is a narrow and egocentric attitude which closes all of the doors of hope when only medical hope is gone.

In concluding this section on disillusionment, it seems that two factors are equally important to the patient. The first is the physician's air of confidence and self-assurance, and the second is his imperfect medical treatment. Medical journals devote much space to correcting errors in treatment and diagnosis. In fact one could say that that is the point of having professional journals. However, very little space is given to changing the doctor's demeanor or questioning its efficacy in treatment. Further, while the space devoted to improving medical technique ultimately helps patients, given the
inevitable fallibility of medicine, more space devoted to teaching patients consumerism might better protect them. Finally, the journals all but ignore the charges of the physicians writing to nonmedical audiences that there are troubling and gravely serious problems in the current (and past) doctor-patient relationship.

Another major area of concern addressed in the medical literature is called "patient compliance." The word compliance itself is telling. It implies acquiescence or yielding rather than cooperation. Two other words in common medical usage are "orders" and "management", neither of which suggest a democratic relationship. Belsky, a physician, recalls his first distaste at hearing the word "orders" and then how he gradually came to think that "Compliance is old fashioned medicine. Cooperation is interim medicine. Mutual participation is modern medicine --being part of the patient-doctor team." Compliance, management, and orders are dehumanizing words, not unlike the ones Nobuo used at the beginning of this chapter. He said his retiring doctor "gave" him to a cardiologist and that this doctor did not meet him at the hospital until Saturday because doctors "take" each other's patients on certain days. These kinds of references, used by both doctors and patients, confirm the inferior status of the patient.
For Marge, compliance certainly meant dehumanization. She saw it as "quietly taking what was coming to me", not unlike a punishment meted out by a superior. Claire, with a rich Chinese heritage, dared not tell even her Chinese doctor that she and her husband sometimes tried herbal medicine. Norman, finally finding a doctor he could respect, merely reached a truce regarding the large doses of Vitamin C he took. He did not find a willing supporter of his self-treatment although the Vitamin C treatment had originally been recommended by a traditional physician doing local research.

Medical literature has much to say about compliance and, according to Belsky, most of it points out patient deficits as its major cause. Doctors often write that patients are unknowingly not complying because of communication breakdown. One article on compliance demonstrates the extent to which doctors "blame" noncompliance on patients and the extent to which they believe their authority allows them to change this negative behavior. Edward Scharfman and Richard Shader write that when a patient refuses to take medications because of some personal beliefs, values or motives he is obviously in the wrong. This error permits the doctor to exercise increasingly coercive tactics in gaining compliance. They suggest:

1. Finding out through probing if resistance to medication is an issue.
2. Being empathetic and patient, not taking the refusal personally.

3. Combating consumerism with such reassurances as medicine is merely a synthetic form of natural substances.

4. Confronting the patient's denial that he does not need medication and acknowledging his fears.

5. Referring him for psychiatric treatment if he seems to enjoy remaining ill.

6. Using the risk-benefit approach to patient concerns about side-effects.

7. Correcting deficits in failure to comply because of misinformation or appearance of being too busy, impatient or technical.

They go so far as to suggest telling spouse or employer if the patient's refusal to comply is prolonging his illness. Finally, the authors lament that even with the best approach some patients "will simply never take medications." With an approach such as this, it is no wonder that language-limited Marge or demure Claire chose the more passive route of switching doctors rather than insisting that they did not want a certain type of treatment.

What reasons did Claire, Norman, Nobuo and Marge give for noncompliance? For the most part they did comply or thought that they did. Even Nobuo, who believed doctors thought they were gods, said, "Well, I think I'd be pretty foolish since I don't have any medical stuff except what I read and usually, 90%, I'm wrong. The doctors went to school for something." Nobuo showed extreme trust and
compliance. He retired early at his doctor's urging (though he saw the necessity of it, the timing was the doctor's) and, remarkably, he stopped drinking at a doctor's order. Still, if Nobuo loses confidence in a doctor, he will change to another one.

Marge ignored transient ischemic attacks for a year prior to her stroke. One could call this refusal to go to a doctor a kind of noncompliance since the public is admonished to seek prompt treatment for any kind of body/health change. But once in the hospital, aphasic, paralyzed and bed-ridden, she saw no choice but compliance for eleven months. She resented the routines, the orders to dress, eat, recreate, bathe, etc., but she complied. Her lack of speech must have made her seem an ideal patient. In fact, after the interviews were complete, Marge had another stroke and I was able to witness the extent to which she could be compliant. She ate what was given her. She dressed when the attendants came with garments and assisted her. She cooperated with endless examinations at any resident's whim. She tried desperately to understand whatever they told her, and she never asked questions. She seemed to have no opportunity to refuse to comply as she was offered no choices.

Not all patients in such a position cooperate so earnestly. Some refuse to eat, grow restless, resist
treatment and medications. Marge chose compliance for herself. Any failure was a result of her intellectual impairment. She could not report symptoms, and she might forget to take her medications properly. Even after her first hospitalization, when she had the Chinese doctor, she tried to follow his instructions faithfully despite not being able to understand him. What did she want from the practitioners? "Respect. Respect for my dignity," she said on one occasion. Later, she insisted, "I didn't want to be [treated as if I was] a nuisance and I wanted to be shown some courtesy. And I wasn't." I suspect that what Marge wanted was to be made a party to her treatment rather than the object of it. Knowing her as I had grown to, I had learned that she had personal rules of not disclosing much about herself to others, of not feeling comfortable with physical contact with strangers, of modesty. She resented their expectation of her compliance and their not discovering or respecting her values.

While much is said about patient compliance, little, according to Lazare, is said about what the patient wants from medicine. He believes this stems from the medical community's reluctance to believe that patients have demands. That doctors have been able to escape this issue is probably due to patients' indirectness in complaining. According to Rosenberg, patients can choose not to comply
once they leave the office by switching doctors, refusing to pay or suing, but rarely do they assert themselves in the office in face to face encounters. Given doctors' insistence for "following orders" as outlined by Scharfman and Shader it is no wonder that the ill patient seeks less direct methods of assertion.

Consumerism, cited as a new threat in the medical journals, can also be viewed as liberating. In fact, the consumer-oriented books by physicians report a feeling of incredible relief and freedom once a patient shakes off the medical mystique and embraces the new religion of "patient responsibility." Rosenfeld, in Second Opinion, states that an informed public [patient] can only "strengthen the doctor-patient relationship," but he does not go so far as others in criticizing what currently exists. He states that the relationship between doctor and patient is and always has been good and that it will withstand the patient's seeking second opinions. He attributes the failure to do so largely to patient timidity and only partly to over-inflated doctor egos.

Belsky, who fully accepts consumerism and individual responsibility, claims,

The consequences for medicine are marvelous to consider. They could mean an end to timidity, fear, confusion, inarticulateness and ignorance among patients. ... They could mean a beginning of a truly helping participation between doctor
and patient—with multitudes of lives enriched and extended.\textsuperscript{47}

Perhaps the most troubling book about consumerism and the doctor-patient relationship has been written by Martin Lipp, a psychiatrist. He begins by describing many troubled physicians and seems to have much sympathy for the patients who are shortchanged. As his own anger increases in writing the book, he begins to see physicians as the more wronged party. They are wronged by a system which expects them to play far too many roles, from administrators, to guardians, to gatekeepers, to mediators, to perfect healers. Lipp is concerned that in doing so we, as a society, are demoralizing our doctors. He seems to lament the harsh criticism leveled by consumers and says that:

The physicians of today, raised with the ideals of the past, often find it difficult to function comfortably in the evolving system of the present. Their internal demands are in conflict with external realities. The real world in which they function fails to support the inner sense of dedication which many doctors feel, and which the public seems to want doctors to feel: to be special to the patient, and to make the relationship between doctor and patient personal and uniquely powerful. The failure of expectations has practical consequences too; for without this specialness, the doctor's power to influence and to heal is weakened.

Lipp adds that the critiques of medicine by consumers, the media and lawmakers have undermined physicians' confidence. He describes them as
... assaulted from within by the impossibility of knowing everything they feel they have to know ... and assaulted from without by a system that removes authority and forces adherence to conflicting allegiances, by a patient-public that increasingly assumes an adversary stance, and by a society that devalues and sometimes even seems to punish experience, expertise and the assumption of responsibility.

Given the ambivalent expressions about the medical profession from the four subjects of this dissertation, Lipp's disturbing suggestion that the public wants the impossible from the doctor must be at least partly correct. For all of the complaints about arrogance, incompetence, their impersonality, these four kept returning to doctors not so much because they felt better but because they had a basic faith in medicine and doctors and they ascribed magical powers to them.

Claire's devastation following the death of Robert became a medical problem by her choice. She sought relief from depression through medical means and her suicide attempts were statements to her doctors as much as to her family that their cures were not working. Finally she decided to move into a hospital-like facility to escape the conflicts she was feeling. Norman also continued seeking medical treatment. He even sought psychiatry to deal with the anger that he felt doctors had evoked. He less than jokingly suggested that doctors should be the ones to decide who among the disabled should live or die.
Marge, the most dependent of the four on medicine and its ancillary services to survive, was least captivated by it. She never ascribed any magical or special power to medicine or its practitioners. She accepted passively what was done to and for her, she never alluded to any hope that they would offer something miraculous would be offered to her. She said that she was "resigned to my fate," and I believe she saw no specialness in doctors. For this reason, despite her incredible physical dependency and the unyielding demands of her medical care, Marge had the fewest expectations.

Nobuo, unlike Marge, had a basic faith in medicine for all his criticism. Faith is the appropriate word because it sometimes seemed to defy logic. Following his severest stroke, he said his wish was to get better and he believed that through his hard work at the Rehabilitation Hospital he would improve. In other instances as well, such as stopping his drinking or changing his medications, he seemed to indicate that he believed that his cooperation with physicians was the key to good health.

Norman, too, for all his complaining continued to seek magical cures from medicine. Shortly after the interviews he embarked on a new treatment program in conjunction with psychiatry to lessen his intellectual impairment and dizziness.
While there is disillusionment, the mystique survives. Some of us want a deity to relieve us of the anxiety of illness or suffering. Some of us want to believe in doctors' infallibility (or a judgment that is better than our own). If we do not want entirely to absolve ourselves of responsibility (as the mystique usually suggests), we at least want to share that responsibility and potential blame. Medicine is much more than a series of rigid protocols; it is judgment calls. If intellectually we know this, emotionally we hope for divine intervention.

In addition to blind faith in medicine, there were some genuinely positive experiences which sustained these subjects in their relationships with medicine. Claire, when family problems were the worst, saw certain physicians as lifelines and hospitals as sanctuaries. Marge always dressed up for doctor visits and as far as I know doctors were the only men in all of society who regularly acknowledged, touched and spoke to her. Young residents smiled at her. Outside of medicine, society offered no such affection. Nobuo was indebted to the Rehabilitation Hospital. After each stroke the staff helped him back to independent living—that which he valued most. The demands of rehabilitation suited his personality and he undeniably improved there. Norman was sustained partly by hope that he would improve, that his symptoms would
diminish. Were it not for the new treatments he occasion­
ally discovered were being tried, I suspect his zest for life would have diminished. Rachael and Norman kept abreast of new medical programs for stroke patients and enjoyed the hope they offered.

The medical establishment had grave faults in the eyes of these four subjects, but it was not guilty of abandon­ment. This was very important to them.

Before concluding this chapter on medical care and the evolving relationship between practitioner and the chron­ically ill, a discussion of nursing as distinguished from doctoring is warranted. Marge was prejudiced against nurses from the outset because of an affair her husband once had with a nurse. Further, I suspect because of her extreme physical dependency, nurses violated her personal space more than other health care providers. Norman did not have much to say about nurses except that he preferred them to doctors. The others said nothing. This was unfortunate but revealing.

The most important health care provider to a sick per­son is the physician because he is the head of the medical treatment team. But nurses have begun to take themselves more seriously and it is evident in the journals. A review of Rehabilitation Nursing for a two-year period uncovered a dialogue among nurses regarding the goals of
rehabilitation itself. In an effort to take the goal of independence and self-care for the disabled to its logical conclusion, some nurses have mentioned that in addition to teaching patients to care for their own needs as best they can, it is also important to wait to provide assistance until the patient initiates a request. Bathing, dressing, eating and pursuing other activities of daily living should be the decision of the patient, as it is in the outside world. This goal is lofty, and the logistics of realizing it in a hospital facility are mind-boggling. What is important is that nurses are looking closely at their relationship with patients and seem to be willing to question the extent of professional control. Though not all the authors fully agree, the central theme of this debate is patient leadership and responsibility in his care plan and care.49-51

While anger, disappointment and disillusionment were articulated by all four of the subjects of this dissertation, they continued to seek out a special therapeutic relationship with physicians. A year's medical records for any one of them reveals few, if any, missed appointments or notations of noncompliance. They would appear to be good patients, cooperative and communicative. Except for Marge, who would have had to act to avoid medical care by resisting, fighting, communicating her refusal as best
she could, the others need not have done any more to opt out of the medical system than avoid it. Yet they did not. They were unwilling to close the door on the hope for the enticing gifts of medical care: freedom from pain, health and extended life. They got a modicum of care from medicine when society's offering was insufficient. I suspect that while they would have been less angry with a doctor who admitted his fallibility before he failed, they believed the doctor of the true mystique exists: the perfect, intensely compassionate, priestly healer who personifies American medicine.

Agnes DeMille, a choreographer/dancer and daughter of Cecil B. DeMille, wrote a book about her experiences following a stroke. Though she herself did not particularly recognize it, she used her performing instincts to get along in the medical system. She enjoyed the attention; she was always "on"; she surrendered "detail" to doctors and other professionals. She cooperated with therapy as though it was a rehearsal. In a hospital she was different, set apart from "normals," but as a "star" she felt comfortable in that role. She must have given doctors the same kind of respect as directors. In short, she adapted to a patient role without much damage to her integrity.

My four subjects were not so successful. The burden of being stigmatized by handicap began in the hospital.
They were acutely aware that they were not normal, and unlike DeMille they believed they were inferior, not superior. They struggled through the reorganization of self with input from an institution that they were compelled not to forsake despite its harshness toward them. In their minds, in this new world they were inferior and supposed to be passive. They surrendered their personal authority to physicians who represented themselves as omnipotent. And they kept their faith in the system even when medicine and physicians failed them. Nobuo's, Claire's, Marge's and Norman's struggle for a new perspective, for a self-oriented consumerism was just that, a struggle to redefine their relationship as chronically ill patients to the system which treated them.
Notes


M. Robin DiMatteo and D. Dante DiNicola, Achieving Patient Compliance (New York: Pergamon Press, 1982). This is eclectic.


Belsky, p. 31.

Lipp, p. 7.


14Lubomir Valenta and Alan Elias, p. 67.

15"Do Fewer Autopsies Mean Less Geriatric Knowledge?", p. 19.

16"Preventing Stroke," p. 46.


18Stanley Batkin, personal interview, October 26, 1984.

19Belsky, p. 169.

20Belsky, p. 158.


24Leslie Champlin, pp. 120-126.


26Rosenfeld, p. 40.

27Belsky, p. 46.

28Lipp, p. 147.


Chapter 5
The Disabled Aged's Relationship
With Family and Friends

Norman and Claire had, by the time of their strokes, proven the staying powers of their marriages. Neither ever reported a time of serious marital conflict, and both reported an increasing intimacy in their retirement years. Nobuo and Marge, on the other hand, had been divorced in their child-rearing years, and neither had remarried although they had been socially active with the opposite sex. Because of his wife's infertility, only Norman's marriage was childless, although he maintained he would have chosen a childless lifestyle anyway.

This chapter will explore the marital, offspring and other social relationships of the four subjects, in the context of a selection of multidisciplinary literature about the state of the family in American society. The literature is both diverse and vast, and selecting texts has been difficult. I have not considered the literature of ethnicity and economic variations in family life for several reasons.

My four subjects, by happenstance, were neither poor nor wealthy. Nobuo's income was slightly under $1,000 a month, Claire's was similar although she also held some real estate. Marge's income was also about $1,000 a month,
largely investment income, the principal from which she dipped each month for her care expenses. Norman's income was much more substantial, drawn from retirement benefits, investments and other sources. His income was easily $25,000 a year. Their economic status is important to a section about families because the literature often distinguishes the poor from the middle class. ¹⁻⁴ While this distinction long remained significant, as Simone de Beauvoir's observations about care of aged in impoverished vs. prosperous primitive cultures suggests, it is not relevant to the cases under consideration.

Neither is ethnicity an important factor in my discussion. Despite the subjects' varied ethnic backgrounds (Jewish, Caucasian, Chinese and Japanese), I obviously cannot claim that they are representative of their subcultures. Indeed, I could argue that they are not. Nobuo was divorced, distant from his children and claimed not to be in touch with his Japanese heritage. Norman was not particularly enamored of Judaism as a religion although he was proud of his Jewish heritage. Marge spent much of her life in California and her Caucasian background was generic at best. Only Claire's life had been closely tied to her ethnicity, from the Chinese furnishings (although overall her house is a mix from travels around the world), to her social clubs and predominant friendships.
I have treated these four people in their individual circumstances as Americans, functioning in the larger American society with whatever resources and limitations they individually possess. While their circumstances are individual, I have maintained that they and their families are representative of some portion of 230,000,000 Americans and important because so little is known of their struggles.

From the interviews, marital relationships were vastly different than any other ties to family members. Norman was married and Claire had been recently widowed and both of them attested to a near-perfect bond unjeopardized by their handicap. All of the three with children experienced no such harmony or acceptance from their offspring. As stated earlier, the thirty-plus year marriages of Norman and Claire had already been tested and proven to be without serious conflict. Interestingly, outside observers of both marriages disputed this. Claire's children saw her as too passive and their father as too accommodating. Professionals observing Rachael and Norman had often thought she was too domineering. In the interviews, however, it was clear that neither of the subjects saw these potential sources of friction as serious structural flaws in their marriages.
With regard to physical dependency after their strokes, Norman and Claire both reported that, while not liking their limitations, they did not feel humiliation, dread, inferiority or disdain in receiving help from their spouses. Perhaps it was because both of them knew that, were the tables turned, their dedication to their spouses' care would be as deep as that which they were receiving.

When asked how Robert felt about giving her help, Claire said, "Oh, he didn't mind," and later, "I never had to ask [for help]. He always right there to give me. And when he died, oh, my whole world fell apart. You know, I did not need nobody if my husband's there." She later said she did not feel troubled because she would have done the same for him. Claire did admit that her dependent role was an extension of her previous roles, of her not driving or cooking and that, were "times" different, she could have comfortably accepted help from her children as well.

Norman also received daily care. Physically, he only needed help in putting on his socks, but he also did not cook, drive, tend to any chores, handle large sums of money, or make major decisions (such as traveling or socializing) without consulting Rachael. This was unlike their early marriage when they both functioned quite
independently. He worked, wrote, golfed and read without her. Of Rachael's concern for him, he said,

During the stroke, I got to know Rachael. I got to know her like I never knew her before. ... I don't think one woman in a thousand would take the attitude she does toward a stroke ... of being helpful at all times.

Of the reciprocity, he says,

Well, I don't know but I couldn't live without her. There are a lot of practical aspects but that wouldn't be it. I just couldn't live without her because I love her. ... And she loves me more than I love her. At least she shows it more. ... And here is something else I'm thinking about Rachael. Rachael seldom gets sick, except for her heart right now, which is properly medicated. If she got sick, I would have to take care of her, or hire a woman to take care of her. Which I would, I would do my best to take care of her.

He did admit that he might not be as good at caring for her as she had proven to be for him. He attributed this to certain qualities she possessed which he did not. His effort on her behalf would, however, be equal.

Attesting to this bond of mutual care among spouses is the fact that few aged married persons live in institutions or with other family members. Married couples remain independent and autonomous longer than do single individuals. A study regarding increasing dependency in Alzheimer's Disease patients points out that the sex of the care giver is a factor in the ability to provide certain types of physical care. Norman bears this out when he says he would have to "hire a woman" for Rachael. However,
Robert's care for Claire certainly proves that men are capable of providing good physical care if they choose to be.

As a social worker, I know of many instances of abuse, abandonment and contempt between aged partners in a relationship of care-giving and dependency. Nevertheless, I am struck by the many instances of supportiveness and helpfulness. Diapering, lifting and turning the bedridden, listening to the continual babble of the severely brain-impaired, playing along with the fantasies of the demented, keeping vigil in the hospital—all are evidence of the extraordinary lengths to which I have seen spouses go.

Besides the commitment a long marriage proves, what other qualities are striking about the American marriage which help it to endure the test of illness? First, it is romantic and mysteriously deep. Writers often note that basing a marriage on romantic love is uniquely American. Some say this is gradually replaced in the aging marriage with such things as obligation, companionship and comfort. However a recent study suggests that the passionate love once thought to diminish in old age may in fact not diminish. Rather the older marriage takes on an intenser companionate aspect than youthful marriages without lessening its passionate qualities. Claire and Norman both insisted
upon deep marital bonds that possessed an ethereal quality far beyond practical mutual obligation. Believing in this bond of romantic love, described by Bell as including idealization, fantasy, high emotion, and exclusiveness—adds to the expectation of commitment in difficult times.\textsuperscript{11} Exclusiveness was a constant theme of both Claire's and Norman's description of their marriages. As long as they had their spouses, they needed no other. Even if actual feelings of romantic, passionate love are not sustained over time, the belief in these feelings as the foundation of marriage places expectations of unflagging devotion on the aged.

Traditional marriages carry certain expectations of roles which are pervasive and clear in American society. Among eight underlying assumptions of the traditional marriage contract according to Otto, the assumptions of sharing life's troubles and insuring companionship in old age were certainly evident in Claire's and Norman's marriages. Otto also suggests that roles, duties and future obligations are set early in marriage and there is a secure expectation that these roles will be honored.\textsuperscript{12}

Consider the traditional wedding vows which very explicitly detail contractual responsibilities as well as the mysterious depth of romantic love:

The bond and covenant of marriage was established by God in creation... It signifies to us
the mystery of the union between Christ and his Church, and Holy Scripture commends it to be honored among all people ....

The union of husband and wife in heart, body, and mind is intended by God for their mutual joy; for the help and comfort given one another in prosperity and adversity ....

In the name God, I N. take you N., to be my husband/wife, to have and to hold from this day forward, for better, for worse, for richer, for poorer, in sickness and in health, to love and to cherish, until we are parted by death. This is my solemn vow.'

These clearly set forth the depth of commitment a marriage is expected to maintain!

While he calls it merely an "illusion," Lasch describes what Claire's and Norman's marriage seemed. "Americans today invest personal relations, particularly the relations between men and women, with undiminished emotional importance. ... As the family shrinks to the marital unit, it can be argued that men and women respond more readily to each other's emotional needs...." Lasch maintains that this is an illusion—that modern marriage is superficial and actually is characterized by emotional abandonment. I saw no evidence of this in Claire's and Norman's marriages.

Norman anticipated the complete and utter devastation of himself should Rachael die first. In fact, he shared a suicide pact with her, and they both stated their intentions on numerous occasions. Their reasons were as much
from the anticipated loneliness and devastation as from the potential of falling victim to an uncaring world. Nothing in life was as important to them as their union and no one else could provide what they felt they would need in their lives. During one interview, Norman referred twice to this when he said he would shoot himself or take poison if Rachael wasn't around and he needed to go into a home. On other occasions they both confided that they had ample medications in the home to kill themselves before "authorities" could take over their lives. The staff at their exercise program took these threats seriously enough to wonder what they should do were one to die.

Claire's adjustment to the death of Robert was indicative of how deep their bond was. She began by speaking of him in the present tense. "Yes he's a wonderful man. I always like to talk about him," she insisted. Of his death a few months prior to the interviews she cried, "My whole world fell apart." The death of other contemporaries, a brother and sister-in-law, compounded her devastation: "It's just like there is nothing left for me. Me in the big wide world. Just like, I don't know where I belong. That's how I feel."

This sense of not belonging was puzzling considering Claire's large and attentive family. She had three living
children as did Nobuo. Marge had two. Despite professing love for their offspring, none felt satisfied with these relationships. Although circumstance differed, they all felt they were in an ambiguous relationship with unclear expectations.

Marge had two children on the mainland. She had severed her contact with her daughter, she said because of a "drug problem." Apparently the daughter did see her mother at sometime following the stroke, and Marge reported "[she] was ashamed to be seen with me and she is off-limits to me."

Despite a touching speech about her son, there were many questions about their relationship. When asked who the most important person in her life was she said,

My son, only because he's not ashamed to take me anywhere and he calls me "Mom" in a loud voice. [Laughter] Most of the time. And, uh, he is compatible to anything I want. And anything I need. He went to the trouble to find me an apartment with everything in it made for a handicapped person. And, uh, I thought that was well. You know he cares about me."

He may indeed "care" about Marge, but he does not care "for" her in any physical sense. She said she refused to move near to him. She turned over her finances instead to a trusted friend and asks nothing of him. He comes over only occasionally when business brings him; the last time, much to the shock of the care home operator, he did not
visit Marge. She reportedly did not get along well with his wife. All of this information was pieced together from scraps of information Marge divulged to individuals. Besides her aphasic speech, which limits her to the barest threads of communication, she described herself as suspicious of people. Her accountant friend felt she withheld details and guarded herself and her privacy even from close friends. No one knew "all" about her.

Marge gave no indication of expecting more from her son. She had not expressed dissatisfaction regarding him to anyone as far as I know. Why? Because when he was with her, their affective relationship was sound in her judgment. He acknowledged his mother; he treated her with dignity and accepted her with her limitations. While others might judge this to be a distant and troubled relationship, she seemed to get what she expected--to be cared about, not for.

Because of close proximity but social distance, Nobuo seemed more disappointed in his relationship with his children than Marge even though he received far more assistance in living and had more emotionally charged contact. Nobuo confided that a major regret of his life was been not being a good parent. He saw evidence of this in his present relationship with his sons. He rarely saw his daughter but he saw his sons in fits and starts until
another fight would drive them away. He had a need for affectionate relationships expressed in tangible acts.

I'd like to discuss my problem with them but there is no shoulder there where I can tell my problems to. But they have their own family. So that's what I told my son, if you don't expect to call me for food and then you come, forget about it. I can do it, I'll make myself do it and wouldn't depend on it for a few small items.

In an angry exchange with one son,

'Don't come here just 'cause I want you to pick up an item for me. Come because, after all, see how your old man is getting along.' There's no one for me to tell my problems to except my boy.

Nobuo attributed the failure of these relationships to several things. Historically, the divorce separated him from his children who then had no strong paternal bonds with their father even though he provided regular monetary support. He described them as feeling they were born and brought up free of paternal ties. He felt an unreciprocated bond and hoped some day they would recognize his regard for them. Despite strong feelings about the affection he wanted from his "boys," Nobuo did not ask for it. Instead he angrily rejected them for not providing it. They hung up the phone on each other. They yelled. They avoided one another for months on end. He refused to allow the hospital to call them. At some level of his consciousness, Nobuo knew that any emotion was better than none.
He did not humbly ask for the love he wanted because he never set himself up for rejection. His failure as a parent might well have provoked his children's rejection. Finally, Nobuo, like Claire and Marge, recognized the secondary status of parental ties. He acknowledged that his children "have their own problems and families." And Marge chose not to intrude in her son's life with his mate because she and his wife did not care for one another. Claire expressed the idea of her secondary importance to her offspring most clearly. She said it was not just that her children had other responsibilities but that she herself saw those other responsibilities as more important. When asked if she felt like a burden, she said,

"Yes! I do. Of course. Sometimes I tell him, you see, the daughter-in-law cooks for me ... And even they go out they still have to worry about me. Henry does all that. She takes 3 days bathing, washing me. And the other daughter-in-law she would come and take the other 3 days. I didn't like that at all because I was really a burden. So I told Henry, 'I can solve this problem. ... I'm going in a home, then everyone can get back to their own routine, don't have to worry about mama...' I lived so long anyway."

Aged parents grow dependent at a time in the adult child's life when his or her responsibilities are the greatest. Adult children are in the midst of extensive career and family obligations, leading some to call them the "sandwiched generation" because of responsibilities in the activities of three generations.¹⁵
Gurian suggests that in kin relationships Americans do not appreciate the positive aspects of dependency as do certain other cultures. If the positive and natural aspects of old age dependency such as their reciprocal, demonstrative and sociable qualities were accentuated, the idea of being a burden would diminish.¹⁶

However difficult these subjects felt their relationship with children were, there was intensity in their emotions. Troll describes the parent-child relationship as one where all feelings run high; both love and hate ebb and flow throughout time.¹⁷ Of the negative feelings one study states,

Although years of separate residence and greater self-knowledge may erase some of the minor difficulties and blunt the edge of some of the major ones, struggles for control, patterns of blaming, disappointments about achievement and such may linger to undermine the possibility of a comfortable relationship between parents and children.¹⁸

The authors go on to cite imbalances in socialized expectations for certain kinds of help and value shifts that dictate contrary behavior. This speaks exactly to Claire's lament at the close of her interview.

The world changes so much. When your children are grown it will have changed again ... the old saying is, "well I take care of you folks and when you grow up you take care of mama and daddy." Not anymore ... [their] needs are more than before ... It's hard to have an old lady to take care too, you know.
Despite its conflict, Laslett has argued the encapsulated modern family is more emotionally significant to the lives of its members. The family is now the only appropriate arena for affection and emotional expression and this includes both the positive and negative. While Demos suggests it has become a retreat from the "strangeness of the work world," he knows it is not a retreat from obligation. The family itself is bound, burdened and supported by mutual obligations and expectations. Perhaps the pluralism of American family life, the observation of diversity in the media and in our neighbors' homes, along with the vagueness in kinship roles, allows a negotiation of responsibility to aging parents. These efforts at negotiation seem to mark the point of tension.

The demands of the parent-adult child relationship are far more complicated and ambiguous than those between spouses. American marriage has been characterized as the "crystallization" of a so-called private sphere of existence ... defined and utilized as the main social area for the individual’s self-realization. Atchley argues that the parent-child relationship is one in which the older parent must recognize his adult child's right to be independent, lest his demands alienate the parent. Most importantly, he must not interfere. The adult child is in turn expected to see his parent as an individual, with
rights, needs, limitations and a history which makes him who he is beyond a parent.\textsuperscript{22}

This characteristically American expectation—mature respect for individuality has led anthropologists Clark and Anderson to conclude that the relationship depends on neither "needing" one another. Referring to role-reversal they say,

The mores do not sanction it and children and parents resent it. ... The parent must remain independent and strong. If his personal resources fail, the conflicts arise.\textsuperscript{23}

While some authors would agree with this assessment that good relationships depend on independence, others do not.\textsuperscript{24-25} Baum and Baum conclude that modern industrial families are assuming responsibility for parents as dependency grows. Possibly from their own sense of weakness, however the sick old often feel dissatisfied about what is happening.\textsuperscript{26}

In the 1970's the myth of abandonment of the aged in America was disputed. Researchers found a preponderance of evidence that the old were cared for within the family. But other research casts a shadow on this assertion. While there is involvement, there may also be an underlying tension or insignificance to these relationships. The willingness to respond to need that earlier researchers discovered has been found to be offset by conflict and tension.\textsuperscript{26} One researcher notes a positive use of dependency
in spousal relationships much as Gurian describes but negative dependency in offspring relationships. Several other studies indicate that offspring have no appreciable (or at times a negative) influence on global happiness or satisfaction. One article concludes "... the best evidence now available indicates that the present young adults should not decide to have children on the basis of expectations that parenthood will lead to psychological rewards in the later stages of life. The prospects for such rewards seem rather dim, at best." Another maintains, "On the basis of current evidence ... the idea that relations with children in particular, and kin in general, are critical to the adjustment and emotional well being of the elderly also appears to be a myth."

Claire and her family and Nobuo and his seem to be victims of this "myth", which promulgates such high expectations.

Two of these families, Claire's and Nobuo's, were in trouble. By trouble, I mean that no party characterized the relationship with the other as satisfactory. They all reported fighting, bitterness and disappointment. Claire disinherited various children at various times. The children sought counsel about how to cope with her moods, demands and capricious expectations. Nobuo's children and he had a volatile relationship of confrontations and
retreats. Nevertheless, these players remained very deeply involved with one another. Without realizing it, they seemed to be trying to strike an agreement about what they all should do about the chronic needs of the aging parent. Claire and Nobuo did not communicate their needs clearly. They admired independence. They wanted affection and respect. They did not want to feel like a burden. They felt their lives were lacking in these regards. The focus of the disagreements were on tangible things the parents wanted such as: more time spent with them and more duties performed.

Why did they remain involved with one another? If the work place were so emotionally charged, I think the average worker would eventually quit. These people, although they threatened to, did not "quit" one another. Lasch would suggest a narcissistic tie based on wanting to feel one's goodness validated by others, in this case family. Functional theories of the family (notably Parsons' and other exchange theories, diachronic solidarity theories) would suggest that obligations, roles, expectations between generations make them stay together. Whether they remain close for neurotic rewards, security or affection, the fact is that family relationships, both positive and negative, are regarded as important to the aged.
In conclusion, even though evidence suggests that the relationships between parent and adult child that work the best are those that demand the least, I think it would be hasty to conclude a selfish or lazy attitude on the part of children. Claire's, Nobuo's and Marge's accounts, as well as the literature, present a number of compelling reasons for the gulf between parent and child.

1. Parents and children arrive at this point in their lives with much family and personal history. Nobuo and Marge's relationships with their children had been complicated by divorce; they were both well-guarded persons in regard to their own vulnerabilities. No doubt their children too shared the conflicts of divorce and certain similar personality traits.

2. The roles adult children are expected to take in the life of their frail parents are vague. Albrecht confirms that other studies have shown that disability of a family member causes the most stress when family roles and expectations are most vague.\(^3\) It seems generally agreed upon that a primary allegiance is owed to the newer family. Dependency needs seem to erode the older relationship with the troublesome feelings of role reversal, guilt, pride, resentment and torn allegiances.

3. The feeling of "near-perfect" love between spouses Claire and Norman reported in marriage is not experienced
with children for the three subjects with children. The parent-child relationship is one which throughout development is fraught with conflicts, and dependency needs of the aging parent seem to accentuate existing tensions.

Studies about family caregivers identify a typical pattern which compounds the inadequacy of the parent-child relationship in caregiving. Though the parent-child dyad is obviously not the same as the husband-wife dyad, when spousal support is removed the typical American pattern is to turn to one other family member to provide the same quality of care. Usually a daughter, then other children and possibly siblings are substituted for the spouse, each one failing in turn to a greater extent. 'So it seems that the parent-child relationship of the frail aged and their children is burdened with higher expectations than it currently fulfills in both affection and personal care.

Turning to the subject of friendships, my subjects reported infrequent and shallow relationships. This may partially explain why the lack of deep affection between parent and child seemed so disappointing.

Norman dismissed the idea of needing friends. He claimed to have found sufficient satisfaction with acquaintances, preferring the solitary pursuit of writing. Except for being good golfing partners, he described how he felt professors in his department shut themselves off, not
noticing their fellow workers. He found some superficial socialization between Rachael and her friends, but he placed little importance on social aspects of life other than marriage. Career, spouse and family seemed sufficient to sustain him. While Rachael and Norman were known for doing kind acts for others in the exercise group, such as organizing parties in other people's honor, driving others home and visiting them, it was really Rachael who initiated these things. Norman happily joined in though he never would have thought of them himself. He did enjoy the rewards of being kind. He reported, however, no deep friendships by his own definition of friendship—merely deeper acquaintances.

Nobuo seemed to share feelings similar to Norman's. Nobuo claimed to have always been initially aloof and this had shielded him from being hurt. After his stroke, he believed this disregard of what others thought had served him well. Still he found several close friends in later life. The first was an unlikely match with Paul, a well-educated salesman, young, married and aphasic with whom he shared many personal feelings about strokes. When Paul and his family moved to the mainland the friendship ended. They could not write or speak on the phone; so it was as if each no longer existed for the other. When word of Paul's death came (a niece in the islands called Nobuo),
he had no way to acknowledge it. He forgot to get the niece's name; he had no address, no family name.

Nobuo had one other friend, a woman who did a few errands for him. He paid her for these, but he considered her a good friend because of her consistent attention and acceptance of him as he was.

Acceptance was perhaps the key to sustained friendships. Marge's boyfriend rejected her right after her stroke. Perhaps because she could not accept herself, she sensed rejection among all her friends. She said, "I felt them pulling away because of my handicap." But she also gave clues to a lifetime of distance in relationships. She talked of generally not liking other women, and after the stroke she discouraged women "friends" from coming or calling. She sold her business without hesitation, without even going to see it again, and many of her social contacts were connected to that business. She retained only her accountant as a friend but he felt himself essentially an agent—he did not feel appreciated for his efforts of friendship such as bringing his family to visit her on Christmas. In short, friendships seemed always to be distant in Marge's life. Believing that no one wanted to be with a "cripple" and admitting to an extreme drop in self esteem, she avoided all people she did not directly
need after her stroke. In fact, one of her only "friendships" was with her maid/aide, who by virtue of accepting employment, accepted her physical condition.

Both Nobuo and Marge boasted of enjoyable relationships with the opposite sex prior to their strokes. Both dismissed the possibility of an intimate relationship again because of sexual dysfunction. Marge said, "You might say, I shut the door," and Nobuo says "Well, I definitely don't think I should get married now; I'm incapable of doing anything. And what woman would care for a guy that is incapable of anything? ... The stroke did all kinds of things unimaginable." The issue of the importance of sexual function is ironic given Norman's declaration that old age diminished the need for sex.

Only Claire seemed not to have lost contact with friends. She claimed the rejection a person feels after a stroke is probably due to a lack of effort or a negative attitude. Her friendships with women were life-long and maintained through various troubles. But they were obviously not sufficient for Claire, for she longed for an intimacy they did not provide. Rather, I suspect, they afforded diversion and activity. She talked of going to the beauty shop to catch up on gossip, and her activities with women friends consisted of cards, parties or excursions. Suffering and sorrow were better shared with
family. For the deepest pains, she sought medical attention, or she recited the rosary.

If the role expectations of families are varied, the roles of friends are unlimited. We accept that there are degrees of friendship from Norman's "acquaintances" to Marge's "true blue friend." We distinguish lovers from friends, expecting much more from the former, yet we also consider them our best friends. Norman, Claire, Nobuo and Marge expected nothing tangible from friends. It was a real bonus that one would drive up the mountain to see Claire, or one would help Nobuo clean. Norman felt no obligation to drive a group member home—he did it because it made him feel good. What all four sought and received in varying degrees from friends was acceptance. After his stroke Norman increasingly sought contact with handicapped people at the University and in the group program. He increasingly shared his illness experience with others, and he enjoyed what he called "camaraderie" with others. Marge enjoyed sharing the ups and downs of her Vietnamese maid's daily life although in return she told very little about herself. She did struggle to eat, talk, live in front of this woman, actions she showed few people. Nobuo enjoyed the acceptance of his two friends as he was—smelling of urine, poorly groomed and often gruff. Claire enjoyed the give and take of banter, advice and philosophy.
The four, however, made few demands on friends which would test the foundations of these relationships. It was at this pivotal point that family relationships began to fail for them.

According to Atchley, the number of friendships usually declines in old age. Friendship losses occur because of difficulty in maintaining them due to external barriers such as physical limitations, geographic distance, death or illness. New friends seem difficult for many aged to cultivate—certainly my four subjects attest to the difficulties of making and maintaining new friendships. But Atchley also says that the need for a confidante—a special friend—is usually met in old age. This seemed not to be entirely the case with Nobuo whose confidante died, with Marge who did not confide, with Norman who valued no social contact except with Rachael and with Claire whose sister-in-law/confidante died and whose other friendships were superficial. It is significant that Claire's and Norman's confidantes were spouses and Nobuo wished his was his son. A friend seemed an unacceptable choice for them.

Mary Jo Bane suggests that friendship in the lives of modern family members provides enrichment for their isolated and confined existence. For the older person, this is possible only insofar as friendships are available
and the aged are receptive. It seems on both measure my subjects had deficiencies.

The four subjects were chosen from an exercise/socialization group which they highly valued because of the cohesiveness and support they shared with group members. While they verbally minimized the need for friendship per se, they did actively seek out the comfortable, nondemanding companionship of others in a group program comprised of peers. It was in these groups that Norman told of his suicide pact with Rachael, that he shared so many stories about his life. It was in these groups that Nobuo spoke of the troubles with his sons and his landlord, that Claire told the others that they were a refuge from family tension. It was only to the group that Marge ventured each week. This program provided, at least in part, the rewards of socialization without the attendant risks of judgment, rejection or demands. Only rarely did contact extend beyond the group time. Except for Nobuo and Paul, it amounted to an occasional telephone call or hospital visit.

Marriage, according to Claire and Norman, was the best environment in which to be handicapped. A mate provided a safe, accepting, nurturing atmosphere without the baggage of guilt and perceived resentment. Caregiving was a reasonable expectation of a mate in old age. These two grew
depressed, even suicidal at the thought or reality of depending on anyone other than their mate.

Children, while being highly significant in the minds of Claire, Nobuo and Marge, were not satisfactory caregivers and relationships seemed threatened by dependency. For Nobuo and Claire the problems stemmed not so much from children not wanting involvement, but because each was having to negotiate an appropriate level of involvement without clear communication. Marge, while reporting being hardly disturbed by her relationship with her son, rarely saw him and made no demands. She was not even in touch with her daughter. Though free of family tension, her relationship with her family seemed most disturbing to me and more disappointing than Nobuo's volatile relationship.

Nonfamilial friendship, rare and difficult to sustain after a stroke, seemed hardly missed. Marge, putting society, acquaintances and friends in the same category, felt general rejection and thus relief to be free of them. Norman dismissed any real importance in friendship. Nobuo, when pressed, admitted to two valued friends and Claire to the importance of socializing. Their only expectation of these friends was in accepting them as they were. However, these four were selected from an exercise/socialization group program for the frail elderly which
supplied a ready-made social experience that was an important part of their day or week.
Notes


5Mary Jo Bane, p. 46.


17Lillian Troll, p. 354.


20John Demos, Images of the American Family, Then and Now, Changing Images, pp. 49, 54.


25Troll, p. 356.


Atchley, p. 313.

Baum and Baum, pp. 166-168.


Norvall Glenn and Sarah McLanahan, "The Effects of Offspring on the Psychological Well Being of Older Adults," The Gerontologist (May 1981), p. 409 cites 9 studies to support this finding and


Glenn, p. 419.

Lee, p. 223.

Lasch, p. 38.


Johnson and Catalano, pp. 612-618.

Atchley, p. 312.

Bane, p. 50.
Chapter 6
Re-Creating Self

Saflios-Rothschild, a noted author in the field of rehabilitation of handicapped adults, has accused professionals of not acknowledging the "wishes, feelings and self-definitions of the disabled." The ramifications, if this is true, are frightening. It explains why Marge felt that she was passively to lie still and "take what was coming." It explains why Norman thought his physicians were not listening. It explains why Nobuo felt that doctors were god-like—"all knowing and never needing to ask anything. If, as some have suggested, medicine is just a microcosm of the larger society, we too can be accused of not knowing or asking just what the disabled want. In this chapter, I will try to explain how the four subjects remade the world after the stroke by calling on their personal resources.

In making an earnest effort to examine the lives of these four, their self-expressions of their needs and the deeds which illuminate them, I have come to some troubling conclusions. While I first saw them as heroic figures, struggling against a harsh reality, I came to see them as existing in a self-determined way, trying to maintain lifelong patterns. While they looked very different than
they did twenty years previously, and they were certainly less capable in many ways, their reaction to the stroke, their reshaping of themselves called upon no magical heroic qualities. They used only the resources already within and they remade their lives as nearly as possible to resemble what they once were. The four had, as a result of lifelong experience, developed expectations of society and did not even entertain the idea that they could affect change.

MARGE

Marge withdrew after her stroke. Perceiving that the world resented "a cripple" and that she was seen as distasteful, she preferred anonymity.

... I can't help but feeling that they resent the fact that I am a cripple and have to be cared for.

Of her brother's visit she had this to say:

He was nervous and I could sense a change on his part as well as mine. Because I couldn't talk or carry on a conversation.

In social situations she felt the attitudes of others were suspect:

They avoid me, and very often they will remark um, to the extent that, uh, I'm leaving something to be desired in my conversation and uh ...

When asked about her former business associates she said she severed contact with them because:
... I don't go there because it was too painful because I was afraid of rejection. I didn't give anyone the chance to make fun of me. ... I felt inferior.

Marge did see a hostile world. But perhaps there are some clues to why this was. The actions of others or her experiences are less illuminating than her comments about how she had always seen the world and how she herself felt about the disabled. Consider the following quotations. The first is about not working.

It makes me angry. I see the miles and miles of uh, nonreturnable... I can't imagine me thinking that I am someone special. Uh, people should work.

When asked if she would befriend a disabled neighbor she said:

No, she doesn't ask and I don't ask and that is where we leave it. She is partially disabled due to a fall. She broke a hip. She is older. Poor thing, I feel sorry for her but I don't know what to do.

Other clues come in recollections of how she interpreted past events. For example, consider how she thought her husband and family felt about her career:

I always worked. And I always felt that this was misinterpreted... Yeah, believe me they resented it... Uh, a great deal of jealousy.... Yeah, I was able to do things that he was not.

What develops is first, a picture of how Marge sees disability, hers or anybody's. It was a disgusting, inferior position, which evoked pity or resentment. Also it seemed that Marge approached people all of her life with a
suspicion that they were thinking ill of her. Of course her experiences might have shaped this: an alcoholic and unfaithful husband, a lover who abruptly ended their affair when she became sick, being a successful career woman in a time when few women worked. Whether her assumptions about the external world were justified or correct is not at issue. The significant point is that Marge interpreted the world poststroke in much the same way she did before. Now, because she was severely disabled, she assumed the role she felt was appropriate for a woman in her position.

Despite all of the negativity about the external world, it is very significant that Marge was not depressed or hostile. This would be very inconsistent with her self-image. I think she accurately described herself as "resigned". This was the way life was for her; no one did it to her. Even in the above remarks she acknowledged her own hand in her new life. She said, "I always felt," or "I can't help feeling" or "I could sense a change on his part as well as mine." It was as if Marge knew she was processing the input of the outside world through her own belief system—her feelings were interpretive.

In an egocentric way, Marge made something good come of her disability. Always one to be aware of what others
were thinking, often assuming it was negative, she experienced some relief from this burden in disassociating herself from others. And she found that she was a good companion to herself. She enjoyed her own insightfulness and found satisfaction in simple daily activities. She maintained the same cheerfulness and attention to appearance she had all of her life.

At the time Marge had her stroke she had certain character traits: a suspiciousness toward others, a need for privacy and guardedness, a cheerful demeanor, a pride in her appearance and accomplishments and a pleasure in carrying out the chores of daily life. Also, and this was what made her appear so passive, she had a sense of fate or resignation which made her seem not to fight or seek to change things. Her stroke drastically changed the reality of her daily life, but it did not change her nature. The way she felt about disability was set long before her stroke. How she thought others felt about her disability was determined less by what they said or did than by how she interpreted their position toward her.

NOBUO

Nobuo always protected himself from rejection by cultivating a cynical, hostile demeanor. He was proud that he never said "hello" to anyone first and therefore never
got stung by someone who did not want to bother with him. He looked at other people's first efforts at friendliness as silly although he valued friendships once they had developed. In a very masculine fashion he liked physically pushing himself to his limits both before and after his stroke. He said:

Well, actually, my wish was getting better, like anybody else. I knew it would be rough and hard, but there's nothing else for me to do but try ...

He rarely acknowledged a softer side. As his children were growing up he willingly gave monetary support but little emotional support. Now, though he admitted he could benefit from some affection from his children, he was too "tough" to ask. He did not even consider initiating a greater degree of closeness with his sons:

No, I haven't been a good father to begin with ... There is nothing I can do about it until my children get a little older and think back and say, "I should have done this or that." Right? [and then as if he himself were aware there were some things he could do, he answered his own question] No.

Nobuo immersed himself in his stroke in much the same way he did work. First, he devoted about 20 hours a week to physical exercise programs run by two social agencies. Secondly, he enjoyed the banter and camaraderie of peers, much as he had drinking with "the boys" on his job. He had always preferred a solitary lifestyle, divorcing early in life and thereafter living alone. Being independent
was very important to him. In his working life it meant traveling to California to work, leaving all his family and friends in Hawaii. He enjoyed being solitary and untethered while working on beams hundreds of feet in the air. Such independence caused him to refuse help from social service agencies and to resist institutionalization. Of his determination to be independent he said:

I can do it, I'll make myself do it and wouldn't depend on it [his son] for a few small items.

Or,

Well, I think it's [independence] important to the individual. I don't want to be a burden to anyone if I can help it.

And Nobuo realized how similar his present attitudes were to those before his stroke. Even though his lifestyle was so radically different he said:

Well, I guess I've been this way all my life. I couldn't get a stroke to revitalize or whatever. [I think he means a stroke could not change him into something he was not already.]

Nobuo came very close to giving up or losing his independence recently because of his approach to others. It began with his neighbors' complaining that he was urinating in the bushes while waiting for the Handi-Van. Nobuo's reaction was to deny that it occurred often enough to be significant and that it harmed no one and was no one's business. His landlord, his children and the social service agencies he was known to all became involved and
began discussions about what could be done. It was a dangerous situation because Nobuo, now disabled, was vulnerable to so many people and agencies who felt "a responsibility" or "a right" to intervene. After several weeks, Nobuo checked himself into a hospital and said he was ready to go to "an old man's home." He actually went and interviewed the operator of such a home, but feeling ignored he refused to move there. He returned home with the issue of urinating in the bushes unresolved. Nobuo's initial reaction, a confrontive approach (he even threatened his neighbor), seemed typical for him. In past years, this might have worked for him although his troubled relationships indicate it was probably not the best style of relating to others. But once handicapped, this style posed dangers.

McMurphy, the hero of One Flew Over the Cuckoo's Nest, eventually loses by being forced to have a lobotomy. His style, marginal but functional in the outside world, destroys him in the world of the mental institution, where the balance of power favors the institution. In the same way, Nobuo, in the role of being disabled, did not realize that his old style of confrontation put him at grave risk. His sense of independence and autonomy only existed as long as others left him alone.
Nobuo acknowledged that he changed little after his strokes. He had deep regrets about his life in regard to his family and if anything, his stroke had only further eroded his troubled relationships. By emphasizing the similarities in his pre and poststroke life, Nobuo was comfortable despite the drastic physical changes which occurred. He gave up sexual encounters, drinking and working but apparently there was enough of the old in his new life to make it feel natural. He unfortunately did not change his confrontive nature when threatened, and it posed a continual threat to his independence.

CLAIRE

Claire too had made her new life feel very much like her old life though it first appears drastically different. She acknowledged a highly dependent relationship with her husband Robert. After her stroke, he seemed to anticipate every need and she felt unthreatened by her physical dependence upon him.

She remembered him in this way:

He did everything. He cooked and everything. I tried to get him to get someone to help us. I said, "Daddy, don't work so hard, you're killing yourself. ..." "I can do, I can do," he would say.

Or,
I never drove but my husband took me all over the place. He wouldn't let me drive, that's why he never wanted me to learn.

Of the naturalness of dependency she offered this:

There was never a need for me to cook. I never cooked my whole life. You see, my father was kind of well-to-do. He had a grocery store and he had help. People working for him ... my father would take it [the meal] home for my mother and I. And so my mother never cooked her whole life.

She did, however, work outside the home for a number of years (though not her whole adult life), and she was an accomplished seamstress and did much needlework. But when she needed something, having Robert provide it was very comfortable.

I never have to ask. He always right there to give me. And then when he died. Oh, my whole world fell apart.

Claire's world did indeed seem to fall apart for a while. While she hoped her children could fill the void left by Robert's death, she found dependency on them strangely uncomfortable. She felt she was a burden and she thought it was improper for them to have to devote so much time to her needs when they had commitments to their own families.

She described her needs and their efforts to meet them as work, not given joyfully as Robert once had.

... you see, the daughter-in-law cooks for me and, before I had the girl, you know. And even when they go out, they still have to worry about
me. Henry does all that. She takes 3 days bathing, washing me. And the other daughter-in-law she would come and take the other 3 days. I didn't like that at all, because I was really a burden. So I told Henry, "I think I can solve this problem." He said, "What do you want to do?"

I said, "I'm going in a home, then everyone can go back to their own routine, don't have to worry about mama." I said, "Enough, I don't care. I'll go to a home, it's got a roof," and I wanted to go.

He said, "No, Mama, that's the last resort because you didn't want the home, you told me way back." He told me that. None of my children want me to go in a home. "We'll find somebody to take care of you, you're going to stay right here. We'll look after you." So I'm still here.

About six months later Claire did move into a care home, and despite the misgivings of her doctor and her family she adjusted well to the move.

Claire found that, even with the cry for help evidenced by two suicide attempts, she could not convince anyone to take complete charge of her life as Robert once had. Unlike Nobuo, who had to fight against placement, her efforts to get into an institution were discounted and regarded as abnormal. Claire seemed to know that she needed the ease of dependency without the complications of indebtedness or feeling a burden and that, next to Robert, the contractual relationship of a care home best afforded this. In acknowledging her dependency needs she risked estrangement from her family, who had strong feelings about how she and they ought to live. In their minds, if
family members cared about one another as they certainly did, then they should be able to care of one another in a physical sense as well. In fact, the state of their mother's happiness seemed a reflection of their adequacy as children.

This was evident when, following Claire's suicide attempt, the entire family became angry, self-critical and disturbed. Claire described Henry's reaction in this way,

After I took them all [aspirin], it dawned on me, I thought "what if I cannot die, I'm going to be worse. Be a vegetable or worse." So I decided to tell Henry. Oh, he was so mad with me.

"Why do you want to do that for, I try so hard to take care of you. And here you do that to me." He took me to the hospital and they got rid of that, they got it all out."

This family was experiencing the burden of trying to replace the uniquely special, perhaps neurotic, relationship between Claire and Robert. It was Claire who finally realized that a care home could better fill that void than her children could.

In the care home, Claire enjoyed easy relationships with other patients and the staff's anticipation of her needs. She had improved physically in the physical therapy classes. She was much more willing to expend this kind of effort than the kind demanded by independent living.
Norman's adjustment to his stroke presented some interesting difficulties because, paradoxically, he was the least disabled of the four. According to Zahn, ambiguity increases as ability increases. He explains that society "knows" just what the comatose patient or the wheelchair bound patient can do, but with the minimally disabled roles and expectations are far more unclear. Every day Norman had to "negotiate" with people about what he could and could not do. Daily he and Rachael discussed just what he was feeling up to doing. She could veto his plans if she felt they were beyond his limits. He was furious at a man at the bus stop who failed to recognize his handicap and tried to make him wait until the women had boarded, yet he would have been devastated had the head of his department suggested he was too disabled to have an office. He himself was unsure of his abilities until he tried. He was anxious to see a soon-to-be published article in print because he was uncertain of its quality. While this constant give and take in his role produced stress, it also afforded him many possibilities.

Two significant aspects of Norman's life stand out. First, he saw himself as valuable, worthy of living and willing to live only if he could be productive, having goals and aspirations. Asked what drove him, he said,
That is a really good question. Rachael and I were saying the other day, when she asked, around the circle, what everyone's ambition was, I said, "My ambition is to write another book." And about half the class didn't have any ambition. I just couldn't understand it. [He was referring to his exercise group.] I feel if I don't have another ambition right away, I might as well shoot myself.

The second striking feature about Norman was that he believed all of the potentials of his life were tied to Rachael's survival.

I would commit suicide. I would commit suicide if Rachael died. Immediately, without any question. This seems kind of funny but it's true. I couldn't live without her. I'd get a gun or some poison and I'd go. I couldn't live without her. ... There are a lot of practical aspects but that wouldn't be it. I just couldn't live without her because I love her. That's all. I really love her.

Throughout his entire life Norman was an isolated man. He had an emotionally cold mother who never kissed him. He talked about the isolation of academia, where he never got to know his colleagues beyond a regular round of golf. He invited only one person into the inner sanctum of his emotions and that was Rachael. With her and his writing he had all he needed. If he lost either one of those things, he did not wish to live.

While it may seem precarious—being so brain-damaged that immediate recall was seriously compromised yet trying to write a book—to base his survival on that of a nearly 80 year old woman with heart disease, at the time of the
interviews Norman's life was working. This was because, in certain respects, he was willing to compromise and lower his expectations. He, after a period of depression, took on a co-author to help him finish his book. He was willing to work with an acknowledged "75%" disability and to produce a book of lesser quality than previous efforts.

One reason was that he did some reflecting in the period following his stroke. He shed some of his self-criticalness. For example,

I was one of those persons who never had a very high opinion of himself. And as I look back at the person I was before the stroke, I should have had a high opinion of myself, ... Now I do. Now that I am handicapped by the stroke, I realize that I was doing things that a lot of people can't do.

After his stroke, he was eventually willing to settle for doing the writing he enjoyed as best he could even if his work was not as good as it once was.

A second factor in his favor was that he had never concerned himself with handicapped people prior to his stroke. He held no preconceived limitations regarding himself. He assumed that all Americans had a similar lack of awareness about the disabled. He said,

I'd grade it C or D. Because of the way I looked at handicapped people. I never paid any attention to people in a wheelchair. I never paid any attention to a person on crutches. It meant nothing to me ... It meant nothing. And now, of course, it does. ... Well, you can't really blame people. I can't blame you, for example,
for not seeing a stroke person because you haven't had a stroke, you don't know what it is.

When I tried to probe the negative aspects of being handicapped he dismissed them, returning again to the fact that, for the most part, handicapped people did not exist for the average person.

For Norman, this was a benefit. Though he knew he had been damaged, he held no prejudices about being disabled. He seemed willing to re-create a new life that very much resembled the old, taking into account his limitations when necessary.

There was an inkling, however, that in the real world people do not just ignore the disabled. Afraid as he was to die, he was far more afraid to fall prey to the care society would offer after Rachael's death.
Notes


Chapter 7
Conclusion

This dissertation began with the thesis that American values and attitudes toward the disabled are so strong that they can alter an elderly person's whole life after a disabling cardio-vascular accident. Presumably family, medicine and society at large can exert such a shaping force on the disabled as to cause them to define themselves by social opinion. The literature I selected generally suggests that the influences of American society are negative and that the disabled are left feeling stigmatized: different and inferior.

Is this the case? There is no simple answer. I would like to list what I found and expand on certain points in this conclusion.

1. First, my subjects' relationship with the institution of medicine did indeed seem rooted in inferiority/superiority; they behaved by what they thought were prescribed rules of interaction. They, even when this was unlike them, were submissive, indirect and even gullible. While they had some realization that they were "buying in" to a possibly faulty system, they seemed to have an investment in maintaining an overriding faith. Medicine stigmatized them in separating them from the care-givers. They were sick and care-givers were well. They were
ignorant and care-givers were all-knowing. They were abnormal and care-givers were normal.

The medical establishment, for its part, encouraged these subjects to assume a stigmatized, unequal and less human role. Some subjects complained of medical arrogance, of disrespect, of being in a system which did not allow questioning, and was unfeeling toward them. The medical journals, by the avoidance of these issues or by skirting root emotions with discussions about such things as spending more time with patients or listening better, not call upon professionals to reappraise a system which outsiders and mavericks within are calling inherently sick. There is an indication that the economic problem of malpractice may soon cause doctors to look at the "image" of arrogance and overconfidence. This may be a less penetrating analysis than is required, it at least puts the onus of the flawed relationship on the physician's role.

2. The verdict on families is far more complicated. The two with spouses into old age claimed that if one had to be disabled there was no more comfortable and natural place to experience it than in the sanctuary of marriage. They cited the mutuality of marriage, the familiarity of the spouse, and the unconditional love and affection. They dreaded the day when the spouse could not help them
any longer because they feared it was a relationship irre-
placeable in this world.

Three subjects had children, and all found them to be
unsatisfactory care-givers. The closest and warmest of
families, Claire's, manifested symptoms of strong tension
because of Claire's needs. They seemed to have expecta-
tions of one another not particularly based on recognizing
their life-long personalities nor direct communication of
their needs and priorities. Their roles were vague. They
felt a responsibility but had difficulty defining exactly
what their responsibility was. Thus the role of being
dependent was uncomfortable for both parent and children.

In Nobuo's case, perhaps the most significant aspect
on which to focus is the complication that a lifelong his-
tory of conflict brings to old age dependency. While his
was an extremely conflicted relationship with his children
because of his personality and a divorce, some writers
suggest that the natural relationship of parent and child
always has an aspect of conflict in it as the child learns
to be independent and grow apart from his parents. Cer-
tainly unsatisfactory communication patterns established
earlier do not improve as the dependency of parents grows.

Marge's relationship with her children is an enigma.
Estranged from one and not apparently close to the other,
she nonetheless seemed to regard her children as important
parts of her life. Some writers have suggested that the American family is a dying institution, and at first Marge's family could be offered as an example of that. But a more recent and prevalent school of thought argues that the family is very much alive and remains an important element in American life. In Marge's case one finds paradoxical support for the latter position. Though distant from her family by geography and emotions, she did not dismiss them as insignificant, and I doubt they did her. When a neighbor moves away, or a co-worker leaves his job, ties are usually broken with little distress. In Marge's home, however, prominently displayed were photographs of the daughter with whom she had severed ties and the son she rarely saw. She named this same son as the most important person in her life. While families sometimes do become fragmented and seem to dissolve, there are strong invisible ties that are rarely completely severed.

Being inadequate caregivers to the frail aged is, perhaps, not the indictment it first seems. The disappointment for these people was not because of lack of affectional ties or abandonment but because they expected much more than that which they received. In short, they believed in the myth that their affectional and physical care needs could be nearly exclusively met by their children and, in Claire's case, that it could replace the
spousal qualities she missed. Rather than emphasizing the positive aspects of family concern that did exist (as Marge seemed to do) too high expectations seemed to negate those qualities for Claire and Nobuo and lead to disappointment.

Struggle and tension seem to characterize offspring relationships with disabled adults more than any deliberately stigmatizing actions such as isolation or degradation. One senses that the children of Nobuo and Claire wanted to be involved in this new situation, but they were woefully unclear about what they each should do and expect.

As to friendship, Marge did report a sense of inferiority, stigmatization if you will. I believe this occurred as much because of her nature as the actions of others. The other subjects seemed able to keep the friendships they found important although they did not seem to attach much value to the friendship of nonrelatives. Unlike their relationships with offspring, Claire and Nobuo made no physical demands on their friends. In a sense these two never tested their friends beyond asking for acceptance of their disability.

3. What struck me about the remaking of these four lives after strokes had occurred was not so much the influence of American society on the victims as their own self-determination. That is not to say that being
American and being in America did not strongly influence what they became. First, as Fordyce points out, their very entry into a rehabilitation process after a stroke was culturally rooted as was the labeling that then occurred. Going back further, even their survival was a product of western medicine. Because of their age they did not get retrained for employment. Where they were sent after hospitalization was decided by contemporary trends in American life. Also all were already steeped in certain American values which had a strong bearing on the outcome of their rehabilitation process. And the rehabilitation process reinforced such values as: achievement, independence, competition.

While aging, like disability, exerted its own cultural force on these four people's lives, they were not consciously aware of this force, preoccupied about it or resistant to it. For the most part these expectations were incorporated into their self-expectations. They lived lives within the bounds of social acceptability for a sick old person in American society, but they were less concerned with breaking out of these bounds than creating a comfortable life within them. In short, the rub or conflict was usually not in defining themselves within the limits of American social acceptability but more with finding comfort in a new life given their disabilities.
There was a homeostatic quality in their lives very unlike Scrooge's re-creation in *A Christmas Carol*. Despite the neuroses, the disappointments and inadequacies of their former lives, these four seemed to try to re-create their past lives as well as they could given their radically impaired physical and mental conditions. They did not particularly seek to be more magnanimous or loving than they once were. They did not try to heal old wounds, to be more successful, independent or competitive than they once were.

I did find evidence that when their own attempts to return to previous patterns were discouraged or blocked they often successfully resisted those trying to dictate to them. Claire found a place to meet her dependency needs rather than rid herself of them. Nobuo managed to postpone the prospect of institutional care for a while longer. Norman worked (without pay) despite his age and disability. Only Marge did not seem to resist anything done to her, she merely withdrew more and more. At my last visit she had stopped attending the exercise program and had had no visitor since myself four months previously.
Notes


'Albrecht, p. 7.

'Albrecht, p. 20.

A cerebral vascular accident (CVA, stroke) is an injury to the brain caused by impaired circulation to brain cells. It can be caused by a variety of factors but by far the most common are: (1) a clot forming in a brain or neck artery and blocking the flow of blood to the brain. Usually arteriosclerosis is concomitant. (2) Hemorrhage can cause a stroke when the leaking or burst artery's blood damages surrounding tissue. (3) A clot from the heart or a major artery breaks off and moves to a brain artery and becomes lodged; this is called an embolism. Or (4) to a lesser extent, something such as a brain tumor might compress the artery from the outside and block the supply of blood to the brain.

The injury to the brain is not equal in all areas; some will function normally while other areas will not. The following is a list of potential intellectual and behavioral deficits frequently experienced by the stroke patient excerpted and summarized from American Heart Association material.¹ ²

(a) Paralysis. If the damage has been to the right side of the brain, left sided paralysis might occur. If the damage has been to the left side of the brain, right sided paralysis might occur. Although paralysis is the most commonly thought symptom of stroke, it is possible to not have paralysis with a CVA.
(b) Behavioral Style Changes. Generally, the right sided brain injury leads to an impulsive behavior style in which ability performance are overestimated by the patient. On the other hand, a left sided brain injury can lead to a slow and cautious behavior style with disorganization and anxiety in approaching a new problem.

(c) Intellectual Deficits. In the right sided brain injury, spatial-perceptual deficits in which judgment of distance, size, position, rate of movement, form and relationship of parts to the whole commonly occur. In the left sided brain injury, language and speech deficits generally called aphasia are more common.

(d) One-sided Neglect. Stroke can damage the visual field (on the same side as the paralysis) and cause the patient to "not see", thus ignore half of his environment. It occurs to one-half the lens of both eyes and can be so extreme that they do not recognize part of their body as their own or eat only one-half the food on their plate.

(e) Memory Deficits. In the right sided brain injury, the memory deficits surround ability to perform tasks while left sided brain injury will manifest memory deficits surrounding language.

(f) Quality Control Deficits. These present themselves as inaccurate perceptions of one's ability.

(g) Retention Span. A stroke patient often has a shorter than usual memory span and is less able to retain complex messages.

(h) Old vs. New Memory. The stroke patient may have difficulty with remembering newly presented information while memory from the past is retained.

(i) Generalization. A stroke patient may not be able to generalize or transfer what is learned in one situation to another or be able to modify or adapt it to a new setting.

(j) Emotional Lability. A stroke patient may have an inability to control emotions; laughing or crying inappropriately or reacting hostilely without actually experiencing those feelings. To distinguish lability from the true feelings, labile stroke patients have little control over the behavior, are easily distracted from it and will later deny it as a true emotional response.
(k) Sensory Deprivation. The paralysis, the distortion of the five senses and the environment may all lead to symptoms of sensory deprivation, irritability, insecurity, confusion and delusions in the stroke patient.

To the healthy individual, action and thought seem smoothly interrelated and it is hard to identify the many steps that are mentally traveled in carrying out even the simplest of tasks. When there is injury to the brain sometimes it is as though only one such step is missing, but the result is that the task is unaccomplishable, improperly done or accomplished by a new process. To demonstrate the complexity of this idea consider the aphasic who cannot articulate nouns, or can blink her eyes and squeeze her hands but not both together. The formulation of speech, understanding it and producing intelligible and appropriate speech is the result of processes in no less than seven different areas of the brain.

The four people presented have had an injury to the brain which unquestionably altered them. Finding out how and why is an important and challenging task made difficult because the injury was to the brain, the seat of personality and intellect.

Understanding how much change occurred in these people as a direct result of the damage versus how much occurred because of their adjustment and encounter with others is not known. For example, severe depression is a common problem after stroke, and its cause can be organic,
exogenous or both. Likewise, the cautiousness of a person with left brain injury is probably the result of the damage as well as learned behavior from contact with the world.

Does the fact that these four were brain injured lessen the credibility of what they said? Insofar as the four report their honest perceptions of themselves and others, no. But distinguishing the role society plays in their attitudes is made difficult by the nature of their brain injury.

It is therefore the task of supporting literature to determine how much their criticism of society can be generalized. Ultimately, the reader must decide what universal truth their words hold and what is the fancy of a damaged brain.
Notes


CONSENT AND RELEASE

I hereby give full authority and consent to Hazel Beh to gain access to all of my social work and medical records including, without limitation, those at the Honolulu Medical Group and at the HMG Gerontology Program, and consent to use all of such material, and any and all material obtained by her interviews with me, and with others concerning me, in her doctoral dissertation and any other writing or publication, and hereby release Hazel Beh, and her successors and assigns, from any and all liability for such use, including any invasion of privacy, libel, slander or otherwise. I hereby waive any and all rights to royalties or payments of any nature whatsoever arising out of such writings or publications.

In consideration of the above, Hazel Beh will make her best effort to conceal my identity.

Name

Date
APPENDIX C

Transcriptions of Interviews
INTERVIEW WITH MARGE
March 13, 1983

Int: When did you have your stroke?
Marge: It was, uh, about 3 years ago.
Int: What were you doing?
Marge: Nothing, that's not quite true, I was in the doctor's office and I had an appointment for a complete physical, and I don't know what happened but I ah, didn't get the physical.
Int: Did you have warning signs in the months before?
Marge: No, I didn't. No, I had vague warning. I felt ...
Int: Numbness? Tingling?
Marge: Yes, tingling.
Int: What did you think about that?
Marge: I didn't think anything. I ah, was working had and ... I was just setting up my clothing store ... and uh ...
Int: Do you remember the thoughts you were thinking when you had your stroke?
Marge: No, I couldn't believe it ... I guess I was quite a troubl [trouble] to the owners of the clinic where they sent me. But I don't remember.
Int: You went to _______ Hospital?
Marge: Originally.
Int: Do you remember much of _______ Hospital?
Marge: No. I just remember that it was distasteful experience there. That's all I remember.
Int: Was it with the staff, a doctor or a nurse?
Marge: It was with the staff.
Int: The way they treated you?
Marge: Yes.
Int: Is there a word to describe it?
Marge: Despicable.
Int: Do you think you were frightened or angry?
Marge: Both. I fought against being ... in the position that I wasn't used to. It was completely foreign to me.
Int: Being dependent?
Marge: Yeah.
Int: Did they include you in your treatment? Did they try to tell you what was happening or make you understand?
Marge: No. No. I thought, they ... expected me to behave myself and take what was coming to me.
Int: You couldn't talk at all then?
Marge: No, I garbled.
Int: Was your doctor a long time doctor of yours?
Marge: Yes, but he was replaced ... and I never got over it. I uh uh ...
Int: Someone replaced him at ________ Hospital?
Marge: Yeah ... without my permission!
Int: So he was your family doctor.
Marge: Yeah.
Int: Was he there when you were admitted?
Marge: Yeah.
Int: And they replaced him and you couldn't say anything.
Marge: Yeah.

Int: So now, did you go back to him or do you have a new one?

Marge: I have a new one and he doesn't understand me and I don't understand him [laughter] it is not very satisfactory.

Int: Did anyone at _______ Hospital really help? Do you remember anything good?

Marge: No.

Int: From Hospital you went to The Rehabilitation Hospital. What was your experience there?

Marge: Well if the truth be known, I wasn't used to being regimented. So much. Oh, boy. But needless to say, they were good to me.

Int: Did you understand at The Rehabilitation Hospital what was happening to you?

Marge: Yeah, they, explained it very carefully.

Int: Did you ever have to make a decision about your treatment?

Marge: No.

Int: It was all laid out for you.

Marge: Yeah.

Int: How long were you at Rehab?

Marge: Uh, about 10 months.

Int: Who notified your family? You have a daughter?

Marge: Yeah, I have a daughter and she wasn't any help.

Int: Did they call her at _______ Hospital?

Marge: No ... I have a ...

Int: A friend ... Bob?
Marge: Yes, Bob. Without question he is a true blue friend. And he has helped me over much of this interim. I couldn't believe it had happened to me.

Int: Did you have a lot of friends before your stroke?

Marge: Yeah.

Int: Did you feel this changed?

Marge: Yes. Indeed.

Int: Why do you suppose?

Marge: Uh, I changed uh ... and they changed and ... that's all. And I, I feel left out. And uh, ...

Int: When you were in Rehab, because you didn't have family, was it ever suggested that you go to an institution? Did you always know you were going to go home: Was there any pressure?

Marge: No, I knew my apartment was waiting for me. I lived here off and on for ... I don't know how long.

Int: Since when you were working?

Marge: Yeah. I worked all my life.

Int: In the fashion industry.

Marge: No, not in town, I was in radio and television for 17 years.

Int: Always aware of how to communicate and to look good? And now you are in a wheelchair and have trouble communicating?

Marge: [Laughter] ... Yeah from the ridiculous to the uh ... from the ridiculous to the uh ...

Int: I don't know how to finish that expression either. [Laughter] Did you ever get depressed about this?

Marge: Yes. I, I uh, am normally a happy person and I, I, don't know if I have changed all that much.
Int: Well, if you were really aware of how other people saw you, wearing good clothes and how you looked to others, did you have to change a lot?

Marge: Oh yes.

Int: Did your self esteem drop?

Marge: Oh yes indeed.

Int: How did you get through it? Because I see that you like yourself now.

Marge: More better. [Laughter]

Int: Did it take time?

Marge: Yeah.

Int: What helped?

Marge: I was resigned to my fate. That helps a great deal.

Int: Where did you learn that?

Marge: Well I don't know. The main thing uh, it is amazing how unchanged I, as I say, I was completely resigned ... Up until a short time ago.

Int: What happened a short time ago?

Marge: Well ... I ordered a new chair. And uh, it didn't come. And it hasn't come. And uh, I don't know if that affected my uh, affected me overall.

Int: It made you depressed.

Marge: Yeah.

Int: You are getting a better chair?

Marge: Yeah! I kept hoping it would arrive and it has been 6 months.

Int: Who helped you order it, rehabilitation facility?

Marge: Initially, Bob helped and Mrs ... [I help with names] I can't think of her name. And in other
words, she owns the business of wheelchairs. And uh, she kept promising me and uh, it still hasn't come to pass.

Int: Did you pay for it? Is it electronic?

Marge: Yeah, and it's got everything I'd ever need. [Laughter]

Int: How come you didn't get one sooner?

Marge: I don't know. Rehabilitation facility issued me this chair. It has been home.

Int: What kind of problems, when you first came home from Rehab, what did you think?

Marge: I was amazed at the attention I was getting and uh it was a very refreshing to think that so many people rallied around me. The people in the apartment.

Int: Acquaintances? But not good friends?

Marge: Yeah. I don't have any good friends ... to tell the truth. I, ...

Int: Was it like that before the stroke?

Marge: I felt them pulling away because of my handicap.

Int: How do strangers treat you in Waikiki, which is so busy? Do you ever go out?

Marge: Not often, once in a very great while I, have my helper to uh, take me shopping and uh, she does it.

Int: What do you think of the people out there?

Marge: I'd just as soon be without. [Laughter]

Int: Is it because you feel differently about yourself or because they treat you differently?

Marge: What was that question?

Int: Is it because you are embarrassed or ashamed?
Marge: Yeah.

Int: Did you ever feel that they treated you differently, like when you go shopping?

Marge: Uh, when I go shopping with uh I've only had one incident where I was really could call, uh an incident. I was set on by nasty clerks and uh, Liberty House. And that's all.

Int: What do you miss the most?

Marge: Oh, I miss dancing. Cause I could always um, pick up and uh, go dancing. That's about all, I miss the usual things.

Int: Do you like your life now?

Marge: No. No.

Int: What is missing, why don't you like it?

Marge: ... I miss the companionship of ... I miss my companionship most of all.

Int: There are groups like clubs and senior citizen's groups. Do you feel that you isolate yourself?

Marge: Well, pretty much. I'm isolated in one sense. Because I want to be ...

Int: Because you don't want people to see you like this?

Marge: I don't know. I, I, ...

Int: Tell me more about your business. Did you like working?

Marge: Oh, yes, yes indeed.

Int: You were unique, as a woman in those times, when they didn't work.

Marge: Yeah, and I was in management.

Int: Would you describe yourself as aggressive?

Marge: Not too.
Int: What made you successful?
Marge: Money.
Int: Money? Your liking it?
Marge: No.
Int: You had money?
Marge: No I was from a very poor family. And success was uppermost in my mind.
Int: How many brothers and sisters?
Marge: Three brothers and four, three sisters.
Int: Do you keep in touch?
Marge: Since the stroke, I don't keep in touch as often as I should.
Int: Why do you suppose?
Marge: I don't know.
Int: Were they all successful?
Marge: That they were all successful except those who didn't work. The daughters.
Int: Why did you choose to work?
Marge: I always worked. And I always felt that this was misinterpreted.
Int: What do you mean?
Marge: Well, uh, I don't know exactly, now but [unintelligible].
Int: Who misinterpreted why you worked? Your daughter?
Marge: Yeah.
Int: Your husband?
Marge: Yeah.
Int: Do you think they resented your working?
Marge: Yeah, believe me, they resented it.
Int: Did it mean you didn't love them enough? Is that what it meant to them?
Marge: Uh, a great deal of jealousy. Which I was ... [can't finish the sentence].
Int: Your husband was jealous?
Marge: Yeah, I was able to do things that he was not. Uh, although I ... 
Int: How long were you married?
Marge: Fifteen years.
Int: Did you take custody of the two children?
Marge: Yeah, because he was an alcoholic. And if you have ever known one. Whoo.
Int: Not much fun.
Marge: No not fun.
Int: Is he still alive?
Marge: No.
Int: So you have had a lot of disappointments?
Marge: Yeah, if you can call them that.
Int: You are Catholic. Would you call yourself devoted?
Marge: No, I don't feel that strongly in anything anymore.
Int: You said at the beginning that in some ways you liked yourself better now. Why is that?
Marge: Because I am alone. I don't know why I feel the way I do, except for, uh, [cannot finish].
Int: Do you know yourself better.
Marge: Yeah. I have always stood on ceremony and it is a relief not to. [Laughter]

Int: Do you have any goals you would like to accomplish in the rest of your life?

Marge: No.

Int: There is something that sometimes happens to the elderly called a life review, where memories come back and you can't shut them out. Has that happened to you?

Marge: No.

Int: Do you have any strong memories of your childhood or adult life which bothers or comforts you?

Marge: I don't remember.

Int: Maybe you are not old enough yet. [Much laughter] What keeps you going?

Marge: I don't know, I don't understand it. Um, I suppose the will to live. That's uppermost in my mind.

Int: Did you ever think your speech would come back this well?

Marge: No, frankly I am amazed that it has come back as well as it has.

Int: I have a question about your aphasia, do you know when you are saying the wrong number, or making a mistake?

Marge: Yeah.

Int: Can you read?

Marge: No, that is one of my tragedies.

Int: Can you read simple words, signs?

Marge: Yeah, I'm practicing.

Int: Some people, after a stroke, their moods are affected, were yours?
Marge: No.

Int: How about your judgment?

Marge: Yeah, I am not as trusting. I don't know what the reason is but I don't trust many people.

Int: How do you feel about American medicine in general?

Marge: Well, I, think it leaves a lot to be desired.

Int: What would you like to see changed?

Marge: Uh, I really don't know, I can't say anything ...

Int: Their attitudes?

Marge: Their attitude, yeah.

Int: In all the doctors that you saw, say one-half or one-fourth cared about you as a person?

Marge: Half.

Int: What about the nurses?

Marge: No. I brought one nurse into my home and found her sleeping with my husband and it was ...

Int: That was a long time before your stroke, but it turned you off to them?

Marge: Yeah.

Int: Did your experience at Queens or Rehab change your attitude toward them?

Marge: Yeah, in fact, I don't know what did you say?

Int: What do you think about different professionals, how they could improve how they care for people. Can you put your finger on what they didn't do, how they could have made things better for you?

Marge: Respect. Respect for my dignity.

Int: Because you couldn't speak, that compounded the problem.
Marge: Yeah, indeed it did. People treat you by what you can verbally give back to them.

Int: Did you ever wish you could die?

Marge: Yes. In Rehab. There is a normal depression.

Int: Do you feel this way now?

Marge: No, I am resigned to my fate.

Int: Do you feel there is a purpose?

Marge: Yes, yes I do.

Int: What do you think it is?

Marge: A greater knowledge of myself.

Int: What do you do every day? When do you get up?

Marge: It varies. What do I do every day? Watch television. Read the paper. As much as I can. Practice, Um, make my bed.

Int: Do you cook?

Marge: Yeah.

Int: Do you do laundry or shopping?

Marge: No.

Int: Do you bathe yourself?

Marge: On occasion. Um if that that, uh, maid isn't here. I bathe three, times, no five times a week and on the weekends I don't.

Int: What gives you the most pleasure?

Marge: What gives me the most pleasure? Seeing people enjoy themselves on well ... the tennis court [under the balcony] and I can hear them laughing.

Int: And getting mad, too.

Marge: Yeah. [Much laughter]
Int: How often do you get a visitor?

Marge: Other than a maid? My brother came last [can't find the word] fall.

Int: How often does Bob come?

Marge: Not often enough. I've got so many things pending.

Int: He handles your finances?

Marge: Yeah.

Int: How often do you go out every week?

Marge: Once. To the Medical Group.

Int: Who does your hair?

Marge: I've got a permanent and then uh I keep it combed.

Int: Is there anything you ought to be doing that you don't do?

Marge: No.

CONCLUSION OF FIRST INTERVIEW
INTERVIEW WITH MARGE

May 14, 1983

Int: Anything about the staff or doctors that made you feel the way you said you did, last time?

Marge: Well, that was unfortunate for me, I didn't want to be a nuisance and uh, still in all, I wanted to be shown some courtesy. And I wasn't.

Int: In what way?

Marge: Well, well, I didn't have any explanations at all for what was happening to me. That was the biggest of my worries while I was in the hospital.

Int: At first you were on I.V., when you began to eat, what was that like?

Marge: Well [laughter], that was an experience. [Cannot recall words]

Int: Were they patient?

Marge: No, not really, I was just another number to them, not essential, I felt put upon. [I think she means, putting them out.]

Int: Did you ever feel the other patients knew too much about you or did you ever overhear staff talking about you?

Marge: No.

Int: Do you feel people treat you differently?

Marge: Yes! In fact um, seeing as I can't get around like I used to has meant, has taken its toll.

Int: In terms of loneliness?

Marge: Yeah, and I can't help but feeling that they resent the fact that I am a cripple and have to be cared for.

Int: They is anybody?
Marge: Yes. My brother came over to visit me. He was nervous and I could sense a change on his part as well as mine. Because I couldn't talk or carry on a conversation.

Int: He felt uncomfortable?

Marge: Very.

Int: Did he ever say that?

Marge: No, never.

Int: So when people feel uncomfortable, and some people resent you how does that show?

Marge: They avoid me, and very often they will remark, um, to the extent that uh, I'm leaving something to be desired in my conversation and uh.

Int: In terms of your aphasia. Inside of you, you understand everything.

Marge: Yeah.

Int: You still have all of the sophisticated feelings.

Marge: Yeah.

Int: When I first came here, you couldn't tell me the number of the apartment.

Marge: I still can't. But I know what I say is wrong.

Int: Incredible.

Marge: Frustrating, I could tell you about frustration.

Int: What about the incident in Liberty House?

Marge: They were rude, well, they didn't wait on me. [Much laughter throughout this.] I was waiting for my aide to come. The clerk got very excited and wanted to know when I made up my mind. I was supposed to let her know ... and I couldn't because I had this problem. It was devastating to me as well as to this young girl. When I am with an aide, they talk to her instead of me. I feel that I don't have anything to say.
Int: Are you embarrassed by your speech?
Marge: Yes, sometimes, when I have difficulty enunciating.
Int: Are you proud of how far you have come?
Marge: Yes I am! Hard to be embarrassed to be proud at the same time.
Int: Is it easier to talk to someone who understands, like our group?
Marge: Yes, much.
Int: Have you had anything to do with children?
Marge: No, I have a grandson but I, he is out of reach.
Int: How about why you stay up here so much. I'm sure there are a lot of reasons.
Marge: Well, I don't feel comfortable in public. And if I um, just stay away, I don't have to make any excuses for my manners. [Something unintelligible, this was difficult to get out.]
Int: So if you go, say to McDonalds [right across the street].
Marge: Yeah, and then uh, I guess I don't know quite what to do about that.
Int: Like you could wear a big sign.
Marge: Yeah [says this seriously, and then laughs].
Int: Does it seem people see you as a handicap rather than a person?
Marge: That is very true, truer words were never spoken.
Int: Who is your doctor now?
Marge: Dr. (Chinese name) he is associated with Rehab. He became my doctor at Rehab.
Int: How does he see you?
Marge: He is very business like and uh, there is no socializing because he cannot speak properly. He is foreign and uh, we don't have anything in common. He doesn't know anything about me. I don't know what he thinks.

Int: Besides yourself, who is the most important person in your life?

Marge: [Long pause] My son. And uh, my son, only because he's uh, not ashamed to take my anywhere and he calls me "Mom" in a loud voice. [Laughter] Most of the time. And uh, he is compatible with anything I want. And anything I need. He went to the trouble to find me an apartment with everything in it made for a handicapped person. And uh, I thought that was swell. You know that he cares about me.

Int: He is special because he didn't change toward you?

Marge: No. And he wasn't ashamed of me. And [daughter] was ashamed to be seen with me. And she is off limits to me.

Int: Did anyone try to tell you what to do?

Marge: Not until, last week. We are in the process of finding a suitable home on the ground floor.

Int: That is your choice?

Marge: Yes, but I don't want to. The manager and uh, after the fire, I became upset and I didn't want to act like I was. [Cannot get this out.]

[Ask her questions about what this is about. She cannot say.]

Int: Did you evacuate the building?

Marge: No, I didn't have to. The fire was in the next building. I panicked.

Int: What did you do?

Marge: I stayed in here and paced back and forth to my door.
Int: Did anyone check on you?
Marge: No.
Int: So now the manager told you they want you to move to the ground floor?
Marge: There was another fire, immediately preceding. Uh, [probe] Another fire, in the uh, trash, on this floor. And uh, no one could put it out until the fire department came. Uh,
Int: Are you afraid to die?
Marge: No, no not at all.
Int: What makes you afraid about a fire?
Marge: [Laughter] I am afraid I'll get burned.
Int: You are only afraid of the way you are going to die?
Marge: Yes, I want to die in my sleep. [Laughter]
Int: How do you feel about going back to the hospital? Most people die in hospitals, does that bother you?
Marge: No, I am used to them, laughter, after 10 months in Rehab.
Int: I guess what you are worried about are pain and disability?
Marge: Indeed, I guess that is everybody's fear.
Int: What happens after you die?
Marge: I don't know. That is an enigma (very enunciated). But I am not afraid of it.
Int: If you had to pick, something good or nothing happens?
Marge: Something good. But uh, that noise [referring to hallway noises] means my neighbor is taking a walk.
She is in a wheelchair too, do you ever go with her?

No she doesn't ask and I don't ask and that is where we leave it. [Laughter.] She is partially disabled due to a fall. She broke a hip. She is older. Poor thing, I feel sorry for her but I don't know what to do.

Part of life is giving and getting. I get so much from people, but I also give. My kids are always asking for feelings, and toys. Do you feel like you give to anyone?

Yes! I have a companion that I feel I have given to her. Uh, not so much in money uhm, but in friendship and uh ... I think she appreciates it because she is a foreigner. But she has a boyfriend and uh, in other words, he fills in what I don't. [Laughter.]

Do you like to pay your own way?

Yes! I'm extremely independent.

Sometimes Americans would rather buy things instead of accepting help and having to feel grateful.

I don't feel that. I am always grateful for what is bestowed on me.

How about not working?

It makes me angry. I see miles and miles of uh, non-returnable ... [Long unintelligible searching, finally we arrive at idea that people who don't work, make her angry.] I can't imagine me thinking that I am someone special. Uh, people should work.

You feel that people should work, be productive.

Yeah, and that bugs me, no end. Like collecting welfare, that is terrible.

And what you do is the same?

Not pulling my own weight.
Int: You got a lot of identity from your work too?
Marge: Yeah, most of my friends came from work.
Int: Women?
Marge: Both, I got along better with men. Because they were more understanding. I just think they're, I never met a man that I couldn't get along with. With very few exceptions.
Int: When you were working, before your stroke, did you have special career goals?
Marge: Yeah, that I didn't get to. I wanted to ... amount to something, not just in monetarily. I uh, but, the sense of respect.
Int: You had just started your Waikiki shop. Do you ever to there; is it successful?
Marge: I don't know, I don't go there because it was too painful because I, uh, was afraid of rejection. I didn't give anyone a chance to make fun of me.
Int: So you never went and offered to give your help.
Marge: Yeah.
Int: So you know you made that choice. Do you regret it?
Marge: Yeah, it shows weakness on my part.
Int: You could have said, "Well, I have had this stroke but I am still going to run things."
Marge: Yeah, but I didn't. I felt that I was inferior.
Int: Do you still feel that way?
Marge: Sometimes.
Int: If you did more, would you get more confidence or more hurt?
Marge: I think I'd get more confidence.
Int: If you made daily goals to tackle, would you feel humiliated and defeated at the end of the day or proud?

Marge: Proud. I think the new wheelchair will make a difference.

Int: As a social worker, I have a romantic view that if you could try, you could do everything.

Marge: But the truth is in the middle. Sometimes you would have a bad time. But you have to face defeat.

Int: There is a lot of safety up here.

Marge: Yeah.

Int: Do you see the stroke as something good in any way?

Marge: To say the least, it was a challenge. Just how much, I can't answer that but because I feel it I wanted to do better than I had been in the past.

Int: You were raised Catholic. Some people feel that a disability was sent from God, perhaps a punishment.

Marge: No, I don't believe that. I don't know why it happens, speaking for myself, I feel that I have been put upon with no explanation. Like lightning striking.

Int: That is easier than believing it was destiny?

Marge: Yeah.

Int: How about being an older woman? You are 65? In your early 60's when it happened. Did you feel anything about growing old?

Marge: No, I still think I am young.

Int: What do you think about aging?

Marge: I don't think about it.
Int: I know you were in television and people on t.v. are not supposed to grow old.

[Laughter]

Int: Do you find aging distasteful?

Marge: No.

Int: But you still feel young?

Marge: Yeah. But I don't plan to grow old.

Int: Did you have any feelings about aging when you were in midlife, say forty?

Marge: No, I had boyfriends to keep me young. (Lengthy pause, loses track.) I can't imagine why, I forgot.

Int: After your stroke, because of the wheelchair and things, did you feel you lost your sexual identity?

Marge: Yeah.

Int: The way others see you, or inside yourself.

Marge: Inside myself.

Int: Do you miss it, has that been hard?

Marge: No, you might say I shut the door.

Int: On your sexuality?

Marge: Yeah.

Int: But it was important before, the way men treat women. The flirting, the way they open doors. The game playing.

Marge: Yeah. [Smiling]

Int: If you were married, would it be different?

Marge: For myself, I don't think it would make much difference.
Int: Are you sorry you don't have a husband now?

Marge: Yeah.

Int: If you had not had your stroke, would you have considered remarrying?

Marge: Yeah. In fact, just before, my stroke, uh, I fell madly in love with this fellow, this man, and uh, it was returned in full measure. Until I had my stroke. And I try very hard to be physical ... no, philosophical about it.

END OF SECOND INTERVIEW

Marge was also interviewed/visited at other times without the benefit of the tape recorder. She was visited daily while in the hospital where I observed several medical examinations. On August 3, 1984, I visited her in her care home. Her speech has not returned other than affirmative/negative responses and some proper names.
INTERVIEW WITH NOBUO

November 16, 1983

Int: I was asking about your wheelchair?

Nobuo: Oh, is that what you want to know about? Well he said no, it would be better for me if I didn't get an electric chair and keep doing with what I've got. It be better, he said, because I'd have to push myself around which is better for everybody concerned.

Int: Why is it better if you push yourself?

Nobuo: Exercising, doing it I guess.

Int: Do you agree with that?

Nobuo: Well the more I think about it, the more I think he's right.

Int: When did you have your stroke?

Nobuo: August, 3 years ago.

Int: What were you doing?

Nobuo: Sleeping. Sleeping like a baby.

Int: You woke up?

Nobuo: And couldn't get up. And called an ambulance.

Int: Did you know what was happening to you?

Nobuo: Well, I guess I knew that that was a stroke. But it took me half an hour to crawl to the door to open the latch for the ambulance guys. And it took me over a half an hour just to get to the door. But I did.

Int: Were you scared?

Nobuo: Actually, I wasn't thinking of anything, I'd had a stroke twice before this and after a stay at _________ I was able to get up and walk with a cane.
Did you have any warnings?

Well, I had a doctor, but my doctor is Caucasian and he retired before I got the stroke and he gave me to the heart specialist at ___ Clinic and I had a stroke, slightly, still able to walk. But I went, they had changed the procedure where the nurse doesn't take your high blood pressure, they turned it to the doctor. And I told the doctor since I had my last stroke you haven't taken a reading of my high blood pressure. I don't know, he's the type of guy because I told him, he wouldn't take it. And I got this stroke a few days later.

Did you ever talk to him?

Well I held it against him 'til now, then I thought oh well, let bygones be bygones.

Did you ever say anything to him?

Well he met me at ______ Hospital on Saturday, and I guess they rotate and take all the other doctors' patients. And when he came, he apologized. I guess it's a bit late. He did apologize and that's the first time they all apologized to me. They all gods you know.

So, how long did you stay at Hospital?

Well, I had a different doctor after that and he believed in Rehab and got me up to Rehab after that. And I'm still with him.

What did you think of Rehab?

Well I think they're pretty nice people there although everybody don't think the same.

What did you think about "rehabilitation"?

Well, I'm glad my doctor believed in it. I was doing, not too good but I felt bad (referring to now). I was telling Paul, when you feel bad, sometimes you know that you have a flu coming, but I was just feeling bad. Then the doctors told me that I was taking the wrong type of pill for three years. And I guess it all accumulated. Now I'm taking an alternate pill and I
get dizzy on it but they have medicine for that; I'm all right now, it keeps my high blood pressure in check.

Int: When you first had your stroke and went to the hospital, could you get out of bed?

Nobuo: Well, I know I could get out of bed, but I had no sense of balance or anything.

Int: What did you think would happen?

Nobuo: Well, actually, my wish was getting better, like anybody else. I knew it would be rough and hard, but there's nothing else for me to do but try. Everybody was pretty nice to the patients up there, they took a lot of guff from me. I was laying there, I was blaming the doctors, I was blaming this but not the liquor I was drinking previously.

Int: You think that had something to do with it?

Nobuo: Well, I think it had all to do with it. You get up, take one shot and there's a whole new tint to the day.

Int: You did that, for how long?

Nobuo: Well, I drank quite a bit before the stroke.

Int: What did you do for a living?

Nobuo: I was a structural iron worker—construction. Do you know about structures. I worked on the beams. For forty years. It does help. I think the reason I keep on exercising is because when you're a structural and you have two holes and you're trying to get a bolt through it, you think you have expended all of your strength you can't get the bolt through it. So you give it another try, hardly any more strength come out but you make the hole so you can put the bolt through there.

Int: Is that the way you live your life?

Nobuo: Yeah, and it's been a good life.
Int: But you drank when you were working.

Nobuo: Well, it got so bad that I couldn't wait 'til I was through working to get to the liquor bottle.

Int: Do you think you were an alcoholic?

Nobuo: No, but I used to drink... You can blame it on others but to keep company. Well it was that way in the beginning.

Int: So what made you quit?

Nobuo: The stroke! Not quite altogether but I only drink 2-3 beers in a week. That shouldn't hurt anyone.

Int: So when you had your stroke, you said, "I don't want to drink anymore."

Nobuo: What? No, the doctors made me stop. They told me, "Don't drink anymore."

Int: So you listen to your doctor?

Nobuo: Why naturally.

Int: You said before, "doctors think they're gods."

Nobuo: Don't they think they are? Haven't you been to some that won't tell you what the medicine will do or what? I was in Clinic because they had a thing operated by batteries to stimulate your hand so your fingers move. The doctor I was to see with a sample, but the battery was dead! He was telling me things, but I knew those things but I wasn't going to interrupt him to tell him I knew those things, I just hear him out. And I think he brought in 2 or 3 samples and all the battery was dead. And he charged me 40 something dollars so I called up that HMSA and told them, "Don't pay that guy." But they did. Yeah. For the advice he gave me. But I'd heard it so many times before. But he thinks he's spouting the gospel.

Int: What do you do if you don't want to follow the doctor's advice?
Nobuo: Well, I think I'd be pretty foolish since I don't have any medical stuff except what I read and usually, 90% I'm wrong. I think the doctors went to school for something.

Int: What about your family, what did they do when you had your stroke?

Nobuo: Well then ... and now. They were very sympathetic, but not now.

Int: Your children are grown.

Nobuo: Yeah, I just called him last night and told him, "Don't come here, just cause I want you pick an item for me. Come because, after all see how your old man is getting along. There's no one for me to tell my problems to except my boy. Because staying in a hotel and I haven't asked my neighbors for help ever.

Int: How come you don't ask for help? We've offered all kinds of things, volunteers, that kind of thing.

Nobuo: Well, you know, it's very difficult for me to talk. If I don't tell them hi, they won't tell me hi. I say, to hell with you, I can do without them. So if they go their way, I'll go mine. Maybe I might be the loser ... but they don't gain anything either!

Int: What do you think other people think of you? When they see you in your wheelchair or with your cane.

Nobuo: I don't know. As humans, we got all kinds. Some people are friendlier than others. Some people think saying hello is bad, some people just say hello. Comes naturally. So the guys that don't say hello, well I don't either.

Int: What about going to the store?

Nobuo: Most of the time they are really helpful. But at rehabilitation facility they had a waitress working in the waitress. They are supposed to be helpful, although they smile, they do the sneakiest things. So they see me coming in, they stand up and walk away. They are supposed to
help you get your dishes. And I called the manager and then the wahine says "oh, I had things to do back there." But the thing is she has a job to do in the cafeteria. But since she is under Civil Service, she smiles at you and to hell with you. Yeah.

Int: Do you ever go to new restaurants?

Nobuo: They have box lunches, I put them in the freezer when I want one I put it in the microwave.

Int: But you and Paul go out to lunch sometimes.

Nobuo: That was before this thing here [referring to the wheelchair, a result of a recent mishap or small stroke]. From now, but I don't know if I can make it because I have that uh, problem of my uh, of going to the restroom is getting faster and faster. I can't control that. I think my insides are getting weaker and weaker with all the pills I'm taking.

Int: Did you ask your doctor?

Nobuo: I keep on telling him but they keep on telling me there is nothing I can do.

Int: You know they have a condom catheter?

Nobuo: I know. Ah, if I prepare myself before going out, I'll be all right. Depends on how long I'll be out. Today, I've really had problems.

Int: So what about your children. How many do you have?

Nobuo: Oh I had three.

Int: Do you see them?

Nobuo: No, I haven't been a good father to begin with, although. Two are boys and my ex-wife had my girl. Then if I go to the mainland to work, although I send money, they are under my ex-wife's care. So whatever they do for me, they think they were born free and raised free. There is nothing I can do about it until my children
get a little older and they think back and say, "I should have done this or that." Right? No.

Int: I don't know. I don't know your kids. When you were at Rehab, you said they came.

Nobuo: Why yes [laughter]. Even my ex-wife was sympathetic, she used to come see me. But I got my oldest son, he don't even know I got this wrong pill or second stroke. My doctor doesn't even know, he consulted another doctor and they think it is the pill. So they gave me an alternative.

Int: But you never told your son?

Nobuo: One of them knows, but just telling him and sometime, I'd like to discuss my problem with them but there is no shoulder there where I can tell my problems to. But they have their own family. So that's what I told my son, if you don't expect me to call for food and then you come, you can forget about it. I can do it, I'll make myself do it and wouldn't depend on it for a few small items.

Int: What did he say?

Nobuo: Well, he was quite aware of what I was talking. He knew I was mad and he could stay away as long as he pleased, it didn't matter.

Int: Why do they stay away?

Nobuo: Well, because they have their own problems I guess.

Int: So what do you think about independence?

Nobuo: For who?

Int: You.

Nobuo: I think I'm independent enough right now.

Int: Do you like it?

Nobuo: Well, I think it's important to the individual. I don't want to be a burden to anyone if I can help it.
Int: Was that what was important at Rehab, getting independent?

Nobuo: Well, I guess I've been this way all my life, I couldn't get a stroke to revital or whatever.

Int: How about the nurses?

Nobuo: They were pretty nice at rehabilitation facility although they had grounds to be mad at me because I wasn't talking much and blaming every damn thing for my stroke. But they didn't take it in and gave me good care up there.

Int: When did you retire?

Nobuo: Two years before this stroke because of heart problems.

Int: What did you think of retirement? Did you like it?

Nobuo: Well, I was drunk every day and ...

Int: Happy or sad?

Nobuo: I was happily drunk. With a glow to go to bed.

Int: Was retirement good for you?

Nobuo: Well, when I had the heart murmur. It got so I couldn't hide it from my fellow workers because once I got it, it took me an hour to get over the heart murmur. So my doctor, the one that wouldn't take my high blood pressure, told me to quit work. So I went under retirement. I might have been 63.

Int: Do you think retirement is good?

Nobuo: Well, I wouldn't have retired before 65 unless I had this illness.

Int: How old are you now?

Nobuo: 66.

Int: So you retired for your health. Otherwise you wanted to keep working.
Nobuo: That's right. But I couldn't hide my condition from my foreman or from my fellow working man because if a heart murmur occurred unexpectedly ...

Int: What did you think you would do when you retired? Did you have plans.

Nobuo: No plans, I would live day to day on a glow.

Int: Do you fish, hobbies?

Nobuo: Well, I was thinking of getting some orchids and do a little of that. Nothing strenuous.

Int: What kind of place do you live in?

Nobuo: An apartment.

Int: How long have you lived there?

Nobuo: Oh, ten or fifteen years.

Int: And you can manage okay by yourself.

Nobuo: A little difficult but I manage.

Int: How about stairs?

Nobuo: No, only a few up to the house.

Int: Is it a high rise?

Nobuo: No, just a ground floor building, with a walkway. But you have got a six inch rise.

Int: What would you do if you couldn't stay there?

Nobuo: I'd like to go the old man's home if I could get an admission.

Int: Which one?

Nobuo: On Kuakini [describes public housing project]. They say it's more spacious.

Int: Are you on the wait list, it's a long wait.

Nobuo: Well, I have a short life.
Int: One more thing, what about women? Have you ever thought about getting married again?

Nobuo: Well, I definitely don't think I should get married now, I'm incapable of doing anything. And what would a woman care for a guy that is incapable of anything?

Int: Before your stroke.

Nobuo: Well, I had friends. But the stroke did all kinds of things unimaginable. You understand? There's a Hawaiian-Chinese lady. She's about 48-49, not bad looking, she goes to the Senior Citizens place and because I happen to be sitting there all the time, I got to know her and she comes over and cleans my place for me.

Int: A friend?

Nobuo: Definitely, I think she is very nice. But she has a daughter that is what you call that, she looks normal when she is running but she is handicapped. She lives at the home in Pearl City.

Int: Waimano Home, she is mentally retarded?

Nobuo: Yeah.

Int: Do you think of yourself as handicapped?

Nobuo: Naturally I do, I won't tell nobody though [this in a whisper to me].

Int: How did you used to feel about handicapped people?

Nobuo: Not too good. I was in California and this guy, he wants to be some kind of marriage counselor. And I said, no I thought, why you nut.

Int: Was he in a wheelchair?

Nobuo: No, he wanted to be a marriage counselor and he was not young, he was about 50 years old. And he was telling us guys that. And I thought he was a nut just because I didn't know a darn thing about it. I thought he was off his rocker to do something like that. Because the iron workers don't
get the best pay but in L.A. it is over $17 an hour and a few benefits besides.

Int: How do you think handicapped people are treated in America?

Nobuo: Naturally I think they treat them pretty well. The last time I was broke my toe, I had 3 doctors. Every one of them consider this exercise good for me. What is good 2 times weekly, I figure 2 times more is twice as good.

Int: I mean, how do people think about you?

Nobuo: I wouldn't know, I wouldn't give them too much to think about. I'm not too friendly, neither am I the worse guy. Sometimes a stranger comes up and makes some kind of remark. I'm kind of cynical about what remark he make. He looks so stupid to me. I'm getting wet and he's getting wet and he comes and tells me it's raining. [Laughter] Oh well, we're all getting old.

Int: Which is worse, having a stroke or getting old?

Nobuo: I don't think about my age, I'll go out, whenever.

Int: Do you ever think about dying?

Nobuo: No, but, a couple of weeks ago, I had my heart murmur come back again. But previous to that, I had the stroke, my heart okay. Only one time the girl at Rehab was trying to measure how far I could stretch. And it was painful, you know, and I said, that's all. Then she yanked me and my heart was so surprised I had to go to Hospital. But that was the last time. This time, I've got to return it, but they gave me the thing to put under my arm and talk on the phone [he is talking about a Holter monitor]. Well, I think, with that thing on, gee, I'm going to pass away, then go see the doctor.

END OF INTERVIEW

Nobuo was also interviewed/visited at Hospital and at The Rehabilitation Hospital after another
stroke in July of 1984. In addition, Nobuo and I had frequent casual contacts for the past two years while he was waiting for his exercise program to begin. These were the times he has spoken of Paul's death.
INTERVIEW WITH CLAIRE

May 19, 1984

Claire: I thought I'd change my mind because I'm so nervous.

Int: Well, if it gets upsetting we'll just stop. You get along really well in this house.

Claire: Yeah, I have a girl, but she's off today. She'll be here tomorrow.

Int: Do you want the chair up so you can sit by the tape recorder?

Claire: Yeah, pull it up. I'm just like a baby. Oh shucks, this is stuck. Why did you pick me from so many?

Int: Because you seem to have an interesting story.

Claire: Everybody has.

Int: You are the third that I have chosen. You, I think, are very local.

Claire: All my life. I've been away, but this is my home. Trips, that's all.

Int: And you live with your family. How long ago did you have your stroke:

Claire: Three years.

Int: And how did it feel, how did it come on?

Claire: Well, I got up in the morning. I felt funny, you know. All of a sudden my eyeballs wanting to come out of the socket. Just pull out. And he said, "Go back to sleep, it's too early. You'll be all right." And I went back to sleep. Just a little while. And I couldn't. I got up again and then, I find myself just like I couldn't move. You know, I couldn't move. So I told my husband, "Daddy, there is something wrong with me. I can't move." He called all my children. I'm not like that all the time. Because he thought it was kind of funny too. And said,
"There is something wrong with mama." So my son, he lives in the back, said take them to the hospital. So the ambulance came, I went to the hospital.

Int: What were you thinking, were you afraid?

Claire: I wasn't afraid. I just thought, what is happening to me.

Int: Did you have any idea it would be a stroke.

Claire: No, no. I think you better ask me questions because I'm not myself today.

Int: Okay. Did you go to ______ Hospital or ______ Hospital?

Claire: I think it was ______ Hospital.

Int: And your doctor met you there.

Claire: Yes.

Int: It was a family doctor?

Claire: Yes, Dr. K. And, you know, I talk so much and now I don't know what to say.

Int: That's okay. Tell me what he did.

Claire: He tested me and then he came in and said. Oh, she had a stroke. You know, I didn't know what it was, I never had any. So, they called the other doctors. They had consultations and all of that. I just stayed in the hospital.

Int: What did you think of the hospital.

Claire: I hate hospitals. I've been there so many times.

Int: You have?

Claire: Yeah.

Int: What do you hate about them?

Claire: Because I've been there so many times. Every time I go there, I think I'll never return. But, I've had about six, seven major operations.
Yes. I've had my colon taken out. I mean, part of it. And I've had, gee, I can't even remember.

Int: Female surgery?

Claire: Yeah, all kinds. I had everything taken out, you know, hysterectomy. I had gall stones. That isn't all. I had goiter. I had that taken out.

Int: How did you become so sick so often?

Claire: I don't know, it's just because. It's just me I guess.

Int: And so every time you sent to the hospital, you thought you'd never return?

Claire: Yes. I hate hospitals. But every time, it seems that when I go, I always come back. You have to ask me a question.

Int: Did you go to The Rehabilitation Hospital?

Claire: Yes. I was in Rehab for four months. I don't like it very well. They could do better, I think.

Int: So you were unhappy?

Claire: Well, no. I wouldn't say that. The nurses and everything like that were nice. But I wanted to be home. I was there four months. And I couldn't even come home again. They wouldn't let me even come home weekends. I just stayed there.

Int: Like a prison?

Claire: Right.

Int: Did you always know you would come home? Did you ever think about a nursing home?

Claire: No. I never thought about any nursing home. I just thought that from the hospital, I'm going to come right home. You know and everything will be fine. And it's been fine, every time, but it seems I'm always going back.

Int: You didn't have any other strokes?
Claire: Just one.

Int: And so you and your husband lived here and he took care of you.

Claire: Yes. He's a wonderful man. I always like to talk about him. We've been married, should I say that? 50, almost 60, 57 years married.

Int: And how did he feel about taking care of you?

Claire: Oh, he didn't mind. He even, you know, I go to therapy. And he would drive back and forth. He'd take me wherever I wanted to go. I heard that some husbands, they don't want to take care of their wives. Especially after wheelchair and handicap. But my husband, no. He takes me everywhere. We have this uh, club parties. I never missed one until I was too sick to go.

Int: So, how did you feel about asking for help?

Claire: My husband? I never have to ask. He always right there to give me. And when he died. Oh, my whole world fell apart. [Tears] You know, I didn't need nobody if my husband's there. And so I thought, you know.

Int: And now,

Claire: Yeah, he took care of me. Even toward the very end. He never dreamed he was going to die, you know. He had a heart attack. Just right out there on the porch. He always think that he get well. I'd take care of him. [Tears] I didn't dream that, I always thought that I would go first. I can't even walk. The Lord took him. I would have gladly gone you know. Excuse me. [Get Kleenex]

Int: So how do you feel about the way you look right now?

Claire: Well, at first the main thing is to get well. That is the first thought. Then I said, gee, a lot of these stroke patients have something wrong with their face or you know, they change. First think I looked in the mirror, if I'd changed any. Oh, and then, you know, when I was in the hospital, 2 days, I couldn't talk, you know. And
then, the third day my granddaughter came to the hospital and my husband says, "Jojo, go see grandma. She'll talk to you. She hasn't talked to anybody. But try see, get her to talk." So she came and she said, "Popo, do you know who I am?" I looked at her. "Oh, you're Jojo." That's her pet name. So she go to grandpa and say, "Oh, she talked." My daughter was there. Everyone was so happy. They were afraid I couldn't talk. So many can never talk. It would break my heart. I love to talk so much. [Laughter] So, it's just that I cannot, my memory not so good.

**Int:** You notice that in what way?

**Claire:** Oh, like days of the week or things like that. Alphabet. I could never get that straight.

**Int:** Really?

**Claire:** Uh-huh.

**Int:** How about reading?

**Claire:** I can read, I can write. But, you know, when I first write, like maybe a 5 or a 7, it would come out something else. I don't know why.

**Int:** Is that getting better?

**Claire:** It is getting better, but I still don't know my alphabet. Some I remember. Pretty good, you know. We went to the mainland and when we come back from the mainland, I have to write the thank you cards because everyone was so kind when we went. I don't ... So I told Daddy, "Daddy, you have to write some cards because everyone was so nice to us when we were there." So my, so he said, "I cannot write, you write." I said, "I cannot write." He said, "You try. You sit over there and you try." I looked at him and he brought the pencil and paper and, you know something, I sat down there and I wrote. Nothing but, you know, baby stuff, just thank you and we had a great time, but I did. Gradually, I write more and more.

**Int:** So even though your husband took care of you, he made you do things too.
Claire: Not very much. He did everything. He cooked and
everything. I tried to get him to get someone to
help us. I said, "Daddy, don't work so hard, you
are killing yourself. Cooking, cleaning, doing
the laundry like that. Get someone to help us." But
he won't. He wouldn't have anyone in the
house. He just couldn't stand having anyone in
the house. "I can do, I can do," he would say.

Int: And when did your children move in?

Claire: You see, at first, the house was just this size,
three bedrooms. I was living here with my chil­
dren. And then Henry, you know Henry, yeah?
Anyway, Henry got married and he asked me if he
could build an addition in the back, you know.
For his house. That he would do everything.
Anything, just use the place in the back. So I
said, "Okay, if you want to do it." So that's
why he did it. My husband always wanted someone
to live with us because he said, "We getting old
and we need somebody," you know.

Int: So it worked out good for both of you.

Claire: Yeah. Henry's a very nice boy. My children all
are. Not that I'm bragging or anything like
that. Even the one out Aiea, he's taking me to
the doctor today because Henry's got to work. So
he doesn't work Saturday. And then, they always
come here, every weekend.

Int: Do you like children?

Claire: Oh, I love children. I had four, I lost one.
And I have, gee, how many, 21 grandchildren. I'm
a great grandmother, you know.

Int: I didn't know that. How old are you?

Claire: 60, 70, 76.

Int: So before you had your stroke, you folks were
already retired?

Claire: Yes.

Int: So what kinds of things did you do every day?
Claire: Nothing. I just sat around, putter here, putter there, because, I used to crochet a lot. I can't even crochet. I can't hold a needle. I don't know what to do with a needle when I hold it in my hand. I can't even make chains.

Int: So you crocheted. Did you garden?

Claire: My husband did all the yardwork.

Int: Did you go to clubs, senior citizens clubs?

Claire: No, not senior citizens. We have Chinese clubs. Social clubs. So he has his, I have mine. I belong to the Chinese Women's Club. And others similar to that one.

Int: Do you know (a socially active Chinese woman)?

Claire: Yes! She's on the same club as me. She had a stroke too.

Int: I didn't know that.

Claire: A mild one, way back. Long ago. Mild, but it was a stroke. She's nice.

Int: Did you work?

Claire: Yes, well before the war I worked in town, you know, the gift shops. And then the war came, you know, Pearl Harbor. That morning, I was going to the cannery. Because I was working at the cannery. I had my apron. My friends were going down to the Supply Center to apply for jobs. So they said, "Why don't you come along?" So I said okay. I just put my cap away. I went with them and on the third day I got hired. And I worked for, how many years? About 15 years.

Int: And then you got married, had children?

Claire: Yeah, I had children. 3 boys and a girl. I lost one boy right after the war. He was ... He was 57. Now, he wasn't. I forget. Around there, I think. No, 67.

Int: No, you are too young to have a 67 year old boy.
Claire: I could too. I was married at 18 and my husband was 20.

Int: So how did your boy die?

Claire: Well, he had some kind of goiter. He had goiter, but they didn't know what it was. You know, I had goiter, too. So I told him, I knew what it was. I told him, "Tell the doctor it's goiter," because, you know, the eyes popped. I knew. But they said it wasn't, it wasn't. So they treated him and treated him and he was in Japan at the time. So, afterwards, when he came over here, I took him to ______ Clinic and they said it was goiter. So, anyway, they sent him to ______ and they took care of him. But, I don't care for the doctors over there. He died. So my daughter-in-law and her children. There are seven of them, you know. And my son, he was 51, you know. Anyway, I think they got some help from the government because the doctors say it was a result of the war. His condition, something like that. All his kids got money to go to school.

Int: Do you still see them?

Claire: Oh yeah, they love grandma! I love them very much. Every single one of them. I love children, big, small any kind.

Int: When you were grieving for you son, was it very hard?

Claire: Yeah, that was my oldest son. That was hard, but not as hard as my husband. You know. That's why, I wonder how my daughter-in-law got over it. She was only in her 20's, no, wait, 40's. I guess she didn't have time to grieve. All those kids, yeah. That's why, when she became like that, Julia is her name. Oh, she's a wonderful daughter-in-law. All my daughters-in-law are wonderful. I have a nice family.

Int: How do you feel other people look at you in a wheelchair and all? Do you go out still?

Claire: Yeah, I was going out more until Robert died because he would take me. I don't care what people think of me.
Int: Do you think people think about it?

Claire: No, I don't think so. I think they should love me as I am. Stroke or no stroke. And I think they do. My friends do.

Int: Do kids wonder?

Claire: No, children never ask me anything.

Int: How do you feel about yourself, are you every angry or frustrated?

Claire: No, oh yeah, sometimes because I cannot go where I want to go because when my husband was living we were never home. Every day we were going someplace, doing something. We were very active in the Clubs. And then when he died, I had nobody to take me. And then, there's a lot of places the wheelchair cannot go anyway. So I don't go anymore.

Int: Are you lonely?

Claire: Well, yes, but not so much ...

Int: And how about bored?

Claire: Bored? Well, yes, I get bored. That's why I go to therapy. I like it very much. Abby, you know Abby has helped me a lot. She's very understanding and has helped me with my problems. How many times I go crying to her, and she takes me to her office and talks. We talk. I like everyone down there, they're very nice.

Int: Getting used to Robert dying has been harder than getting used to the stroke?

Claire: Yes, I think so. You know, I have to go to the psychiatrist. Did you know that? When I was in the hospital, when I had my stroke ... They wondered why ... Oh, you known when Robert died, I wanted to get rid of myself. I really did. I took aspirin, a lot of aspirin, but evidently aspirin didn't work. Funny though, funny part is that I didn't think nothing, I just kept taking them. I took like, 17, something like that. After I took them all, it dawned on me, I thought, what if I cannot die, I'm going to be worse. Be
a vegetable or worse, in everybody's way. So I decided to tell Henry. Oh, he was so mad with me. "Why do you want to do that for, I try so hard to take care of you. And here you do that to me." He took me to the hospital and they got rid of that, they got it all out.

Int: So, like a kid, you got in trouble.

Claire: Yeah! I try not to be too much trouble, he's been so nice to me.

Int: Do you feel like a burden sometimes?

Claire: Yes! I do. Of course. Sometimes I tell him, you see, the daughter-in-law cooks for me and, before I had the girl, you know. And even when they go out, they still have to worry about me. Henry does all that. She takes 3 days bathing, washing me. And the other daughter-in-law she would come and take the other 3 days. I didn't like that at all, because I was really a burden. So I told Henry, "I think I can solve this problem. Only me, I can solve this problem." He said, "What, what do you want to do?" I said, "I'm going in a home, then everyone can go back to their own routine, don't have to worry about mama. I won't be in the way. I lived so long already." I said, "Enough, I don't care. I'll go. I'll go to a home, it's got a roof," and I wanted to go. He said "No, Mama, that's the last resort because you didn't want the home, you told me way back." He told me that. None of my children want me to go in a home. "We'll find somebody to take care of you, you're going to stay right here. We'll look after you." So I'm still here.

Int: Does that please you?

Claire: I think so. But I thought I'd solve the problem so nobody would have to sacrifice anything. Coming all the way from Alea to bathe me. That's crazy, you know.

Int: But you never felt that your husband sacrificed.

Claire: Because I would do the same for him.
Int: You were a team. I think most people feel that way.

Claire: All my friends are like that, you know. I always tell my friends with husbands that are still living, I say, "Don't fight too much, love each other. You know, after he's gone, like me, I like love but he's not around, so take care of each other and love." I always tell them. [Tears]

Int: What about Chinese culture. What is it like?

Claire: Well, you know, with Japanese, the oldest son have to take care of the family. Where he likes it or not. But Chinese, no rules. And the children. My friends say, "Why don't you go live with your daughter?" They think it is easier to get along with a daughter than a daughter-in-law. But she doesn't have any room for me. She's got 4 children at home, all marriageable age but they're not married. She has a 4 bedroom house. She doesn't know where to put me. And, furthermore, my daughter is not well herself. She's going to the doctor. And my other son has a 2 or 3 bedroom house.

Int: So you are practical.

Claire: Very practical, no rules. I lived here 32 years.

Int: I just noticed the cross, are you Catholic?

Claire: Yeah, when my mother was Protestant, my father was Catholic and I was raised Catholic. Robert didn't care one way or another but now he's a Catholic because we're all Catholic so he joined us and you know, he's more devout than we are. He's very ... "Oh, we have to go to church, we have to fast." At our age, we don't have to fast anymore. After you get 65, you don't have to anymore.

Int: Did your friends change much after your stroke?

Claire: No, no they still call, come up. But it is so hard to come up here to the heights. Transportation is so hard, even the bus hardly comes.
Int: Most people say that there is some change after a stroke.

Claire: They may think that way. I don't think it's true. Maybe they feel that they're neglected, you know, they simply don't try. Maybe they are happy to see a friend, but the friend is not in the mood to talk or something like that. And so you think, "Oh, I don't think she wants to be my friend anymore. Maybe 'cause I got a stroke," or this and that. And you don't go back and try. My friends are like that, I'm not like that. It doesn't make any difference. I shouldn't make any difference; I'm the same me. I'm only skinnier and older.

Int: Did you ever feel funny going to a store or a restaurant?

Claire: No. Just like, I accept myself as I am. And I, I don't feel like I still got a stroke or something like that. Or I had a stroke.

Int: You take good care of your appearance. You do your hair.

Claire: Well, I like to. I go over there for my morale. I go over there and I listen for news. You know, that's the best place to listen for news. The beauty shop where all my friends to, see. So I figure I'm not missing out on anything.

Int: What can you do for yourself? Can you cook?

Claire: No, I have all the conveniences. I have a microwave, a cooker. You just name it, I've got it.

Int: What keeps you from cooking?

Claire: I don't try. There was never a need for me to cook. I never cooked my whole life. When I was young, my mother never cooks. You see, my father was kind of well-to-do. He had a grocery store and he had help. People working for him. See we had a cook there and so every evening the cook would fix up everything, the rice and everything and my father would take it home for my mother and I. And so my mother never cooked her whole life.
Int: So how did you raise kids without cooking?

Claire: Robert cooks! He loves to cook. Oh, because I worked Pearl Harbor too. I used to work 12 hours a day during the war and so, he'd get everything ready 'cause he gets through early. Because he worked for (a Hawaii corporation). He got through at 2:30. So he comes home and puts everything on and when I come home we just finish the table.

Int: How about in the bathroom, can you do everything?

Claire: Oh, yeah. Except I cannot get in the tub. That's why I need a maid. I cannot go inside the shower. Maybe I can, but Henry is afraid I might fall.

Int: You travel by Handivan yourself now.

Claire: Yes, I call them myself and when I don't go, I call them up to cancel. And I can dress myself, my own shoe and brace.

Int: You are very independent then?

Claire: I'd like to be more independent.

Int: Who built the ramp for you?

Claire: You know, he built this side first because and then afterwards he discovered that it was too steep for the girls to push me to the van. So Henry made it on this side, much better now. Well, he used to be a carpenter, he used to work in the Navy Yard when he just graduated from high school. As a foreman. Now he's a policeman.

Int: What was Robert at (a Hawaii corporation)?

Claire: Just a clerk, that's all. Go down to the wharf, check for stuff.

Int: Is there anything more you want to say about a stroke, anything you want?

Claire: I would want to walk again, that's for sure. Well, I don't know what else to tell anybody because I hope I don't get another stroke. I had just one. That frightens me.
Int: What frightens you?

Claire: Being disabled. Not being able to go out, doing the things you want to do. You have to have help. Mostly, it's not being able to go out. I miss that so much. I never drove but my husband took me all over the place. He wouldn't let me drive, that's why he never wanted me to learn. He didn't trust me. So he said, "Why do you want to drive, I'll take you anywhere."

Int: How do you feel about your doctor, or doctors?

Claire: Oh, I think they're all right. But, like my husband, if he didn't have the operation for, what do you call, gallbladder, my husband wouldn't have died. Because he didn't have any symptoms of it. I know because I had had mine out.

Int: You think it was unnecessary?

Claire: Yeah! And you see, he'd been complaining he can't sleep so well, but no pain. And gallbladder has strong pain. Anyway, he went to the doctor, doctor checked everything, they said nothing wrong. Then another one said so. After the operation, he didn't come back like other people. After the operation, you know, in a certain amount of time, you are supposed to recover, but he didn't, he kept going downhill, kept on losing weight, losing weight. I was so worried about him. He went to another doctor, and they said, "Oh, your nose is broken." Because they couldn't find anything wrong. All these years he lived with it and now, because they couldn't find anything, they said to fix it. I though, "Oh no, not another operation." He didn't live to see it done anyway.

Int: You think they interfere too much?

Claire: Well, I think you should ask for a second opinion, we didn't, that's why. Our fault.

Int: So how about Chinese medicine. Herbs?

Claire: Oh, yes, my husband believes in that. You have a cold, you take that. My husband, never sick, you
know. That's why, when he died I was so surprised, he was so healthy.

Int: What's it like to go to a Chines herb doctor? Is he different?

Claire: Sure. You go in the store, the drug store. That's where all the druggists work, the little stores. Always in the little drug stores, everyone has one [doctor] and they call your name, you go in and they take your blood pressure, ask you all kinds of questions: your weight, age, what's wrong with you. After that, he puts everything down and then he prescribes the herbs and then you come home and cook the herbs and take them. And you know, it's not like a little teeny pill but like a bowl of medicine.

Int: Do you think it works?

Claire: Sometimes. I always wind up going back to American doctor. Sometimes the American doctor don't work, I go Chinese doctor. But anyway, I always have to go back to Dr. K. again. But my husband, he believes in the Chinese doctor, he gets well too. I think it all depends.

Int: Do you feel your doctor listens to you?

Claire: Haole or Chinese?

Int: Western.

Claire: Yeah, I know. My doctor does. He listens.

Int: After your husband died, did you tell him you were depressed?

Claire: Oh, yes. I told everyone I was depressed.

Int: You were supposed to be.

Claire: But I never dreamed it would hurt me so much. I thought I'd get over it fast. But I didn't, and now it's one thing after another. I'm through with this and something else pops up. And I get into another mess. And like this, when I'm through with it, something else happens. [Referring to a rash] Like, when Robert died, a half year before, my brother died. Yes, my youngest
brother, my pet, then Robert died. [Very tearful, sobbing] Robert! As if that wasn't enough, half a year later my sister-in-law died, my other brother's wife. And we were so close. Everyone is dying on me. I don't know what I'm doing here.

Int: Leaving you alone.

Claire: Yeah.

Int: Are you afraid to die?

Claire: No, I wanted to die.

Int: What will happen when you die?

Claire: I didn't think that far. I just wanted to die. I guess I wanted to join Robert.

Int: When you had your stroke, you didn't want to die.

Claire: No, it was funny, I didn't want to die. But the first month that Robert died, I didn't feel anything. I just can't believe that he went. Just like he's still around. I see him all around the place. The second month, when everything died down, then it dawned on me, "Oh, Robert isn't here, Robert isn't coming back." [more tears] My sister-in-law, I just can't believe that he went. Just like he's still around. I see him all around the place. The second month, when everything died down, then it dawned on me, "Oh, Robert isn't here, Robert isn't coming back." [more tears] My sister-in-law, when she died, I wanted to crawl in the coffin with her. I felt so bad. I told her, "I should die, not you." Every time, I could call her up, tell her my troubles. And my brother, the one that died, he was very close to me. Very close. Just like my whole world fell apart.

Int: What is so bad about being left behind?

Claire: It's just that there is nothing left for me. Me in the big wide world. Just like, I don't know where I belong. That's how I feel.

Int: Children aren't the same as brothers and sisters, husband?
Claire: Oh, no. Lord, they're different. Not like a husband. All my children, they're very nice, they never give me trouble, they're all good kinds, you know. It's not like a husband. There are things you can tell a husband that you can't tell them. The world changes so much. When your children are grown, it will have changed again. You know, before the wife doesn't work. She depends on the husband, she depends on the children. And the old saying is, "Well I take care of you folks and when you grow up, you take care of mama and daddy." Not anymore. Because the wife, the husband, the children go to work. And then, I don't know, the children's needs are more than before. Our needs were so simple those old days, you know. But now they got to have this, they've got to have that. It's hard to have another old lady to take care of, you know.

END OF INTERVIEW

Claire was also visited in her care home on August 3, 1984, as well as at her exercise program from time to time.
INTERVIEW WITH NORMAN

August 3, 1984

Int: How long ago did you have your stroke?

Norman: Seven years ago. I was coming from England. I got the stroke on the plane. Rachael had to call an ambulance to get me to HMO from the plane, I was unconscious.

Int: Did anyone on the plane know what was happening?

Norman: Well, Rachael says no, but I was unconscious.

Int: So there were no doctors on the plane, like in the movies?

Norman: No, there weren't any doctors. And they didn't want to order the ambulance, but they finally did order the ambulance to come out to the airport and take me to the hospital. I was unconscious for ten days.

Int: What does Rachael recall about that time, was she frantic?

Norman: No, she wasn't. Rachael is a wonderful person, she wasn't frantic, she played it cool really. She wasn't frantic anytime that I saw her. Even when I was near death, and recovering she wasn't frantic as far as I know. She takes things as they come, she's a realist.

Int: When you woke up ten days later, did you understand about what was happening to you?

Norman: No, no I didn't. I didn't know anything about strokes. I thought I was going to fully recover. And it was very depressing for me when I realized that I wasn't going to recover my hand and so forth.

Int: How long did your depression last?

Norman: About a year, no, about six months.

Int: Did you go to Rehab Hospital?
Norman: Well, I went to rehabilitation facility actually, for a month but I argued with everyone there and they kicked me out. I was terrible really, I was frantic. You wouldn't know me if you'd seen me. Because I didn't like what was happening to me. And rehabilitation facility was no good. They gave me some speech lessons and it was too elementary and I thought, "To hell with this," and I just couldn't stand it.

Int: How did you feel about your physician?

Norman: Terrible. Absolutely awful. I had six, I finally got the seventh physician, Dr. _ of the University of Hawaii, I accepted him and I go to him once a month.

Int: What about the others, what didn't you like about them?

Norman: Well, what I didn't like about Dr. _ was that he would say something and that's it. He wouldn't regard your feelings at all. Terrible. I told that to a psychiatrist. I went to a psychiatrist for six months I cussed [Dr. _] every time I saw the psychiatrist.

Int: Why did you go to a psychiatrist?

Norman: An eye doctor at HMO recommended that I go to one.

Int: Because?

Norman: He thought it would do me good. As far as I know, I didn't need to go but the psychiatrist was pleasant and I started cussing [Dr. _] and the rest of them out. But I, my stroke really changed my opinion of medicine. It made me realize that maybe 50% of the doctors are not really qualified. Especially in stroke they are not qualified.

Int: You had a feeling of confidence before.

Norman: Oh, yes. I really respected doctors, I liked doctors. But I got this feeling particularly with respect to doctors, they don't know anything. It is just terrible but it's true.
Int: You had a heart attack previously, didn't you?
Norman: Oh, yes. I had a massive heart attack.
Int: And you felt comfortable about them back then.
Norman: Oh, yes. I was cured, and so forth. And I really made wonderful progress. After my heart attack I took those little pills [nitroglycerine] for a year and a half and then I stopped taking them. I started playing golf, with Dean ______ and Dean ______. I played one hole, two holes, three holes and in a month I was up to nine holes and then I finally played eighteen holes perfectly comfortable. I got myself cured in about three years.
Int: How long ago was that?
Norman: It was about 20 years ago.
Int: Well, that must have been frightening, you were really a young man.
Norman: Yes, I was about 45 or so. And I was frightened, but after I saw how I recovered, I wasn't frightened anymore.
Int: How was Rachael during that crisis?
Norman: She was cool. I know that she felt terrible and would have liked to cry, but she didn't cry and she put up with me. During the stroke, I got to know Rachael. I got to know her like I never knew her before. What a woman. I'm speaking professionally about her. I don't think one woman in a thousand would take the attitude she does toward a stroke. My God.
Int: What attitude is that?
Norman: An attitude of realism, of being helpful at all times. I cuss like hell.
Int: She puts up with a lot?
Norman: No, she doesn't put up with anything, she lays down the law to me. She did everything that was good for me. I just can't tell you.
Int: She was like a therapist.

Norman: Well, yes, she was. And she got me on to the things that finally rescued me from my stroke. 10,000 units of vitamin C, she got me to go to the doctor that was recommending that. There was a doctor at HMO actually experimenting with that.

Int: And you still take it?

Norman: Absolutely, for five years. And I'd fight anyone who would try to take it away from me.

Int: What did Dr. ___ say about that?

Norman: Well, he thinks it's excessive but he goes along with it. And he realizes by now that it's all right for me.

Int: What about you and Rachael, what kind of marriage did you have?

Norman: Well, we had a good marriage. You know, we knew each other for three days, I proposed on the first date and we were married 3 days later. I asked her if she'd like to get to know me better, if we should put other things aside, and she said, "Nope, if I knew you any better, I wouldn't marry you." She was actually going with a fellow and was going to marry him. She married me on the rebound.

Int: You both worked throughout your marriage?

Norman: Yes, she worked as a management analyst for [federal government] and at [military base].

Int: You have an interesting relationship in that you don't have children, that's very unusual.

Norman: Well, I knew when I married her that she couldn't have children. She told me that. I didn't want children. I think, at the stroke, she more or less treats me like a child, you know. [Laughter] And, I don't know, she really does everything that needs to be done for me, and more.

Int: Does that ever bother you?
Norman: Well, yes, she does too much for me. In fact, when I got the job at the University a couple years ago, she took me down and I told her I'd take the bus home. And she didn't like that but that was the way it worked, I take the bus home. Now, my illness is getting slightly worse and if I'm going to need her, I tell her. She'll come for me.

Int: So you have had to assert your independence?

Norman: Well, yes. I try to.

Int: You said before, sometimes she treats you like a child. Do you ever feel less of a person for it?

Norman: No, no I never do. But I think it makes her feel better. [Laughter]

Int: What about with other people?

Norman: Well, I'll tell you, I really have very few acquaintances. For example, when I think of the men and women I used to know, I don't know them anymore.

Int: Why don't you know them anymore?

Norman: Well, I depend on Rachael and I rely on Rachael. Well, I just don't ... Well, I was writing before and when you are writing you just don't ... you sort of lose your acquaintances.

Int: So it wasn't because of your stroke.

Norman: Well, to a certain extent because of my writing, I got absorbed in it. And then after my stroke ... I was still absorbed in it.

Int: Sort of a loner?

Norman: Well, I am a loner, really. A loner. I think most professors are loners really. I am thinking of when I was on the other side (of the building). There was a professor right next to me. And I would talk to him and so forth. One day he said to me, "Say, I see you had a stroke." For six months, I was talking to him and he didn't
know that. It took him six months to find out I had a stroke.

Int: Do you regret not having good friends?

Norman: Well, I do to a certain extent. But frankly, no. I have to say no. What I regret more is the lack of movement. For example, I used to play golf once or twice a week and I had to cut that out. And I used to walk about 10 miles a day, now I can walk a half or quarter mile a day.

Int: Do you think people look at you differently?

Norman: I do, I notice that. Well, I'll tell you one incident that really riled me, that nearly got me in a fight with a man. One day I was waiting for a bus, I usually get on the bus first because everyone makes way for me. So I was getting on the bus first and he stopped me from getting on before the women. He didn't know that I had a bad stroke, you know. And he avoided me from then on. He used to take the same bus but then he never came around again. Because I said, "I'd like to sock you with something." I was very furious because he stopped me. He said, "Let the women on first," and he held me back, he held my coat or something. I was really in a rage. You've never seen me in a rage have you. I fly into rages every once in a while. Just since the stroke. I just get into a rage. An uncontrollable rage.

Int: How often?

Norman: Oh, about every two months, or one.

Int: You think it's just anger?

Norman: No, it's part of the stroke, really. Uncontrollable rage.

Int: You mean, part of the damage of the stroke?

Norman: Yes! It's uncontrollable. I simply fly off and I'm dying. I had one of these yesterday with Rachael. At the psychiatric hospital I was accepted there for my stroke. They have a very good psychological program there where they treat
you individually. I didn't think they would take me because I'm not bad enough. But they did.

Int: So on one hand, you say you have lost respect for physicians, on the other hand you turn to them for treatment?

Norman: Well, yes. I haven't lost respect for all of them. For example, there is Dr. ____, head of the ___ Historical Society. I used to know him personally, he's a general surgeon. He's a good man. But the number of good ones is way below what the average person thinks. The others stand up here, and you're way down here and they look down at you and say, "Do this, do that." It's a lot of crap. Of course since my stroke it's worse because I've seen so many of them that I judge them. And I've seen so much of them. I don't know what it is.

Int: Do other medical staff have the same attitude?

Norman: Well, the nurses don't. The nurses are generally pretty good compared to the physicians. It's a certain personality that I don't like among the doctors. Especially the stroke doctors because they don't know anything. It's just amazing.

Int: I know you hang around the University a lot, students, young people. How do they react to your stroke?

Norman: Well, they don't think about it much. My relations here are pretty good. Outside there are two graduate students, girls. They are much nicer to me because I've have the stroke. Everyone about the University is. I didn't realize that.

Int: Is that all right with you?

Norman: Well, it's all right with me although I don't take advantage of it. I don't associate with people, mix with people around here except for a casual word.

Int: You also go to the stroke club?

Norman: Yes, there is a huge turnover and I don't think much of it. Now the president of the stroke club
is good, K. He is the one who told me about psychiatric hospital, he went there for about four years.

Int: About the turnover, they come for a short time?

Norman: Yes, they come and then they leave and I don't know why they do either. They leave quickly there.

Int: Do you have brothers or sisters?

Norman: Yes, all in Chicago. One brother and sister.

Int: Do you have any feeling about whether they would help you or you them?

Norman: They would give me their last dollar and I would give mine to them. That's the way our family is. Although distant as far as feelings go, we're close as far as ... My brother could ask me for $500 and I would give it, without asking why.

Int: They didn't come out when you had your stroke.

Norman: No, although I see them once a year. This time we are not going to Chicago for the first time. And they always write to me.

Int: What about Rachael's family?

Norman: Well, she doesn't really have very much. She has an older sister in Honolulu and she takes excellent care of her, too. She visits her almost every day. Usually she takes me to the University and then visits her.

Int: Do you have a circle of friends?

Norman: No, Rachael does. I have none.

Int: Do you go along?

Norman: No, well, once in a while when they have a big meeting. But I don't know the people and I don't enjoy it. I don't know the people but I talk to them.
Int: You go to the University practically every day?

Norman: I go every day, Saturday and Sunday included. I spend an hour or hour and a half here.

Int: Then what is the rest of the day like?

Norman: Mostly rest. I go to bed as soon as I go home. I listen to the 5:00 news and the MacNeil Lehrer Report and then go to bed about 8:00. I do everything in the morning.

Int: Do you do any physical work like gardening?

Norman: No, Rachael does. I don't cook, I've never washed a dish. I put it in the sink, I found out later it's been washed. I say, "Who do you think washes those, the menehunes?"

Int: Do you read?

Norman: Only a little bit, I can't read much. I can only listen to t.v.--an hour and a half a day and then my eyes are swimming. I've had a cataract and lens implant which is not properly fitted yet. And then I've had herpes zoster which caused near blindness in one eye. And the blindness went from 20/500 to 20/200 after the implant. And let me tell you, I had a furious argument with one time, in fact, that was my reason for leaving and going to clinic. One day, at HMO, after telling them I was going to clinic to get an implant which Dr. B recommended, the doctor at clinic said, "Your folder shows that we recommended an implant years ago." And I said, "You never told me that, I don't care what you write down in the folder, you never told me." I swore at them and left there immediately.

Int: So now you don't go to HMO?

Norman: No, well, I try to avoid it although up until then I thought their eye section was pretty good.

Int: How would you like to see the relationship with doctors improve?

Norman: I generally have no use for doctors and don't want to relate to them. I don't want them to treat me differently if they're good. Dr. ___
at clinic is good. If they listen, if they care
about people then I like them. If they don't, I
don't. At HMO, if I could only tell you the
manner in which they would stand up here and you
down there and tell you this and that. I just
couldn't stand it. And their problem was they
would never listen to me. Never listen. He
would examine something on me and say, "This is
my diagnosis," and I'd think to myself, "What the
hell? I don't feel that at all." But he'd never
listen to a thing I'd say.

Int: What about your plans for the future?

Norman: My plans for the future?

Int: If something happens to Rachael?

Norman: I would commit suicide. I would commit suicide
if Rachael died immediately without any ques­
tion. This seems kind of funny but it's true. I
couldn't live without her. I'd get a gun or get
some poison and I'd go. I couldn't live without
her.

Int: In what way couldn't you live without her?

Norman: Well, I don't know but I couldn't live without
her. There are a lot of practical aspects but
that wouldn't be it. I just couldn't live with­
out her, because I love her. that's all. I
really love her. And she loves me more than I
love her. At least she shows it more. You see,
our marriage was never a close marriage. It just
grew. And we feel we are closer than 99% of the
couples we know. And well, if anything happens
to me, it would be bad luck for Rachael. Rachael
seldom gets sick, except for her heart right now
which is properly medicated. If she got sick, I
would have to take care of her, or hire a woman
to take care of her. Which I would. I would do
my best to take care of her. But life would
practically be shot for me if that happened.

Int: So you do think about those things.

Norman: Naturally. I see that Rachael is failing slightly.
She's getting older. I'd try to take care of
her, or get some woman. Who would really know
her. Rachael is a remarkably generous person.
When you first meet her, you are inclined to think that she is quite superficial. Did you get that impression? Do you remember your first meeting with her? But she is not. She is genuinely quite friendly and helpful to people.

Int: My mother is very similar to her.

Norman: Is that right?

Int: What about religion, does it play a part in your philosophy?

Norman: No part whatever. I go to the Jewish Temple about once a month. I go to the Jewish Seniors Club and I like the Seniors Club but and Rachael goes with me, she likes the people there.

Int: Is she Jewish?

Norman: No, no. She is not Jewish. No, not at all, Rachael was born a Catholic but she goes to the Temple, she acts Jewish, she likes the people there; she learns the words and has a good time. Well, we both have a good time there.

Int: But you don't feel it has anything to do with your philosophy?

Norman: No, not at all. I don't believe in the Jewish religion. I was brought up to believe in it, to train in it. But I'm not religious at all. I don't believe it. But, here's something that might interest you. You'd think I did believe in it [he gets out an article to show me which has historical Jewish and Hawaiian significance and is about his work in this area]. I wrote six articles about it.

Int: What are you working on now? Are you writing a book?

Norman: It's all written. This is it [referring to a manuscript in front of him].

Int: And what is it about?

Norman: Well, it's about _________ [a Hawaiian historical figure].
Int: Why is your office in the Business building if history is your subject?

Norman: Well, history is my avocation. I liked it better than finance and accounting. My PhD is in economics, from [an Ivy league university].

Int: What was your dissertation subject?

Norman: [historical business leader in Hawaii].

Int: You did this from an economics standpoint?

Norman: Yes, economic history. I wish I had it here to show you because it was a good dissertation.

Int: And so, you have many publications.

Norman: Oh, yes, about 40 articles and this is my fourth book. If they accept this book.

Int: Now writing this book has been very difficult.

Norman: It is the hardest thing I've ever done. Of course, I have a collaborator. [a well-known professor of economics].

Int: So he is helping in the writing of this. Your stroke is what is causing the difficulty, is that right?

Norman: Certainly does. In fact, I've lost certain things in my writing that I'll never get back. And I don't know what I'll do.

Int: Did you ever work outside of the University?

Norman: I started at [Company, Ltd.]; I worked downtown, it was the largest company in Hawaii. And I worked there for two or three years right after the war. I worked there until 1947 and then I was going to go to the University. I'd got my CPA and I was going to go. But they said, well stay here. So I worked downtown, then I ran up here and worked downtown and they gave me my full salary while I was doing that but after a year I gave that up. And I cut my salary by over half. And I asked Rachael if I could do
that, would she continue to work. And she said, "Go ahead, if you want to do that, go ahead." And that was really the biggest sacrifice she made but she said go ahead.

Int: Why do you keep going now, what drives you?

Norman: That is a really good question. Rachael and I were saying the other day, when she asked, around the circle what everyone's ambition was, I said, "My ambition is to write another book." And about half the class didn't have any ambition. I just couldn't understand it. [He is referring to the exercise group participants.] I feel if I don't have another ambition right away, I might as well shoot myself.

Int: Did you retire at all after your stroke?

Norman: Oh, yes, for about 5 years.

Int: And what did you think of it?

Norman: Terrible time. I didn't have anything to do. I just wandered around town. Well now, even today, there's some remnants of that. I might just go out to the airport from the University once in a while. And I walk about 10 minutes out to United Airlines and I'll see a plane come in, then I'll come back. Rachael thinks that is related to my desire to go to the mainland by United Airlines. That may be but I think it's just an adventure. I go different places. Some days I go around Kailua to go home, some days to Ala Moana, I go to Kahala Mall.

Int: Does that satisfy you or do you feel restless?

Norman: Well, I feel restless.

Int: But you don't have a desire to radically change things?

Norman: No, no. I don't have a desire to change things at all! Everything that is good comes by accident. For example, I was exercising at Ala Moana about 3 years ago when I ran into __________, he's the president of __________, and he used to be dean of the college of __________ here. And at that moment, having never thought of it
before, I said, "Do you think you could get me an office at the University?" And he said he would talk to ________, and he did and I got the office. Sheer accident. And then Rachael was against it because she thought she couldn't take care of me and so forth. And I said "I can manage."

Int: Have you actually published anything since your stroke?

Norman: Not a thing. My first publication is going to be a chapter from this book in __________ Review in ______ [month]. And my tongue is hanging out because I can't wait to see that publication.

Int: One time I was with Rachael and she seemed to discourage you from talking about the book.

Norman: Well she might not think it will get published. In fact, it might not get published. This book has not been accepted by the University Press. But eventually this book will be.

Int: Do you think it is good?

Norman: Well, it's not as good as some of the stuff I've published but it's good. And ________ is responsible that it's good. I couldn't write it like he does. I did all the research before my stroke. [He now shows me all the research and how it's organized.] Until you get yourself organized, it's difficult. [Shows me the way he files usable quotes and sources.]

Int: Does someone check each footnote?

Norman: I do. I check like hell. My books are well-known for that. It takes about 5 years of research and 2 of writing. [Goes on about the process of publication.] The first book was accepted for publication with certain changes. The changes took about a year. [This is considerably shorter than the actual conversation about bookwriting.]

Int: You were writing and teaching then?

Norman: Yes. In fact, that's why I had a heart attack.
Int: What about your feelings about having had the stroke. Do you feel damaged?

Norman: Yes, I do. Well, I feel damaged but I don't want to be pitied. Not damaged that way. A stroke restricts you so much. I used to be jumping all over. All hours of the day and night.

Int: Do you feel less than what you were?

Norman: Oh, yes. 75% less than what I was.

Int: How about in value. Do you like yourself less?

Norman: Well, it's hard to say. I was one of those persons who never had a very high opinion of myself. And, uh, as I look back at the person I was before the stroke, I should have had a high opinion of myself but I didn't have it. I really don't think I have a high opinion of myself. Do you think I do?

Int: I can't tell.

Norman: Well, I really think I didn't. I didn't realize how good I was. [Laughter] Now I do. Now that I am handicapped by the stroke, I realize that I was doing things that a lot of people can't do. Before the stroke, I didn't think of myself as a good writer, or one of the best writers in the college of __________, now, since my stroke, I think of myself as one of the best writers in the college of __________.

Int: What do you think of yourself now?

Norman: I think I was the best writer in the college of __________, now.

Int: But what do you think of yourself now. Not what you used to be, what you are right now.

Norman: Well, I think less of myself because I'm handicapped. I'm 75% handicapped. But it is hard to say. Because people are inconsiderate of age, inconsiderate of stroke.

Int: In what way?

Norman: Well, for example, I'm thinking now of the Burger
King shop, I was in it and a fellow pushed by me because I was going too slow or something. And he said, "Oh, shit," and I wanted to take a poke at him or say something but I couldn't because he was too big.

Int: What about sexuality, do you feel different about your manhood because of the stroke?

Norman: Well, my sexuality was not diminished because of the stroke. My sexuality has been diminished by age. And sexuality means less as you get much older. Well, before, Rachael and I had a wonderful sex life. And we don't have a wonderful sex life now because we are not sexual creatures really. But we love each other more than we did.

Int: What about the outward appearances of being a man, opening doors, carrying suitcases. Symbols. You're supposed to be strong and hairy, that kind of thing.

Norman: Well, I don't carry suitcases because of my stroke and I don't intend to and I don't feel it demeans me. Some people would feel it demeans them but I don't feel that at all. I really don't.

Int: I don't know what else to ask you.

Norman: Well, it seems to me you might have a lot more to ask me. If you do you can call me.

Int: Well, why don't you just talk for a few minutes about what life now means to you.

Norman: It's hard to say.

Int: How do you think America looks at handicapped people. If you wanted to give it a grade.

Norman: I'd grade it C or D. Because of the way I looked at handicapped people. I never paid any attention to people in a wheelchair. I never paid any attention to a person on crutches. It didn't mean anything to me. It meant nothing to me.

Int: Like they didn't exist?
Norman: Well, that's right. It meant nothing. And now, of course, it does. I'll see a person around the University in a wheelchair and I'll ask him what happened to him and so forth and try to give him a little comfort. But I, well, if you have a stroke, it wakes you up.

Int: So you think people don't see.

Norman: Well, you can't really blame people. I can't blame you, for example, for not seeing a stroke person because you haven't had a stroke, you don't know what the hell it is. Well, of course, you're more sympathetic because of the kind of work you do.

Int: All my life, I didn't grow up with any handicapped people. None in my school, none in my family. So it's like they don't exist for me.

Norman: I see. Well, you know, Rachael. I'd like to say this about her. Her attitude toward me before and after the stroke is absolutely the same. That fact that I had a stroke, and was dying as far as anyone knew, she treated me just the same. And that was a wonderful thing. Here I was, a man with a stroke and she treats me just like she always did. And she doesn't baby me really. Although sometimes she tries to. [Laughter] She treats me just like I was. And that's a tremendous step. I don't know, most people would defer to you or something. She doesn't really.

Int: We have a lot of laws about the handicapped, about ramps, and transportation.

Norman: Yes, those are good things. Some of them are recently passed laws. At the University those laws didn't exist before.

Int: That's right, even hiring the handicapped. Do you think people are afraid of the handicapped?

Norman: No, no, they just ignore the handicapped. Most people, if they are not handicapped, they don't know what it is. That's really what I'm saying. They just don't know what it is. Even Rachael probably didn't know what it was until she had a handicapped person on her hands. And it didn't
Int: Would it have made a difference to you? What if Rachael were in your place?

Norman: Well, it would, it would, it would have made a difference to me. I would not have treated her as well as I am treated by her. And you know, that is a serious question. If she had been the one to have the stroke, I don't think I could have stood it. I don't think I could have treated her like she has treated me.

Int: Did you folks ever talk about nursing homes?

Norman: No, never.

Int: You are sure you'll never go to one?

Norman: Well, I'm pretty sure because if there is any reason I have to go to one and Rachael's not around, I'd shoot myself. [Laughter]

Int: You don't want to go.

Norman: No, I don't want to go, and Rachael doesn't want to go. Now here's another example of that. My mother died last year in a nursing home. She was 96 years old. She was in a nice home. They, we, paid $2000 a month so you can imagine it was pretty nice. It was in Chicago. And my mother only lived about 6 months in that home and then she died. But when they wanted to put her in the home, all the sons and daughters (there were 4 sons and 1 daughter) and they wanted to put her in the home. Rachael thought that was crazy, she just couldn't understand it. And she called my mother and said "Mother, come out here with us." But my mother didn't come because she wanted to die in Chicago. Well, my mother had never been close to us really. My mother had had a very tough life really. She had been married and had 4 children when my father died. He was 25. Then she married my uncle. And he had a lot of money, 300,000 or 400,000 dollars and he lost all his money in the Crash. In the Depression. And my mother came through all this but it left her, I don't know, kind of hard. And she never was really very close to us. For example, we never
kissed my mother, we didn't kiss my mother. What I'm trying to say, my mother'd never go to stay with any of the family but she liked to stay with Rachael! And so she came out here every year, we bought her a ticket. And one of the interesting things along that line, I said to Rachael one time, "Why don't you buy her a first class ticket one time because she's never flown first class and she's an old woman and she'll appreciate it." And then after that we had to buy her one every time, it always had to be first class. [Laughter] And so we brought her out here every year for about 13 years and we paid her fare out--her first class. That was a mistake. [Laughter] She liked Rachael and I didn't know why she liked her.

Int: Maybe for the same reasons you did.

Norman: Well, I couldn't see it, because she never went to live with any of the family but she liked to come to Rachael's for 13 years straight. And Rachael, when they wanted to put her in the home, wanted her to come here. I couldn't blame her at all, but Rachael never thought she should be in the home. Although she had a nice home and was happy there. And the children, one of the brothers or sisters went to see her every day. And we went last year in August and she died in September but she still had all her faculties.

Int: What about physical care, Rachael doesn't need to feed, dress or bathe you, none of those things.

Norman: Well, no she doesn't have to. The only thing she does is put my socks on in the morning because I can bend down but it's a little uncomfortable. So while I'm lying on the bed she puts my socks on. And she delivers the eye drops for my eyes. And she gives me my prescriptions and that, I never even know what it is, I don't worry about it.

Int: So she's your manager?

Norman: Well, yes, she manages me.

Int: Do you have any thoughts about having a stroke, doctors, family?
Norman: Well, I have certain thoughts on my own. If I'd known a lot, I might not have had the stroke. Now, my stroke was probably a case of encephalitis and it's not a stroke because the herpes zoster in the eye caused the stroke. There's no question about that. They aren't sure encephalitis was the cause. They aren't but I'm sure.

Int: So you didn't have the typical high blood pressure or anything?

Norman: No, my blood pressure is normal. In fact, if you took my blood pressure, it's 120/80. It always is.

Int: So you think the herpes wasn't treated properly.

Norman: No, it wasn't. I entered a hospital in England and they didn't diagnose it the first day and the second day they did diagnose it and I told them I wanted to enter the hospital and they let me in the hospital and then they shipped me out by giving me some phony business about getting out. And then I stayed in the hotel room while Rachael and her sister was traveling. See, they didn't know what was happening, they didn't know even that I had something serious. When they got back they were frantic.

Int: So that was the first flare up of herpes zoster. You never had it before?

Norman: Yes, yes.

Int: And they think it damaged a nerve to the brain?

Norman: Yes. Well, at psychiatric hospital, Dr. [really had to search for his name] says that his wife had herpes zoster but not of the eye but near the eye on the left side of the head and so he knows all about it. I think that's one of the reasons I got in. Well, he said that they had six herpes zoster patients at the hospital, six who had herpes zoster followed my strokes. And three of them have died and three have lived. Which interested me. [Laughter]

Int: So you're one that lived, right? How many years since you had your stroke?
Norman: Seven years, seven years is pretty good, right?

Int: What happens after you die? You have any feelings or thoughts about that?

Norman: No, I don't, really. I don't even think about who I'm going to leave the money to. [Laughter] Oh, there is no afterlife, when I die, they can throw my body in an ash can. [Laughter]

Int: You're so adamant that if Rachael died first you would take your own life. There's no thought that you would join her somewhere?

Norman: No, none at all. Really.

Int: How about Rachael, does she have any feelings about it?

Norman: No, she's worse than I am. She's really more radical than I am but she doesn't say so publicly because she knows what religion is, but Rachael has no religion whatever. Not the slightest.

Int: Nothing happens when you die?

Norman: No, I don't think so.

Int: Are you afraid of it?

Norman: Well, I think you're afraid of it as you get closer to it. Well, I'm afraid of it to a certain extent. I'm more afraid of it than I have ever been. It's funny, but I realize now that death is closer than it's ever been. I might live three years, I might live two years, I might live one year, but I regret leaving. I regret dying because there's so much more to do.

Int: How about people around you dying? Your mother died.

Norman: Really, I haven't run into many deaths. And my mother's death, I thought it wouldn't affect me much, but it did. It did affect me. And we have some pictures of my mother and I look at them and I get sad. That still doesn't remove the fact that she's dead. Now, they asked me if I wanted to come back for her funeral; you know, they called me and wanted to know if they should wait
for the funeral. I said, "No, we're not coming back." And Rachael really felt that way, too. There was no sense to it. But you take her. You know her father died when she was in Japan and she went all the way to Boston from Japan right after her father died. Well, she felt it important to be there. I don't know, I suppose she should but I wouldn't of gone back.

Int: Maybe in her case there were relatives.

Norman: Death doesn't mean a thing to me except that I am afraid of it as it gets closer. Now years ago, even one or two years ago I didn't think about death. If I did, I didn't think of myself dying. I wasn't afraid of it but now I am afraid of it.

Int: Tell me how you feel about having another stroke.

Norman: If I had another stroke I hope I'd ... I hope it would be the last one. I'd want to die. I wouldn't want another one. Now some of those fellows in a wheelchair. I wouldn't want it.

Int: You've made the best of this one, what makes you think you wouldn't make the best of another one?

Norman: May be I would, but I don't think I would. I just don't.

Int: In the group, people have had different degrees of damage.

Norman: I wouldn't want it. But I admire some of them tremendously. Now Vicky, she has a bad stroke and aphasia and so forth, she walks with a cane. She's in very bad shape. I admire her tremendously. She tries so hard. But I wouldn't want to be in that position. You know, I told Abby one day, Abby was shocked, I told her that they ought to have a doctor come up and examine these people and then shoot them. [Laughter]

Int: You'd give that decision to a doctor?

Norman: Well, yes, to decide if they were Rehab cases or not. Of course, I was kidding, but I don't know how much I was kidding. Abby was shocked.
[Laughter] I said, "Why don't you shoot those that aren't capable and so forth?" I don't know.

END OF INTERVIEW

Norman and Rachael have been part of the group program for about three years and much of my knowledge about them comes from the group discussions following the exercise program.
BIBLIOGRAPHY


