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THE UNIVERSITY OF OKLAHOMA
GRADUATE COLLEGE

A DESCRIPTIVE ANALYSIS OF THE IMPACT OF A NURSING HOME
ENVIRONMENT ON PHYSICALLY DISABLED YOUNG ADULTS

A DISSERTATION
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MARION RUSSELL DAVIS
Oklahoma City, Oklahoma
1973

A DESCRIPTIVE ANALYSIS OF THE IMPACT OF A NURSING HOME
ENVIRONMENT ON PHYSICALLY DISABLED YOUNG ADULTS

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A DESCRIPTIVE ANALYSIS OF THE IMPACT OF A NURSING HOME
ENVIRONMENT ON PHYSICALLY DISABLED YOUNG ADULTS

CHAPTER I

STATEMENT OF PROBLEM

With development of nursing homes and the increased utilization of nursing care facilities for disabled people of all ages, the effect of housing disabled young adults with physical or mental disability in a traditional nursing home setting has become of concern to rehabilitation specialists and other members of medical and paramedical professions. Specifically, this study concerns the impact of the traditional nursing home environment on the young adult patient between 21 and 55 years of age.

Nursing homes have been called custodial care facilities, convalescent homes, social establishments, and other institutionally-oriented terms. Goffman's (1961b) definition of social establishments fits the nursing home concept as it is known today. Goffman states that social establishments are institutions in the everyday sense of that term, are buildings or plants in which activity of a particular kind regularly occurs. He states that each captures something of the time and interest of its members and provides something of a world for them.

In this context, nursing homes are social establishments with responsibilities that are not always clearly defined. Goffman (1961b) touches on Weber's bureaucratic ideal type when he comments:

The handling of many human needs by the bureaucratic organization of whole blocks of people--whether or not this is a necessary or effective means of social organization in the circumstances--can be taken as the key fact of total institutions (p. 314).

In keeping with Weber's ideal type and Goffman's total institution concept, each facility housing the disabled can be viewed as a unique world: an ecosystem with continuous interaction between staff, patients, visitors, and others making up this environment. Each individual patient senses in his particular way the varying influences that make up this world. He may react to the size of the nursing home, the staff and patient ratio. His outlook will be affected by the relationship he has with staff or fellow patients. His degree of mobility influences his morale, both within the home itself and for outside excursions. Proximity to family and quality of relationship with his family are factors in his self concept and affect his opportunity for going outside to activities some of the time.

In considering the impact of a nursing home on its younger inhabitants, one of Goffman's (1961b) descriptions of total institutions is particularly apropos:

Total institutions are social hybrids, part residential community, part formal organization, and therein lies their special sociological interest. There are other reasons, alas, for being interested in them, too. These establishments are the forcing houses for changing persons in our society. Each is a natural experiment, typically harsh, on what can be done to the self (p. 316).

Opportunity for socialization with friends of the same and

opposite sex has bearing on how he feels about himself. His attitude toward himself is influenced by the degree of independence he feels through living in the nursing home and by the amount of dependence he must accept in personal care activities. Overall morale is affected by the quality of care he is getting, by quality and quantity of food, and by availability and accessibility of diversional activities.

Length of stay in one or more nursing homes can be a factor in his total attitude as is the length of time he has been disabled and his current level of adjustment. Employment prospects figure into his interpretation of the future. Desire for achieving future ambitions influence his adjustment to nursing home living and the world beyond.

The total philosophy of care for the older patient afflicted with such infirmities of aging as arteriosclerotic changes, senility, and mental deterioration, because of the nature of geriatric requirements, differs from that needed by the young adult patient who might be permanently or transitionally housed in the nursing home.

The regimentation of the geriatric nursing homes in which the young adult patient is also housed can be incorporated in Weber's statement that the monocratic variety of bureaucracy is superior to any other form in precision, in stability, in the stringency of its discipline, and in its reliability (Weber, 1952a).

This very regimentation which offers an element of security and reliability to the older population in nursing homes contributes to the sterile, inflexible institutional flavor that stymies creativity and spontaneity in the younger patient.

Inevitably, the young adult patient is positively or negatively

influenced by the nursing home environment, whether he is convalescing from a temporary disabling accident or illness, or is permanently disabled in some way.

This descriptive analysis provides guidelines for the needs of these young adults to state, federal, and community agencies. This information also can benefit nursing home staffs, rehabilitation professionals, and private foundations. A special need for this type of study has been triggered by United States servicemen returning from the Vietnam conflict with war and prisoner-of-war disabilities. Veterans Administration personnel providing care and rehabilitation for these veterans should find the present study significant to this recent need.

The effect of the nursing home environment on these physically disabled, mentally alert young adults will receive close scrutiny through this study of the physical, social, and psychological adjustments to the ecosystem in which these individuals are living.

Today more than 12,000 licensed skilled nursing homes (as distinct from extended care facilities) contain approximately 600,000 beds, the result of a tremendous building boom that started in the early 1960's (Morris, 1973, p. 4).

The purpose of nursing homes is generally recognized as custodial care with nursing care the primary emphasis. Rehabilitation in the form of self-care training, diversional and recreational programs, and vocational planning seems to be determined by the individual philosophies of each administrator or director of nursing.

Staffing

Some nursing home administrators own and operate one or several homes while others are trained and hired as managers. The nursing director is responsible for quality of nursing care and emphasis on rehabilitative measures. Usually this is a registered nurse or licensed practical nurse, who supervises all aspects of care and all levels of staff. Staffing includes licensed practical nurses, male and female nursing aides, dietetic assistants, and housekeeping personnel. Size of the staff is determined by total patient population. Many staff members double as diversional activity aides, social activity coordinators, or physical therapy aides.

In connection with staffing and administrative procedures, Weber (1952a) maintains:

Experience tends universally to show that the purely bureaucratic type of administrative organization is, from a purely technical point of view, capable of attaining the highest degree of efficiency and is in this sense formally the most rational known means of carrying out imperative control over human beings" (p. 24).

Some nursing homes practice this type of organization and some have modified their administrative practices. Each has its own particular impact on the young patient. This is the environment in which the young disabled adult finds himself, the industry which has grown so dramatically since the 1960's.

Attitudinal Considerations

Morris (1973, p. 2) states that every year, more than half a million families in America face the agonizing problem of deciding how to care for a relative too old or too ill to live alone or with the

family. For most, it is a traumatic experience. He discusses a point made by Elsie K. Y. Ho, of the National Institute of Mental Health, that the family may know that a nursing home is best, yet feel a terrible guilt over not taking a relative into their home.

The young adult entering this unique ecosystem may view it as a step toward eventual recovery and independence if he has spent the preceding weeks or months in a hospital. If he is recently disabled, he may consider this a temporary transition from hospital to home, and well it may be.

If he is living at home under the care of spouse, parents, or other relatives, the circumstances of the decision to seek nursing home care influence his perception of the nursing home. If he is bedfast he sees this move as a way to free aging parents of the responsibility of his physical care, and will react with relief and optimism. If a separation or divorce, his own or his parents, precipitated the decision, he views his move to a nursing home as the end of the road, with resultant depression and bitterness.

If he is bedfast, his perception of the nursing home will be limited to the perimeter of his room, the staff who takes care of his needs, his roommates, visitors, and those residents who are able to pass by his door in the hallways or who may come in for a visit. He may be hazy as to the general arrangement of the home, the direction it faces, and the total dynamics of operation and function.

If the young patient is comparatively active, via wheelchair or ambulation, he sometimes chooses the nursing home life as a way of being independent from family and as a mature gesture of living his own life to

the degree that he is capable. He may avail himself of all activities within the setting and go by special bus to local recreation centers for the disabled to participate in additional activities.

The recently disabled young adult experiences his own internal adjustments of self concept, body image, and inter-personal relationships. All affect his outlook toward life and his aspirations for the future. The category, "severely physically disabled," into which most of the young adults living in nursing homes fall, has been summarized by Maxwell (1973, p. 11), who is Patient Services Coordinator at Ohio State University Dodd Hall and a quadriplegic. He defines the severely physically disabled as:

- (1) Confined to a wheelchair.
- (2) Unable to transfer between chair and bed, etc., without some assistance, human and/or mechanical.
- (3) Weakened trunk and arm movement.
- (4) Partial or complete loss of hand movements.
- (5) Partial or complete loss of bowel and bladder control.
- (6) Cannot live or care for his many physical needs independently.
- (7) Requires some degree of skilled medical supervision to sustain health.

Maxwell (1973) describes a quadriplegic as "a person who is active and very much alive from the shoulders up" (p. 10). Many young residents in nursing homes could be described in this way.

Rehabilitation in Retrospect

Dr. Howard Rusk revealed in 1949 that one person out of every 20 was disabled by sickness or accident in any 24-hour period, 25 million

suffered from often disabling chronic ailments, with half the sufferers under 45 years of age. One million deaths occurred yearly from chronic diseases. Ten million man/days of disability each year resulted from chronic disease. Those suffering disability from accidents numbered over 10 million in 1949. Mental illness accounted for 8 million and diseases of heart and arteries, 6,850,000. The total hidden costs of sickness and disability, including wage loss to workers, and costs to industry, totaled more than \$15 million in 1943.

Additional statistics released by the Baruch Committee on physical medicine from that year indicate that 23 million persons in the United States were handicapped because of disease, injury, maladjustment, or former wars. According to the Baruch study, two trends were evident even in the year 1949--increasing age in the general population and a rising accident rate (Rusk, 1958).

A look at more recent figures adds dramatic impact to the need for suitable nursing care among the young disabled adult population. World War II, with its returning casualties, brought impressive strides in rehabilitation efforts. Care of the disabled veteran intensified all services to disabled people and prompted accelerated efforts on the part of medical personnel for amputees, paraplegics, and quadriplegics. The goal of rehabilitation nursing is still achievement of a maximal degree of independence in personal care and total living.

Many are disabled to the point of part time or full time use of a wheelchair. In 1967 almost 300,000 persons in the United States were in wheelchairs, which was 1.5 per 1,000 population. Many of these were in the category of needing more nursing care than they could receive at

home. Many were probably already nursing home residents (Antler, 1969, p. 24).

Further evidence from 1967 indicates that one-quarter of the expenditures in nursing homes was for the care of young patients recovering from a serious illness or accident. Half the nursing home patients in one 1967 study were over 77, one-third were 85 or older. Half were confused part or all of the time, and half needed assistance in walking (Changing Times, 1969, p. 7). This could explain, at least in part, why the nursing home as it is known today is keyed to the senior citizen. In addition to the younger civilian population, disabled veterans of World War II and the more recent Korean and Vietnam conflicts are in the age range of this study. Many are housed in nursing homes either under Veterans Administration contract or some other third party payment arrangement.

An increase in veteran care has occurred along with a corresponding increase in the disabled among the general population. More than 13,438,000 persons in the United States are limited in their activity by one or more chronic physical conditions (Kennedy, 1972). Many of these individuals can be expected to demand medical-vocational rehabilitation services.

CHAPTER II

REVIEW OF LITERATURE

Fragmentation

Literature on the subject of the disabled reflects a fragmented approach to delivery of health services to the young disabled adult. A wealth of material focuses on hospitals; less covers nursing homes with emphasis on care of the aging. Some deals with rehabilitation, principally the rehabilitation of prisoners, drug addicts, and alcoholics. The physically and mentally disabled with diagnosis of spinal cord paraplegia, poliomyelitis, hemiplegia from stroke or brain injury, mental retardation, or mentally disturbed receive broad and concentrated attention at the diagnostic and descriptive levels, but the literature focuses little on the present and future needs for living as productive and active lives as physical and mental limitations permit.

Yet, Ford and Dyer (1971) state that the handicapped are one of our largest minorities. While dramatic advances have rapidly occurred in civil rights, women's liberation, and other fields, the effectiveness of efforts toward equal opportunity for the disabled remains thwarted, not only by their immobility and other hindrances, but by attitudes of rejection and overprotection. A wide range of disability types is represented in this minority group.

Disability Types

Disability types requiring nursing care include spinal cord injuries, residuals of polio and other central nervous system diseases such as multiple sclerosis, muscular dystrophy, or cerebral palsy, arthritis, amputations, residuals of strokes or cerebral vascular accidents, psychomotor seizures, mental disorders, and respiratory limitations. According to Rathbone and Lucas (1959, p. 37), more and more disabled individuals who have experienced accident or disease residuals resulting in the need for bed care tend to go to nursing homes if they cannot or do not desire to stay in their own homes.

Spinal cord injuries resulting in paraplegia (paralysis of both lower limbs) and quadriplegia (four totally or partially paralyzed extremities) create some of the most formidable adjustment problems. Hemiplegia (total or partial paralysis of one arm and one leg on the same side) and arthritis (progressive limitation of joints) often necessitate extensive nursing care. Because of the sensory and motor involvement of these conditions, individuals experiencing these disabilities are often residents of nursing homes and often experience great emotional trauma as well as tremendous problems of physical adjustment.

Many of the young disabled adults living in nursing homes are quadriplegic, either from illness such as polio or other diseases of the central nervous system, or spinal cord damage. Maxwell (1972) initiates a discussion of what the quadriplegic faces by asking, "Where is the quadriplegic to live?" (p. 11). Before a quadriplegic can be a functioning, contributing member of society, he must have an adequate facility and environment in which to live. Financially, it is almost impossible for

an individual to live by himself or with his family, and nursing home welfare support is limited.

At the present time, a young quadriplegic has two broad choices: to emotionally vegetate at home or in an institution. While the nursing home may provide appropriate care for the aged, it is less likely to offer an adequate environment for a young person. In a depressing and desparately unstimulating atmosphere, Maxwell continues, it is impossible for a person to grow as an individual or contribute anything to society. The young quadriplegic may have the capacity and the ability to be a functioning part of his society. At the present, nonetheless, no facility offers a positive, working, continuing program and environment for the young paralyzed person.

The inevitable dependence that the quadriplegic faces, because of his extensive physical limitations, is cogently described by Maxwell (1973):

With time the quadriplegic adjusts to the physical disability and accepts it as something that cannot change, but the most damning consequence is the constant emotional destruction resulting from dependence on others. The mind is whole and working, having needs and desires, but they must be fulfilled by other hands. This is possible most of the time, but you cannot put another's arms around someone you love. It means that even simple wants must be explained again, and again, and again. It means that every time he comes into contact with someone new, all the explanations that have been repeated a thousand times must be told again. It is a life with a longing, burning desire for independence and individuality, with the horribly real fact that it is constantly impossible.

The feeling of dependence is a constant in his life. It means he cannot afford to alienate anyone within his environment, no matter what type of personality conflict is involved (p. 11).

Olshansky (1971, p. 509) points out that of all the older handicapped workers, few are so frustrated as the person suffering a stroke.

After undergoing months and months of treatment within our most modern rehabilitation centers, the patient-victim rarely enjoys complete recovery. He is left with some speech difficulties if the stroke is on the dominant side, along with little or no use of one arm and one leg. In addition, he is at times moody and depressed, and often anxious and fearful of suffering another stroke. In a sense, the stroke victim is to physical medicine what the schizophrenic is to psychiatry. Regardless of the type of disability experienced, adjustments in role expectations are inevitable and necessary.

Role Expectation

The decision to enter a nursing home has a number of positive and negative components. Sometimes, as with the quadriplegic, it is not a matter of choice. The dynamics of participation in the decision play a part in the individual's acceptance of the decision. The decision-making process also influences the attitude of the disabled person in developing his new concept of sick role as opposed to his concept as a well person.

The institutionalized disabled adult is subconsciously in the process of forming a revised self-concept. Gradually he resolves this dilemma in his own way. He may continue the sick role started in the hospital, continuing to wear gown or pajamas and robe in the nursing home, ostensibly because it is less trouble than dressing, and, perhaps, more comfortable. However, this external manifestation of the sick role may be an internal reluctance to give up the dependence and psychological nurturing he has received in the hospital or from his family.

Haber and Smith (1971, p. 88) state that although disability has received relatively little theoretical consideration, the general tendency has been to treat disability as an extension of the sick role or

as a form of deviant behavior. This distorts the nature of the normative prescriptions for incapacity and obscures important conceptual distinctions. They view disability as a form of adaptive behavior provided for by the norms of role relationships. As with other forms of social behavior, the adaptive enactment of disability may take deviant forms or it may follow the expectations for behavioral contingencies.

In describing the term "disability" and its accompanying implications, Haber and Smith add that the term disability refers to the pattern of behavior emergent from incapacity: loss of ability to perform expected role activities because of a chronic physical or mental impairment. This definition focuses on the behavioral consequences of impairment. Other definitions have emphasized medical conditions, physical impairments, or social implications such as age, unemployment, and cultural deprivation.

The authors state that analytically, disability is differentiated from disease, injury, impairment, and acute or short-term incapacity by the nature of the consequences. Pathological conditions or functional abnormalities do not entail extensive and persistent behavioral changes.

According to Thurz (1969), people often generalize from the standpoint of a "true handicap" to the other aspects of behavior. Behavior which exaggerates the actual degree of handicap--by the disabled person and as perceived by others--is a form of invalid role synchrony which Thomas describes as "the fictitious handicap".

Yet, this is the pattern followed by most institutions in dealing with the admission of disabled persons, even if the purpose of admission to the hospital or clinic is diagnosis, rather than treatment. The "consumer" is expected to assume the "sick" role. The role is

defined, at least in part, on the basis of the needs of the system, rather than on those of the disabled person. Thurz adds that the first general expectation is that of dependence. The patient is expected to comply to hospital rules and regulations, to follow daily routine, and to adhere to decisions made for him by physicians or nurses. Therefore, the compliant patient is likely to be perceived as the good patient by hospital staff, whereas the patient who tries to exert independence will be perceived negatively. In line with dependence, the patient is expected not to fulfill his normal role responsibilities.

A third expectation concerns the de-emphasis on external power and prestige which the patient carries in his life outside the hospital. The taking away of the patient's clothes is a symbol of this loss, all patients being rendered as naked as the day they came into the world and supposedly as innocent.

While such procedures may help to "manage" the patient or client, and thereby serve the interests of the staff, such measures are counter-indicated as a treatment mode, are destructive to personality, and violate fundamental rights of all citizens.

Haber and Smith (1971, p. 89) deal with the role expectation aspect of disability in a similar vein. They contend that although individuals vary in their response to disease or injury, most chronic conditions and impairments are accepted as outside the conscious control of the individual. The authors quote Friedson, who holds "most illness, and most impairments, are not motivated--they are contingencies of inheritance, accidents of infection, and trauma." Excusing an individual from responsibility for his condition, however, does not relieve him of accountability for his subsequent illness behavior. Role expectations

and obligations may be redefined in terms appropriate to his capacities and his limitations; the requirements for the acceptance of short-term and long-term incapacity differ substantially, however.

Because of these adjustments pertaining to the sick role, it is necessary for the disabled person to go through a period of adaptation which may be enhanced or hindered by the nursing home ecosystem. As Haber and Smith point out, the disabled person is no longer able to conform to the usual expectations of the interaction systems upon which he is dependent for his social and material needs. The reciprocal role members or their functional alternatives, therefore, are called upon to meet their residual role commitments by providing alternatives for the losses entailed by role incapacity.

The development of this adaptive process starts with the social processes which bring the applicant to the control agent with a claim for support, rehabilitation, job placement, or other services. The individual has acknowledged his incapacity and is searching for adaptive mechanisms to normalize his relationships. Haber and Smith maintain that these may consist of efforts to manage the effects of incapacity by: (1) removing or adjusting the impairment to permit a return to conventional expectations; (2) adjusting the person through the addition of new or improved capacities; (3) adjusting the situation through changes in the role requirements or the environment to fit existing capacities; or (4) providing alternative systems as income replacement or institutional care.

As a result of these efforts at social management, the disabled individual may recover from his disability or may adapt to his capacity limitations. Since recovery reverses the process of disability when the impairment no longer limits the role-relevant activity of the individual,

on recovery he is expected to resume normal role activities.

Normal role activities are unique to the individual. The active, independent person may opt for a modified active independent revised image, revising his dependency needs to a level at which he is comfortable. If the pre-disability personality leaned heavily toward the neurotic, the disability affords an ideal opportunity for carry-over neurotic behavior.

Haber and Smith point out that after the disability is accepted by the disabled person, to whatever degree is possible, behavioral expectations which take account of the impaired or residual capacities of the individual can develop, as variant but equivalent obligations. The behavioral response to these contingency norms can be sanctioned by providing or withholding gratification for conforming or deviant behavior.

Intentionally or unintentionally, these adapted expectations become means for the "normalization" of behavior, as a new set of rules by which to measure or evidence conformity. If the costs of adaptation are too high for the individual, family, or community to tolerate, the incapable may be isolated or expelled. Some primitive societies practice abandonment of the aged and the helpless, as "the simplest and perhaps the most humane method of dealing with inescapable necessity," . . . custodial care institutions, to some extent, fill the same function, according to Haber and Smith.

Self Concept

Resolution of role expectations plays a vital part in the necessary development of a revised self concept after a disabling condition occurs. Whether the disability stems from a birth malformation or from

accident or disease later in life, each disabled person must work out his own concept toward himself as a person and toward his disability. Body image plays an important role in this development and in self-acceptance.

According to a study cited by Antler (1969), "The severely disabled patient may see the wheelchair as an extension of his own body" (p. 23). Acceptance of this and other appliances plays a part in self-acceptance as a disabled person.

Antler states that the disabled person tends to be relatively uncertain of his ability to cope with the physical world, of his acceptability in the social world, and of his value as a person. Yet, he adds, "the difference between people is only in degree of ability. The so-called 'disabled' person is far more like--than--unlike--the average individual. His need--in society and in business--to be recognized and treated as such lies at the root of fuller acceptance and opportunity for the handicapped" (p. 23).

Further comment is made by Braceland (1970, p. 34) who states that whether these revisions of self concept start in the hospital or the after care of the nursing home setting, a physical handicap or disablement alters the person's concept of himself--what he is like, what he is worth, what he is capable of. The obvious disabilities eliminate some of a person's accustomed methods of meeting basic emotional needs.

According to Braceland, the loss of a body part does considerable violence to the concept of self. This type of loss is dramatic and apparent. More serious but less dramatic medical conditions constitute well over half the disabilities. Painful anxiety is practically inevitable in all of these conditions. Often this anxiety is a prelude to a

loss of self-esteem. The burden of inadequacy, whether real or imagined, may be sufficient to create psychic distress in an individual no matter how well adjusted he might have been previously. Throughout the striving for physical and emotional equalization, social adjustments are also in progress.

Socialization

Rehabilitation may be analyzed advantageously as a process of socialization. A socialization model focuses attention on the processes by which individuals acquire new roles and it leads to questions on the development of new self-definitions, skills, activities, and associations.

Socialization of disabled people has been studied by a number of researchers. Kleck (1966, p. 55) notes that research by Kelley et al. in 1960 suggests that the physically stigmatized disabled person may be in a distinctly disadvantageous position vis-a-vis the behavioral outcomes which he experiences from others. Several aspects of normal-disabled interactions would suggest this is a reasonable expectation. Normals both self-report uncomfortableness and uncertainty when interacting with the physically disabled and give objective evidence of being physiologically aroused. Kleck notes Goffman's observation that the presence of a physically disabled person may result in "anxious, unanchored interaction" which presents the normal with high uncertainty regarding what constitutes appropriate behavior.

A central finding of the research to date, according to Kleck, is that the behavior produced by the physically normal person, when interacting with a physically stigmatized person, shows certain distinct

behavioral biases. Kleck, for example, found that persons interacting with a physically disabled confederate, when compared to a control group, terminated interaction sooner, demonstrated less variability in their verbal behavior, and expressed opinions which were less representative of their actual beliefs. Kleck extended this analysis to the nonverbal dimensions of behavior and found that normal-disabled interactions were characterized by a general inhibition of gestural activity but not by avoidance of eye contact.

Kleck discusses the disabled person's perception of the responses of others to him over a period of time. If persons interacting with him characteristically move in the direction of less positive impressions, how will this change be interpreted? It is easy to speculate that he can conclude "the better people get to know me the less they like me"; and the possible negative implications of this for self concept formation are obvious.

Another viewpoint in the socialization of the disabled is Goffman's (1963) postulation that longer-term encounters with stigmatized individuals may engender less acceptance and less spontaneity of behavior than brief interactions.

Stigmatization of a physical disability receives further attention from Cogswell (1968) who holds that in our society the disabled role is socially devalued. Effective socialization results through learning to reduce the stigmatizing effects of disability. Paraplegics must learn the physical and social skills necessary to play the role with sufficient ease to prevent contamination of their identity as well as the performance of their roles.

Physical disability, like most stigmas, is not equally stigmatizing in all social situations, according to Cogswell. Saliency of disability as a stigma varies with the type of individual encountered and the type of social setting. It also varies with the paraplegic's definition and projection of self as worthy or demeaned and with his skill in managing others' definitions of his disability.

Discussing further the social adjustments faced by the paraplegic, Cogswell indicates that physical disability is potentially stigmatizing, and saliency of stigma increases outside the hospital. To become successfully rehabilitated, paraplegics must diminish this effect. This, however, occurs through self-teaching, for paraplegics generally are left to chart their own course.

Dependency is another social adjustment that the disabled individual must work out for himself. A degree of dependency is inevitable because of the existing physical limitations.

The loss of independence is dealt with by Ludwig and Collette (1969) through their studies on disability, dependency, and the conjugal roles. Few marriages of paraplegics and quadriplegics remain intact. Ludwig and Collette hypothesized that among couples where husbands become dependent on wives for help in personal care, such as bathing, dressing, and getting around the house, modifications in role definitions and conjugal role behavior would take place. The general hypothesis was tested in a population of applicants for social security disability benefits.

Couples in which the husband was dependent on his wife for personal care spent more time together and less time with friends and

relatives than did non-disabled couples. Dependent husbands were less likely to be involved in decisions such as the purchase of a new car, computing the family income tax, and car repairs. Husbands dependent on wives were also more likely to endorse statements reflecting conjugal role flexibility and less role rigidity. These differences were found to hold regardless of the level of physical limitation.

The dependency of a disabled wife brings a new set of relationships to the conjugal roles. No studies of such marriages were evident. However, such role expectations as housework, grocery shopping, child care, and personal needs of daily living are among those to be considered in the disabled dependent wife marital situation. Each couple, regardless of which partner is the dependent spouse, must, as a practical matter, work out a comfortable adjustment role pattern suited to their particular identities.

Application of Key Problems

One practical problem that must be met is the issue of employment, returning to a previous job or training toward a new vocation. With some adaptations, many employers are willing to adjust duties to make returning to a work assignment possible. Alternate plans must be made if physical demands are too great on the previous job.

Sexual adjustment is another key problem in the socialization adaptations that occur following a disability. As with employment, prognosis for sexual potential and performance may need to be deferred for a considerable recovery period.

Sexuality

Numerous psychosocial adjustments are experienced by the married or single disabled young person. He may have to deal with sensory deprivation if he has had a spinal cord injury or stroke which often results in difficulties with bowel and/or bladder control and function. This also makes him more susceptible to pressure sores or decubitus ulcers because he is unable to feel pressure spots as they develop. These adjustments, which result in the need for catheters and other modifications that make socialization possible, prompt questions in the mind of the patient regarding sexual adequacy in the male and sexual fulfillment in the female. The male patient may wonder if he is capable of achieving an erection or satisfying a sexual partner by other techniques. The female paraplegic or quadriplegic may wonder what she has to offer a man sexually since her feeling or sensory level may be limited to body areas above the waist or nipple line. Both may wonder if they will again be able to date, drive a car, travel independently, or resume sexual intercourse.

Comarr (1973, p. 58) stresses that only with time will each patient actually know whether he will be able to perform sexually and to what extent. He indicates that sufficient statistical data have been accumulated to aid the physician in attempting to prognosticate what sexual potentials a patient will have who has sustained injury to the spinal cord, but encourages limited superficial counseling with the patient until he has spent some time with a sexual partner, determining for himself whether he can experience successful coitus.

Employment

Another question in the mind of the recently disabled person is his prognosis for securing and holding a job. His return to society and his social acceptance are determined, to a large extent, by his employment potential in his present state.

The enforced idleness facing the young adult in a nursing home setting is described by Goffman (1961b) as one basic adjustment required of inmates, "untrained often in leisurely ways of life, suffering extremes of boredom. . . . the work-oriented individual may tend to become somewhat demoralized by the system" (p. 316).

Sommer (1969, p. 264) explains the area of employment and social acceptance with his comments that anyone concerned with the capacity of a person to function in society must be concerned with employment as a prime area of social functioning. He says that in many clinical settings the therapist has a major task--to help the patient so that he is better able to deal with the reality of his outside world, including his work. In treatment situations with a rehabilitation goal, this means dealing with the intrapersonal, interpersonal, and external stresses that block the patient from finding and maintaining a job. When a patient's internal difficulties cannot be resolved in terms of his functioning in a job, rehabilitation often becomes an untenable goal at that point in time.

Work or employment is one evidence of acceptance and opportunity for the disabled person in or out of the nursing home. Nagi, McBroom, and Collette (1969, p. 22) state that although, for most people, work is a means of gaining economic support, the effect of work on an individual's life goes far beyond economic instrumentality. They identified

five functions for work: economic support, regulation of life activities, identification, association, and meaningful experience. Work remains an important and often a necessary aspect of life for persons with impairments.

Gilbertson (1970, p. 444) presents the situation of employment of the disabled person from both viewpoints--that of the disabled individual and that of the employer. He observes that the problem of fitting disabled people into modern industry becomes continually more complex. Superficially this problem appears to be simple. An individual is incapacitated and, therefore, has certain limitations on his ability to serve. Yet, he wishes to work. With the growing need for brainpower rather than physical effort and most jobs in industry not calling on every talent that an individual possesses, it should be possible to match job with worker. As Gilbertson points out, however, there are complications.

Today industry is frequently a complex interrelationship of groups and individuals. Anyone, disabled or not, should be able to play his full part in meeting the objectives of the group. Psychological problems, just as much as any physical disability, disrupt the work of the group and Gilbertson includes in this a "chip on the shoulder" attitude which can occur among the non-disabled as well as the disabled.

The second need cited by Gilbertson, is for a much more careful assessment of the categories of jobs available today in various industries. Mechanical aids, computerization, and electronics are increasingly making it possible for any individual who can press a button to move mountains of work during eight hours. Many formerly unemployable

individuals residing in nursing homes could become employable with such innovations.

Related to the two considerations presented by Gilbertson of the individual and the type of job available is the urgent need to harness the technological inventions of the present day to supplement the inadequacies of the disabled. The resolution of these inadequacies could do a great deal in re-establishing a feeling of self-worth that the disabled individual may have lost. Self-esteem is important to all people and especially to the disabled person who may be working to re-establish his level of self value, whether he is among the younger disabled or those in the upper limits of this study.

The designated age range of 21 to 55 years in this descriptive analysis brings in a group in the upper levels who could be termed "older workers". Those who fall above age 55 are unlikely to be employable if they have very extensive physical limitations. Moreover, they may be receiving disability compensation from one or more sources making it less necessary for them to consider working. Many hemiplegics, some amputees, and some spinal cord injured patients in nursing homes are in the above-forty age range and would be classified as the older worker.

Of the above-forty workers, Olshansky (1971) states that motivation to work is discussed much of the time in rather abstract terms, while forgetting what is central to work motivation: opportunity. Without opportunity there is little motivation to work.

Opportunity comes in a variety of ways. The changing ecology of the world is offering industrial innovations and new job possibilities. It is also providing new challenges of adjustment to the world

at large and in the nursing home ecosystem as well.

Ecological Impact

A closer look at the changing influences of the world today should offer a broad perspective to the more specific analysis of the nursing home as an ecosystem and the ecological variations imposed on the residents.

Dubos (1971) points up the changes that are occurring in the human being and his environment. Although life expectancy at birth has increased, the expectancy of life past the age of 45 has changed insignificantly, if at all. Modern adults live about as long as their counterparts at the beginning of the century. Even with affluence and modern medical care, according to Dubos, they are still disease-ridden. Cardiac conditions, cerebral strokes, various types of cancer, arthritis, emphysema, bronchitis, and mental afflictions are among the many chronic ailments that plague all affluent technological societies--they are the diseases of civilization. These are the diseases that require nursing care, often at a comparatively early age.

The noted ecologist concludes that very little is known about most chronic and degenerative diseases. They are not inherent in man, but are caused by ubiquitous environmental and social influences in the technological world. They are expressions of man's failure to respond successfully to modern life.

Dubos feels that man should not try to conform to the environment created by social and technological innovations; instead he should design environments really adapted to his nature. He should be dissatisfied with palliative measures treating the effects of objectionable

conditions, but instead should endeavor to change the conditions.

Nursing homes are among the new technological adaptations in man's struggle for existence. The ecological balance within the nursing home provides a many-faceted influence on the residents, just as the external environment of climate, economy, and societal influences exert pressure from outside. The nursing home as an institution deserves a closer look because of its impact on the lives of those living and working in this special environment.

Concept of Institution

Institutionalization of any type varies in its effect on the individual. Thurz (1969) stresses the importance of the decision-making process in deciding on nursing home care. He says the loss of self-determination which often accompanies entry into one of our institutions can offset all the physical therapy and other efforts at helping the individual, is overwhelming and destructive to the personality. He quotes Goffman's (1959) classic, Asylums, published nearly 14 years ago, which expresses forcefully the impact of our total institutions which:

. . . disrupt or defile precisely those actions that in civil society have the role of attesting to the actor and those in his presence that he has some command over his world, that he is a person with 'adult' self-determination, autonomy, and freedom of action. A failure to retain this kind of adult executive competency, or at least the systems of it, can produce in the inmate the terror of feeling radically demoted in the age-grading system (p. 43).

Denzin (1968) discusses the effect of the total institution which is virtually the role that the nursing home plays in the lives of its residents. Denzin also refers to Goffman's characterization of life within the total institution:

. . . a place of residence and work where a large number of life-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life. . . . the central picture of total institutions can be described as a breakdown of the barriers ordinarily separating these three features of life--sleeping, playing, and work. First, all aspects of life are conducted in the same place. . . . Second, each phase of the member's daily activity is carried out in the company of a large batch of others. . . . Third, all phases of the day's activities are tightly scheduled" (p. 359).

Wahler (1971) says that one of the most important indices of how effectively an individual is dealing with the environment is whether he is developing as a person, whether he is able to establish some close human relationships, maintain his efforts to be self-staining, and above all, direct his life in ways that will yield more enjoyment than otherwise.

The closeness mentioned by Wahler receives a contrasting look from Dubos (1971) who comments that adaptation to crowding may also have unfortunate results in the long run if in a particular setting. Dubos maintains that man is a gregarious animal who commonly seeks crowded environments. This does not mean that man can indefinitely increase the density of his populations; it means only that the safe limits are unknown. In animals, crowding results in behavioral and even physiological disturbances. Man has generally avoided the worst of these disturbances through a variety of social and architectural conventions and by learning to develop psychological unawareness of his surroundings. In extremely crowded environments each individual lives, as it were, in a world of his own. Eventually this adaptation to crowding decreases man's ability to relate to other human beings. He may become unaware of their presence and totally antisocial. In some institutional settings these conditions could exist and these reactions or behavioral adapta-

tions could conceivably occur. In addition to congested living conditions, the transitory element of moving from one living arrangement to another contrasting environment must be considered. The adjustment of relocation to another living facility and its relationship to mortality is another psychological hurdle facing nursing home residents.

Not only are total institutions, according to Goffman, incompatible with the basic work-payment structure of our society, these establishments are also incompatible with another crucial element of our society, the family. Goffman (1961b) states that the family is sometimes contrasted to solitary living but the more pertinent contrast to family life can be described as batch living, an apt term for the type of living that exists in all types of nursing homes.

Many feel that the nursing home is the place one goes to die. Ogren and Linn (1971) have studied the reaction of nursing home patients to relocation. According to these researchers the differences in the disability scores may have been less significant to outcome than the longer length of the last hospital stay which has been considered another possible predictor of death to the patient. The impression was that instead of being a traumatic event to overcome, the change in the nursing home setting may even have contributed to extending these patients' lives.

Ogren and Linn say that some of the transferred patients may have already worked out any feelings of separation from home and love objects while in the hospital setting. Undoubtedly, they had felt stress in the hospital when they learned they would be unable to return home at discharge, an event expected upon admission. For the patient

with a family unable to care for him, the nursing home change could heighten feelings of rejection, unless the move was of his own instigation.

The effect of the institution is described from a different viewpoint by Lieberman (1969), who says that it is commonly believed that most institutions have deleterious effects caused by the "dehumanizing" and "depersonalizing" characteristics of institutional environments.

Townsend (1962) succinctly summarizes this general view:

In the institution people live communally with a minimum of privacy and yet their relationships with each other are slender. Many subsist in a kind of defensive shell of isolation. Their mobility is restricted, and they have little access to a general society. The social experiences are limited, and the staff lead a rather separate existence from them. They are subtly oriented toward a system in which they submit to orderly routine, non-creative occupation, and cannot exercise as much self-determination. They are deprived of intimate family relationships and can rarely find substitutes which seem to be more than a pale imitation of those enjoyed by most people in a general community. The result for the individual seems fairly often to be a gradual process of depersonalization. He has too little opportunity to develop the talents he possesses and they atrophy through disuse. He may become resigned and depressed and may display no interest in the future or in things not immediately personal. He sometimes becomes apathetic, talks little, and lacks initiative. His personal habits and toilet may deteriorate. Occasionally he seems to withdraw into a private world of fantasy (p. 332).

Lieberman adds that those who come to institutions and why they come is an exceedingly complex issue that no single study answers. He mentions Webb's finding that the type of individual who applies and resides in such institutions differs in specific socio-economic factors as well as personality variables--rigidity, stereotyped thinking, apathy, resignation, ego-eccentricity, passivity, strong needs for love, affection, and care. Regardless of these personality variables, each individual must find the setting that meets his specific needs at his

particular phase of recovery.

To some disabled people nursing home care is the primary concern. Often rehabilitation facilities are a later consideration. The advisability of remaining at home with private nursing care if finances permit is another alternative. In evaluating the decision to utilize nursing home care or to remain at home with hired assistance, Gilbertson (1970) emphasizes:

Finally I turn to training. When individuals leave a hospital disabled they should not return home to wives and neighbors, who quite naturally do everything to alleviate their difficulties. No person is cured until he is once more contributing to society. To arrive at the point where he can leave hospital is good, but it is only part of the problem. The core of the problem for every disabled person is how to cope with life, given his disabilities. Training centres that concentrate both on the attitude of mind to work and on the training in new skills; training centres that can have the best advice on the mechanical aids available; and training centres that can go to industry, not begging for work but rather offering a first-class deal, such centres are essential if the problem is going to be solved (p. 444).

Gilbertson concludes that disabled people need help, and the right sort of help should be aimed at putting them in a position to cope with life themselves and to depend to the least possible extent on others. The objectivity of a professionally trained staff can play a vital part in the recovery to maximum independence of the disabled individual. How the person adjusts to the chosen institution is also of vital importance to his recovery.

Adjustment to Institutionalization

Evidence from environmental studies strongly suggests a multi-causal theory of psychic and social dysfunctioning (Gelfund, 1972). According to Gelfund, appropriate environmental modifications doubtless can prevent individual dysfunctioning. The major task of the environ-

mental and social sciences is viewed by him to specify the populations that are vulnerable to environmental stress, or to identify which individuals are vulnerable to certain types of ecological stresses.

Esty and Geoffrey (1969) elaborate on the development of feelings of adequacy among the disabled by the need to provide an environment conducive to self esteem and dignity. They state that many other emergent psycho-social economic problems of society affect human survival and behavior. Among these are the welfare and the aid programs, whether local, national, or international. According to these authors, the often repeated cliché "helping people to help themselves" is a semantic fallacy largely without relevancy to the psychology of human behavior. Aid or assistance should be based on a mutually respecting and helping relationship if feelings of inadequacy and injury to self-esteem and dignity, whether personal or national, are not to be intensified.

On an international level, rehabilitation and its accompanying services to the disabled citizen receive study and attention in such countries as Sweden and Great Britain revealing problems unique to those nations.

International Implications

The United States is not unique in its efforts to meet the nursing care needs of disabled population of all ages. Literature from Sweden, a country with many educational and sociological advances, indicates concern about the disabled. Olsson (1969) holds that no one knows how many handicapped there are in Sweden (population in 1968 was 7.8 million). According to Olsson, they number hundreds of thousands, not

tens of thousands.

A British survey indicates that the total number of impaired people were calculated in Great Britain at 3 million, of whom about one and three-fourth millions were estimated to be 64 or older. The Government's two-volume report, based on a postal survey of nearly 250,000 people, of whom 16,000 were later interviewed, justifies itself in one statement: "It is estimated that there are 110,000 handicapped people living alone and receiving no welfare services whatsoever.

One indication of Britain's efforts to meet the needs of its handicapped citizens of all ages, is the Chronically Sick and Disabled Persons Act, which requires local authorities to provide, under stringent conditions, such help as adapting homes, providing television or telephone for handicapped people. In 1968-69, at the time of the British survey, only 1 in 20 of the handicapped was living in specially designed accommodations; 1 in 20 of the very severely handicapped, needing constant help day and night, lived alone; 1 in 8 of the house-bound living alone had no telephone.

Crossley and Denmark (1961) cite figures from the Britain Salvation Army booklet, "Tragedies of Affluence," stating that this organization provides 8,141 beds per night in 57 hostels in Britain. The Salvation Army believes that they only provide for some 25 per cent of the need, as they estimate that every night probably there are about 35,000 looking for lodgings.

The British Salvation Army categorizes the men in hostels in the four basic groups giving these very approximate percentages:

- (1) Ten per cent are men who are tramps, men who seek work

spasmodically, and walk from one hostel to another. Some may be genuinely seeking employment.

- (2) Forty per cent are there through broken homes, disrupted family life, running away from home, or ex-prisoners seeking anonymity.
- (3) Twenty-five per cent are there through physical or mental ill health.
- (4) Twenty-five per cent are old-age pensioners.

Although these percentages do not necessarily apply to the United States, many of these categories are symbolic of modern times and their accompanying ecological changes in community and society living. Such social changes bring about the increasing use of nursing homes by the disabled and aging.

CHAPTER III

RESULTS

Research Design

The impact of a nursing home environment on the young adult patient between 21 and 55 years of age is the focus of this study. The designated age range has been selected because it represents the younger population of nursing homes, a population that is generally still active mentally, relatively healthy physically except for the physical limitations constituting the disability, and still in the age range that could be considered employable if suitable opportunities and adaptations were available.

A subject is defined as a nursing home resident between the ages of 21 and 55 inclusively, who is considered by nursing home staff and research interviewers to be mentally alert enough to be interviewed. This decision is based on functional intellectual level, absence of severe brain damage, and oral or written communication skills. Of the 38 nursing homes in Oklahoma County, staffs and patients of 20 cooperated in the research. In the remaining 18, staffs were either unwilling to cooperate in the study or stated they had no suitable subjects.

With modern advances in medicine prolonging the lives of individuals of all ages following illnesses and accidents, the care and treatment of disabled people has grown from a "do-it-yourself, live-in"

arrangement to a multi-million dollar nursing home business. In the earlier, formative years nursing homes primarily housed patients who were in the older age range whose families found it impossible to provide adequate care at home. More recently, nursing homes are being increasingly utilized by younger patients who are temporarily or permanently disabled by illness or accident. Morris (1973, p. 4) comments that in little more than a decade, the once ragtag nursing home business has become a flourishing \$2-billion-a-year industry.

The nursing home environment, in many ways, is a world all its own, an ecosystem of bricks and mortar, of clerical and nursing staff, of old and young patients, all woven into a complex web of interrelationships that affect the ecological thermostat controlling the physical and emotional climate in that particular home.

Research Setting

Observation of the physical accommodations of the 38 nursing homes (Appendix B) in Oklahoma County revealed that some were converted houses with maximal utilization of living areas as bed space. Others were spacious, carpeted, specially designed buildings featuring outside exposure for each room, convenient bathroom facilities, and brightly decorated lounge areas. They ranged in size from a small home with a few beds to a multi-winged, many-windowed building accommodating over 100 patients.

In keeping with licensing requirements most had set aside space of varying size for diversional activities. Some claimed availability of physical therapy with basic equipment visible to substantiate this claim. All featured one or more dining areas where ambulatory and

wheelchair patients gathered for meals and socialization. These areas were also used intermittently throughout each week for recreation in the form of bingo and other organized activities.

Decor in most homes was a basic bed and chest in each room with some rooms reflecting the occupants' personalities by addition of floral displays, a rainbow of ribbon bows from bygone gifts and flower arrangements, crocheted items if the resident participated in this hobby, and colorful "mod" posters and hangings in the younger residents' rooms. A favorite arm chair from an older occupant's home added a touch of comfort to some rooms. A guitar or typewriter gave individuality to certain rooms of younger, more active residents.

The psychological atmosphere of the nursing homes studied was as varied as the physical environment. Upon entering the front door of most of the homes, a visitor was aware of men and women, wearing robes or casual clothes sitting in wheelchairs or on sofas in the lounge area, conversing or staring silently into space. Ambulatory patients who might have been in the home for mental disorders or mental retardation usually greeted the visitor enthusiastically, with varying degrees of appropriateness. With nursing staff in the centrally-located nursing station which provided a view of all wings radiating from this hub, and business staff located in the office area just inside the front door, the atmosphere resembled a virtual beehive of human activity. In some of the newer homes a one-way mirror provided observation from the administrator's office off the lobby.

As the visitor moved further into the interstices of the nursing home he found himself aware of a potpourri of odors--a blend of anti-

septic, air freshener, urine, and hints of the next meal being prepared. As he passed doorways in his tour, he glimpsed a kalaidoscope of beds, some smoothly made with bright spreads, others occupied by human beings displaying fluctuating degrees of alertness to their surroundings.

Social climates varied from warm camaraderie between patients and staff to professional formality among the individuals whose primary world had narrowed to the confines of this particular custodial ecosystem.

Interview Procedure

Interviews were conducted evenings and weekends over a five-week period from April 14, 1973 to May 21, 1973 by a team consisting of two male and two female behavioral science specialists. That the primary interviewer conducting this study is in a wheelchair and one of the male interviewers has a visibly impaired hand may have elicited positive or negative reaction from nursing home staff and residents. The two younger interviewers were non-disabled. Each interview was oral with the exception of one which utilized written responses since a severe speech disorder existed.

In each nursing home the interviewer explained briefly the purpose of the questionnaires and secured approval of the administrator or nurse in charge before the interviews took place (Appendix A). Nursing staff collaborated in providing names and room numbers of suitable subjects. Each interview lasted approximately 30 minutes and consisted of: a personal data sheet (Appendix C); an evaluative check list on reaction to nursing home living, on attitudes toward life, health, and the future (Appendix D); a true-false scale on feelings and outlooks (Appendix E);

and an open-ended phrase completion list dealing with self concepts, emotions, inter-personal relationships, aspirations, and death (Appendix F). Interviews took place in the patients' rooms, in lounge and dining areas, and in private examining rooms.

In most cases, interviewers were received by staff with a cautious reserve which, as elaboration of the purpose of the study progressed, gradually changed to cooperation and, on occasion, enthusiasm. Some hostility and resistance were felt by the interviewers from some nursing home personnel. To some degree this seemed to stem from weekend staff who lacked the authority to grant the interview without further clearance. It may have been the situation that Weber mentions in stating that dutiful obedience is channeled through a hierarchy of offices which subordinates lower to higher offices and provides a regular procedure for lodging complaints. Technically, Weber (1961) maintains operation rests on organizational discipline.

It is possible that this resistance manifested itself in a few of the non-participating homes when the staff stated there were no suitable subjects and when two administrators refused to cooperate.

Patient reaction toward the interviewers was generally interpreted as helpful, interested, and intrigued, while some displayed reluctance or resistance. Three patients terminated the interview midway and interviewers discontinued four when subjects proved unable to answer the questions adequately or were beyond the upper age limit. These were not included in the data analysis. Many patients appeared to welcome having a willing listener and care had to be taken by the interviewers to return to the questionnaire topics when too much

divergence in conversation occurred (Appendix H).

Ecological considerations of physical and psychological aspects of each of the 38 nursing homes were evaluated by the interviewers through a check list based on observation and staff contact. This list categorized staff and patient reaction to interviewers and to each other, size of the home, exterior construction, condition of the grounds, interior decor, room furnishing, housekeeping quality, and effectiveness of ventilation or air conditioning (Appendix G).

On the basis of these findings, for the purpose of comparative study, the 20 cooperating nursing homes were categorized as those with a personalized atmosphere and those with an institutional atmosphere, each category further delineated as: (a) 100 or more beds, and (b) less than 100 beds when appropriate to certain areas of the research.

Personalized Nursing Home Characteristics

A personalized atmosphere was determined by comfort of surroundings, home-like furnishings and wall decorations, evidence of personal belongings and keepsakes in assigned room space, flexibility in interpretation of regulations, and degree of warmth and sincerity of staff. On the basis of these criteria, 13 of the 20 cooperating homes, or 65 per cent, were classified as personalized, seven of these having 100 or more beds and six with less than 100 beds.

These categories were selected because for many of the residents the nursing home setting will be their home for the rest of their lives. Those in the facility categorized as having a personalized atmosphere may have found in the physical arrangements a degree of comfort and security not found in other settings, they may have felt from

the staff the affection and acceptance of a substitute family, and they might have found from fellow patients the companionship and closeness that they would ordinarily have had at home with their own families. In the personalized category interviewers observed administrators and other staff affectionately putting an arm around a patient as he walked down a hall or warmly patting the shoulder of a patient sitting in a wheelchair. Staff in the personalized facilities were observed dropping by the rooms of bedfast patients to visit a few minutes about topics other than personal comfort and physical needs. Staff in these settings seemed to know each patient at a personal level, to know about his family, and to show genuine interest in his thoughts and desires. Patients were observed interacting with each other in a relaxed close manner, were encouraged to vary their routine schedules with mail delivery to other patients or to giving help to other more physically limited patients.

In one home of this category a female wheelchair patient was asked to serve as guide for the interviewers in locating residents and orienting them to the purpose of the interview, although she had a severe speech problem she was able to notify each resident as his turn came to be interviewed and was a gracious hostess to the interviewers. It was evident that this responsibility meant a great deal to her and that she was a capable person despite her multiple handicaps. Ironically, during her interview, part of which had to be answered through writing rather than speaking because of her speech disorder, she became tearful in answering a number of questions pertaining to family because contact from her family was extremely limited. This, indeed, seemed to be her home and the staff and patients her family.

In the personalized setting younger residents were permitted the freedom of watching late movies on television in the lounge areas long after the geriatric patients were in bed for the night and snacks were accessible to them as they might be in their own homes. In the rooms family pictures were evident on bedside tables, bows from gifts were on display on walls or mirrors, and knitted or crocheted handwork made by the patient might adorn the bed or bedside chair. All of this created an individual personality to each patient's assigned living area which, in fact, was the essence of home. Some degree of neatness was probably sacrificed, but a human being surely felt better about himself and about his life as a result.

Weber (1961) maintains that charismatic rule rests on the affectual and personal devotion of the follower to the lord or leader and represents a specifically extraordinary and purely personal relationship which was evident in the attitudes of the staff in the personalized homes. The less flexible staff attitudes found in the nursing homes rated as institutional reflect Weber's comment that in the case of continued existence, at least when the personal representative of charisma is eliminated, the authority structure has a tendency to routinize.

In evaluating the nursing homes and determining those most appropriately termed personalized, Goffman's (1961b) comment regarding permeability is pertinent:

Another dimension of variation among total institutions is found in what might be called their permeability, that is, the degree to which the social standards maintained within the institution and the social standards maintained in the environing society have influenced each other sufficiently to minimize differences.

This issue gives us an opportunity to consider some of the dynamic society that supports it or tolerates it (p. 337).

Observation and maintenance of the societal similarities of the outside world and the permeability of environment is strongly evident in the personalized homes in this study.

Granted, a delicate balance must be maintained between the amount of time the staff visits with mentally alert patients and the possibility of neglecting needs of the bedfast geriatric patients. However, in some cases where families are some distance away and visits are infrequent, the staff is often the only contact with the more active outside world. In most of the facilities termed institutional, uniformity seemed to be strongly emphasized in physical arrangements and in enforcement of regulations. Furnishings appeared to be more institutional and less home-like, more functional than attractive. Bedside tables were arranged with precision-like neatness regardless of the time of the interview, and there seemed to be a minimal number of personal touches in patients' rooms. Nursing staff appeared to be concerned with medication and routine nursing duties more than with the individual needs of the patient.

The polarization of staff and patients mentioned by Goffman (1961b) appears to characterize the limited interaction in homes evaluated as institutional. Goffman says:

In total institutions there is a basic split between a large class of individuals who live in and who have restricted contact with the world outside the walls, conveniently called inmates, and the small class that supervises the, conveniently called staff, who often operate on an 8-hour day and are socially integrated into the outside world. Each grouping tends to conceive of members of the other in terms of narrow hostile stereotypes, staff often seeing inmates as bitter, secretive,

and untrustworthy, while inmates often see staff as condescending, high-handed, and mean (p. 315).

Institutional Nursing Home Characteristics

Homes classified as institutional were those viewed as having a more rigid physical and emotional atmosphere, institutional-type furnishings, clinically neat housekeeping practices, emphasis on policies and procedures, and a sterile emotional climate maintained by a professionally efficient or indifferent nursing staff. Seven of the 20 cooperating homes, or 35 per cent, were categorized as institutional, four having 100 or more beds and three having fewer than 100 beds.

As Goffman (1961b) comments, social mobility between the two strata of staff and patients is grossly restricted; social distance is typically great and often formally prescribed; even talk across the boundaries may be conducted in a special tone of voice.

In the setting categorized as institutional it was observed that staff interaction toward patients appeared to be dutiful and professionally profunctory. In looking at the impersonality of the staff-patient relationships in the institutional setting, Weber's (1952a) comments on the social consequences of bureaucratic control come into focus. The reverse is visible in the personalized homes:

The dominance of a spirit of formalistic impersonality, 'sine ira et studio', without hatred or passion, and hence without affection or enthusiasm. . . . The dominant norms are concepts of straightforward duty without regard to personal considerations. Everyone is subject to formal equality of treatment; that is, everyone in the same empirical situation (p. 27).

One well-meant but misplaced departure from routine nursing care was observed in an institutional-type of home when a young nursing aide was overheard talking to two incoherent severely mentally retarded

girls who were restrained in wheelchairs by lap trays for their own protection. She was attempting to teach them to pronounce a two-syllable word. After several attempts to motivate the two patients through increasing verbal pressure to try the pronunciation, the nursing assistant was overheard exclaiming in exasperation, "What's the matter with you, don't you want to learn Spanish?" This episode plus one involving what could be interpreted as verbal harrassment of a depressed male patient asking for medication could be symbolic of the staff attitude in the institutional setting and could have occurred through lack of understanding of the limitations of the severely mentally retarded and the emotional needs of the physically disabled. In-service training can alleviate some of this. However, sincere interest from staff is quickly sensed by patients and is a quality that requires no orientation or training. It is a quality that is an integral part of an individual's personality and it is a quality that seemed singularly lacking in the staffs of the institutional-type of facility.

The typical official is a trained specialist whose terms of employment are contractual and provide a fixed salary scaled by rank of office, not by amount of work, according to Weber (1961). This description seems to fit more closely the institutional staff member. Weber continues that this official's right to a pension is according to fixed rules of advancement and that his administration represents vocational work by virtue of impersonal duties of office.

On the other hand, Weber develops this by stating that ideally the administrator proceeds sine ira et studio, which fits the staff observed in the personalized homes, "not allowing personal motive or

temper to influence conduct, free of arbitrariness and unpredictability; especially does this official proceed without regard to person, following rational rules with strict formality" (p. 7). Weber maintains that where rules fail he adheres to functional considerations of expediency. These qualities were visible in the staffs of the personalized homes.

Statistical Data

A look at the figures of cooperating homes as shown in Table 1

TABLE 1
NURSING HOMES COOPERATING IN THE STUDY
BY EVALUATIVE CATEGORY AND SIZE

	Personalized Home	Institutional Home	Total
100 or more beds	7	4	11
Less than 100 beds	6	3	9
Total	13	7	20

gives an overall view of the division of figures in the personalized and institutional settings.

To see the total picture in perspective, Table 2 shows division of subjects by nursing home categories.

TABLE 2

SUBJECTS INTERVIEWED BY TYPE AND SIZE OF HOME

	Personalized Home	Institutional Home	Total
100 or more beds	21	17	38
Less than 100 beds	21	7	28
Total	42	24	66

Size of the home did not seem to be a determining factor as to personalized or institutional category. Some homes with 100 beds or more reflected the relaxed, home-like atmosphere rated as personalized. Patient and staff interaction revealed a warm friendly interrelationship. Activities were varied and individualized.

Some of the smaller homes with considerably fewer than 100 beds had the regimented, impersonal physical and psychological atmosphere of the institutional setting. Flexible or rigid staff attitude and patient-oriented or policy-oriented philosophies are felt to be the determining ingredients in making a nursing home personalized or institutionalized.

Of the 20 participating homes, the interviewers rated seven as very neat, eight as moderately neat, five as clean but cluttered, and none as visibly dirty. These homes were visited at varying daytime and

evening hours with no advance notice and twelve were rated as having fresh air either through natural ventilation or adequate air conditioning, eight were considered basically stuffy even with air conditioning, and two of the eight were not only stuffy but one had noticeable anti-septic smells and one urine odor (Appendix G).

Staff attitude was evaluated by the interviewer through staff reaction to the study explanation and observable attitude toward patients as interviews were taking place. Qualities used to evaluate staff were whether they appeared to be warm and friendly, professionally efficient, indifferent, or unkind. With degrees of variation, thirteen homes were rated to have warm, friendly staffs, and seven were rated as professionally efficient as contrasted with warm friendliness. No staffs were observed to be indifferent to the patients' needs and no overt unkindness was observed at the time of the visit (Appendix G).

Table 3 shows details of cooperating nursing home typology as evaluated by interviewers' observations. A positive-negative numerical rating scale is used to indicate evaluative measures. Based on the sliding scale of four being highest quality in housekeeping and staff attitude, and five as most positive estimate of physical atmosphere, interviewer impression of personalized homes showed individual strengths in staff attitude and physical atmosphere with some moderation indicated in cleanliness. The clean but cluttered rating of 2 which is evident in the smaller personalized homes may have contributed to the home-like atmosphere as compared with the more institutional measures of very clean observed in the institutional settings. The warm caring attitude of staff prevailed in the personalized homes as evidenced by the top

TABLE 3

TYPOLOGICAL CHARACTERISTICS OF COOPERATING NURSING
HOMES BY INTERVIEWER IMPRESSION

Type Home	Total Beds	Total Inter-views	Not Available for Interview	Percentage of Subjects Per Population	Housekeeping Quality	Physical Atmosphere	Staff Attitude
<u>Personalized</u>							
1	161	1		0.6	4	5	4
2	146	3		0.2	4	5	4
3	120	6		5.0	4	5	4
4	109	3		1.8	3	5	4
5	108	3	1	0.3	3	5	4
6	105	4		3.8	4	5	4
7	100	1		1.0	4	5	4
8	72	6		8.3	2	4	4
9	61	8		13.1	3	4	4
10	55	3	1	5.4	2	4	4
11	55	1	1	1.8	2	4	4
12	52	2		3.8	3	5	4
13	50	2	2	4.0	2	4	4

TABLE 3--Continued

Type Home	Total Beds	Total Inter-views	Not Available for Interview	Percentage of Subjects Per Population	Housekeeping Quality	Physical Atmosphere	Staff Attitude
<u>Institutional</u>							
1	142	10	3	7.0	3	5	3
2	110	2		1.9	4	5	3
3	105	1		1.8	4	5	3
4	103	4		3.9	3	4	3
5	60	1		1.6	2	4	2
6	58	3	1	5.2	3	4	3
7	44	3		6.8	3	4	2
Total	1,825	66	9				

KEY: Housekeeping Quality Measurement Scale - 4 - very clean
 3 - moderately clean
 2 - clean, but cluttered
 1 - visibly dirty

Physical Atmosphere Measurement Scale - 5 - fresh air
 4 - stuffy
 3 - antiseptic
 2 - cooking odor
 1 - urine odor

Staff Attitude Measurement Scale - 4 - warm and caring
 3 - professionally efficient
 2 - indifferent
 1 - unkind

rating of four in all homes in this category. Staff attitude of institutional-type homes rated 3 (professionally efficient) and 2 (indifferent) in all homes classed as institutional.

Physical atmosphere seemed about equal in both types of homes, indicating that ventilation, whether natural or artificial, was of good quality in both types of homes.

In addition to the interviewer evaluation of all 38 homes, patients in cooperating homes evaluated such items as quality of care, food quality and quantity, and freedom to come and go to outside activities. In the facilities categorized as personalized there was an indication of good nursing care with freedom to come and go, as well as flexibility of regulations permitting individual tastes in having meals brought in occasionally to be shared with other patients and for privacy accompanying visiting privileges.

Positive and negative aspects of each cooperating nursing home as viewed by patients are shown in Table 4. A numerical value is used for comparative purposes. With positive ratings scored as 2 and negative as 1 on patient evaluations of quality of care, freedom for outside activity, food quality and quantity, personalized homes were rated by patients nearer the 2 level in all four areas of consideration. Size of the home seemed to make little difference in either category. Flexibility of routine was evident in the freedom of activity in personalized homes with institutional receiving a lower overall rating in this area.

Most of the eighteen homes whose staffs declined to participate or stated they had no suitable subjects were observed by interviewers to fall more in the institutional-type category than in the personalized

TABLE 4
EVALUATIVE SCALE OF PATIENT IMPRESSION OF
NURSING HOME TYPOLOGY

Type Home	Total Beds	Total Interviews	Quality of Care	Freedom for Outside Activity	Food Quality	Food Quantity
<u>Personalized</u>						
1	161	1	2	2	2	2
2	146	3	2	2	1.66	2
3	120	6	1.33	1.33	1.33	1.83
4	109	3	2	2	1	2
5	108	3	2	1.33	2	2
6	105	4	1.2	1.2	1.2	1.4
7	100	1	2	2	2	2
8	72	6	2	2	1.5	1.66
9	61	8	1.88	1.63	1.63	1.75
10	55	3	2	2	1.66	1.66
11	55	1	2	1	2	2
12	52	2	1	2	2	2
13	50	2	2	1.5	2	2

TABLE 4--Continued

Type Home	Total Beds	Total Interviews	Quality of Care	Freedom for Outside Activity	Food Quality	Food Quantity
<u>Institutional</u>						
1	142	10	1	2	0.9*	1.2
2	110	2	2	2	2	2
3	105	1	2	2	2	2
4	103	4	0.5*	1	0.5*	2
5	60	1	2	1	2	2
6	58	3	2	1	1.66	1.66
7	44	3	2	1.67	2	1.33

KEY: Measurement for Quality of Care - 2 - good or adequate
1 - fair or poor

Measurement for Freedom of Activity - 2 - yes
1 - no

Measurement for Food Quality - 2 - good or adequate
1 - fair or poor

Measurement for Quantity of Food - 2 - good or adequate
1 - fair or poor

* Some subjects declined to answer certain questions.

home classification. These homes were evaluated as to type but no patients were interviewed.

Through tabulation of the patients who were interviewed in the personalized and institutional homes, subjects were found to be a population that represented 4.1 per cent of the total cooperating nursing home bed occupancy. Sixty-six interviews were conducted in the 20 participating nursing homes which had a total of 1,825 beds. Nine in the subject population were unable to be interviewed or were away at the time. Clustering seemed to occur among the younger residents with three of the 20 homes surveyed providing 29.5 per cent of the total subjects.

Age distribution of the subjects included seven in the 21-30 range (10.6% of the total number interviewed), 17 in the 31-45 range (25.7%), and 42 in the 46-55 range (63.6%).

Among the respondents, 37 were male and 29 were female. Marital status included 31 (46.7%) divorced, 24 (36.3%) never married, six (9.1%) married, and five (7.9%) widowed. Many of those who had never married were disabled at an early age or had congenital disabilities.

Educational backgrounds of the 66 subjects ranged from 4 with no formal education to one with a Master's Degree. A total of 37 (56%) had less than high school completion, 18 (27.5%) had finished high school, six (9.1%) had some college, three (4.4%) had college degrees and one (1.5%) a graduate degree.

Occupational history showed a cross-section of job categories as primary former occupations with 18 (27.4%) in the labor force, 18 (27.4%) in skilled trades; six (9.1%) in clerical, five (7.5%) in professions, ten (15%) in "other" such as housewife, semi-skilled, and sales, and nine

(14.9%) having had no work experience at any time during their lives.

Present sources of support, as shown in Table 5, indicated that

TABLE 5
SOURCES OF SUPPORT OF PATIENTS IN
COOPERATING NURSING HOMES

Source	Number	Percentage
State Welfare	41	67.7
Social Security Disability	21	31.8
Disability Insurance	2	3.1
Veterans' Compensation	11	16.6
Family	7	10.6
Wages	2	3.1
Teachers Retirement	1	1.5
Other	1	1.5
Total	86*	

* Some subjects received support from more than one source.

a number had two or more income sources, often combining welfare and Social Security Disability Insurance or the latter combined with some other type of retirement benefits. State welfare was received by 41 (67.7%) of those interviewed. Others showed 21 (31.8%) receiving SSDI benefits, two (3.1%) receiving other types of disability insurance, 11 (16.6%) veterans' compensation, two (3.1%) wages, one (1.5%) receiving teachers retirement, and one (1.5%) with other support. Exact amounts

influence these figures.

Disability types, shown in Table 7, included many with multiple

TABLE 7
SUBJECTS' DISABILITY CATEGORIES

Disability	Number
Orthopedic	23
Amputation	2
Paraplegic	6
Quadriplegic	4
Hemiplegic	14
Cerebral Palsy	3
Multiple Sclerosis	3
Epilepsy	5
Mental	11
TB of Spine	1
Encephalitis	2
Lung	2
Arthritis	6

Note: Many subjects had multiple disabilities. Percentages could not be calculated by subject for this reason. Duplications occurred in disability types.

handicaps, some having as many as five different disabilities. Since categories inevitably are overlapping as well, definitive data is difficult to pinpoint or to evaluate other than through the table.

Length of time the subjects had been disabled revealed a degree of overlap because of the cumulative nature of additional physical and mental problems. Table 8 presents a total of 22 (33.3%) had been disabled less than five years, 10 (15.5%) from five to ten years, five (22.7%) from ten to 20 years, and nine (28.7%) had been disabled more than 20 years. Many of the latter were birth injuries or congenital problems.

TABLE 8

LENGTH OF TIME DISABILITY EXISTED
IN TOTAL SUBJECT POPULATION

Time Period	Number	Percentage
Less than 5 years	22	33.3
5 to 10 years	10	15.5
10 to 20 years	16	24.5
More than 20 years	18	27.7
Total	66	100.0

Observed frequencies and expected frequencies gave additional insight into the relationship between the length of time the patient had been disabled and his predictions of nursing home living in the future. Twenty-eight (42.4%) of the subjects predicted temporary nursing home living for themselves and 38 (56.6%) felt it was a permanent arrangement as demonstrated in Table 9.

TABLE 9

PREDICTION OF PERMANENCE IN NURSING HOME RESIDENCE

Prediction	Number	Percentage
Temporary	28	43.4
Permanent	38	56.6
Total	66	100.0

There appears to be some relationship between the length of time an individual has been disabled, shown in Tables 8 and 9, and his own

TABLE 10
LENGTH OF TIME PATIENT HAS BEEN
DISABLED AND TYPE OF HOME

Time	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Less than 5 years	14.00	15	8.0	7	22
5 to 10 years	6.36	7	3.6	3	10
10 to 20 years	10.20	10	5.8	6	16
More than 20 years	11.50	10	6.5	8	18
Total		42		24	66

$$\chi^2 = .86$$

TABLE 11
PATIENT PREDICTION OF NURSING HOME LIVING
STATUS AND TYPE OF HOME

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Temporary	16.5	16	9.5	10	26
Permanent	25.5	26	14.5	14	40
Total		42		24	66

$$\chi^2 = .08$$

prediction as to the temporary or permanent status of his nursing home occupancy. That 33.3 per cent of the younger residents from both types of nursing homes had been disabled for less than five years and 28.7

per cent for more than 20 years shows an almost equal population as to length of time of disability. Yet 56.6 per cent of the total subject population viewed nursing home living as permanent and 42.4 per cent as temporary. In the personalized home of those disabled less than five years, observed frequencies were 1.0 higher than expected frequencies and in the disabled of over 20 years 1.5 lower than expected. The reverse was true in institutional with fewer observed than expected in the disabled less than five years and more observed than expected in the disabled more than 20 years population.

The close percentage of predictions of temporary or permanent nursing home living from the two poles of length of disability could be the result of several factors. Some of the patients who had been disabled less than five years could be aware that their disabilities are of such degree of severity that nursing home care is a permanent necessity despite the short duration of disability. Many of those disabled more than 20 years have probably reached a point in the progression of disability that nursing care is essential with the added consideration that aging family members can no longer provide the type of care that is needed. These, too, may see nursing home living as permanent.

Regarding the temporary nature of this type of care, some of those disabled less than five years are in the transitional stage convalescing from hospital to home, perhaps only a few months after becoming disabled, hence they realistically view nursing home care as temporary. It was evident during the interviews with some of those disabled more than 20 years that they continued to cling to the often unrealistic hope that they would soon be returning to the care of their families,

even after already experiencing five or more years of living in nursing homes.

Levels of significance of Chi Squares were minimal with .08 on patient prediction of nursing home living and 0.86 on length of time patient was disabled, both as related to types of homes. Prior living accommodations could influence subject outlook as to nursing home living being temporary or permanent.

Table 12 shows the prior living accommodations of subjects with

TABLE 12
SUBJECT LIVING ARRANGEMENTS PRIOR TO MOVING TO CURRENT
NURSING HOME, NUMBER AND PERCENTAGE

Location	Number	Percentage
Another Nursing Home	38	57.57
Home of Relatives	14	21.21
Own Home	10	15.15
Hospital	4	6.06
Total	66	99.99

38 (57.57%) living in another nursing home prior to their location at the time of the interview. Some listed as many as three or four previous nursing homes. Fourteen (21.21%) lived in the homes of parents or other relatives, 10 (15.15%) were in their own homes prior to the present nursing home, and four (6.06%) listed hospitals as the previous living arrangement. In choosing to live in a nursing home, 16 (23.8%) stated they chose to do so and 50 (77.2%) stated they felt they had no choice.

A few of each group had relatives with whom they could live but preferred the degree of independence and lack of obligation to relatives that nursing home living provided.

Regardless of the prior living arrangements, the decision to move to a nursing home is a dramatic and often traumatic one for family and for the disabled individual. His participation in the decision is important to his adjustment to the new living arrangement.

Decision for choosing nursing home care was made by 27 (40%) of the subjects, 25 (39.4%) by physicians, 17 (25.7%) by family, and four (6.1%) by others which included caseworkers, veterans administration officials, friends, and employers. These figures are represented in Table 13.

TABLE 13
PERSON MAKING THE DECISION FOR NURSING
HOME CARE FOR SUBJECTS

Person	Number	Percentage
Subject	27	40.9
Physician	25	39.4
Family	17	25.7
Other	4	6.1
Total	73*	121.9*

*In some instances, more than one decider functioned.

Although expected frequencies and observed frequencies were very close in the patients' choice regarding nursing home living, shown in Table 14, and the individuals responsible for deciding on nursing home

TABLE 14

PATIENT'S CHOICE REGARDING NURSING HOME LIVING AND TYPE
OF HOME, EXPECTED AND OBSERVED FREQUENCIES

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected	Observed	Expected	Observed	
Patient Chose to Live in Nursing Home	9.5	9	5.5	6	15
Patient Had No Choice	32.5	33	18.5	18	51
Total		42		24	66

$$\chi^2 = 0.17$$

care, a higher percentage of patients from both types of homes felt they had no choice regarding moving to a nursing home than those who chose to live in a nursing home. Yet, a higher percentage of patients from both types of homes participated in the decision with physicians figuring nearly as strongly in the decision (Tables 13 and 15). This could mean that the patients recognized the need for more care than their families could provide so they made the decision, on the recommendation of the physician, to seek nursing home care. The physician's participation in the decision legitimatizes the need for care and gives a medical emphasis to the move which partially relieves the family of some of the guilt feelings they may be experiencing in relinquishing some of the responsibility for the personal care of their disabled relative to an institution.

These choices, whether self imposed or made by others, emphasize the significance of a study of this type. The impact of the earlier

TABLE 15

INDIVIDUALS RESPONSIBLE FOR DECIDING ON NURSING HOME CARE
AND TYPE OF HOME, EXPECTED AND OBSERVED FREQUENCIES

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Patient	15.3	15	8.73	9	24
Physician	15.3	16	8.73	8	24
Family and Other	11.5	11	6.55	7	18
Total		42		24	66

$$\chi^2 = .25$$

environment previous to moving to the nursing home probably has some bearing on this decision. It is important that the young disabled adults are involved in the decision to move into a nursing home. Those who find the ecology of a particular nursing home incompatible with their needs soon move to another, and another. Some had been in as many as four prior to their moving to the one where the interview took place. Some who were in their own homes previously may have felt isolated and limited in self care so the nursing home environment may have been viewed as a welcome change. A look at the length of stay in the present home and its influences on the residents will give further insight into the impact of a nursing home environment on its younger residents.

Table 16 presents the time periods of residence in the present home ranging from 12 (18.1%) listing less than one year, 30 (45.4%) listing one to three years, 11 (16.6%) listing three to five years, 10 (15.5%) listing five to ten years, and three (4.5%) listing more than

TABLE 16

LENGTH OF TIME PATIENT HAS BEEN
IN PRESENT NURSING HOME

Time Period	Number	Percentage
Less than 1 year	12	18.1
1 to 3 years	30	45.4
3 to 5 years	11	16.6
5 to 10 years	10	15.5
More than 10 years	3	4.5
Total	66	100.0

ten years in the same nursing home.

Self care needs and mobility play an important part in the decision by the family or disabled individual regarding moving to a nursing home. In evaluating their own needs for personal care, 21 (31.8%) of the subjects rated themselves totally independent in self care, 28 (42%) needed some help, and 17 (25%) stated they were totally dependent for all self care such as dressing, eating, and personal needs. These figures are shown in Table 17.

Mobility ratings showed seven (10.5%) were bedfast either temporarily because of healing decubiti, convalescing from recent illnesses or accidents, or permanently because of a progressive condition such as multiple sclerosis. As shown in Table 18, 22 (33%) rated themselves able to walk unassisted, three (4.5%) could walk with help, 14 (21%) were in a wheelchair part time with the rest of the time spent in bed or with the partial ability to ambulate, and 20 (30.3%) were in a wheelchair

TABLE 17

SUBJECT ESTIMATE OF SELF CARE NEEDS
BY NUMBER AND PERCENTAGE

Degree of Care Needed	Number	Percentage
Totally Independent	21	31.8
Needs Some Help	28	42.4
Totally Dependent	17	25.7
Total	66	99.9

TABLE 18

SUBJECT SELF RATING OF MOBILITY
BY NUMBER AND PERCENTAGE

Degree of Mobility	Number	Percentage
Bedfast	7	10.5
Walk Unassisted	22	33.0
Walk with Help	3	4.5
Part Time Wheelchair	14	21.0
Full Time Wheelchair	20	30.3
Total	66	99.3

full time. Of these full-time wheelchair users, a few were independent in self care and more needed help in self care activities but were able to propel the wheelchair with some degree of success.

Rusk (1972) maintains that any disabled individual who can maneuver a wheelchair even to a limited degree should be considered a candidate for rehabilitation. Many of the nearly 90 per cent who rated

themselves mobile in some way were unable to use this mobility beyond the confines of the nursing home because of transportation difficulties. Transportation is an essential part of mobility if outside trips are to be accomplished. Transferring from wheelchair to car and finding someone who can assist with this in addition to providing transportation can sometimes seem to be an insurmountable hurdle, virtually trapping the younger disabled nursing home resident in the confines of the home.

It was anticipated that the personalized home population would express more freedom to come and go to activities outside the home than would those in the institutional homes. Contrary to expectations, however, the reverse was true as expressed in Table 19. In the personalized

TABLE 19
PATIENTS FEELING OF FREEDOM TO ATTEND OUTSIDE
ACTIVITIES AND TYPE OF HOME

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Free to Come and Go	31.8	30	18.2	20	50
Limited to Home Activities	10.2	12	5.8	4	16
Total		42		24	

$$\chi^2 = 1.17$$

home observed frequencies regarding freedom to come and go were 1.8 lower than expected frequencies and 1.8 higher in those who limited their activities to the home. In the institutional setting there were 1.8 more observed than expected responses to freedom to come and go, and corres-

pondingly less observed than expected who limited their activities to the home. Chi Square results were insignificant at 1.17.

Table 20 reveals a number of variables could have had an effect on this finding. No institutional residents listed themselves as

TABLE 20
PATIENT ESTIMATE OF SELF MOBILITY AND TYPE OF HOME

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Bedfast	4.5	7	2.6	0	7
Uses Wheelchair	24.8	24	14.2	15	39
Ambulatory	12.7	11	7.3	9	20
Total		42		24	

$$\chi^2 = 4.70$$

bedfast while the personalized homes had seven, 2.5 more observed than expected. One factor could be that the bedfast patients who seemed to have chosen to live in personalized homes were unable to go to outside activities because of their immobility which could have influenced the observed frequencies in the outside activity category.

Another strongly weighted observed frequency showed those who rated themselves totally dependent with 2.8 more in the observed than the expected frequency in the personalized homes (see Table 21). Patients who rated themselves totally dependent in institutional homes revealed a correspondingly lower observed frequency than the expected frequency.

TABLE 21

PATIENT STATEMENT OF SELF CARE NEED AND TYPE OF HOME

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Totally Independent	14.0	12	8.0	10	22
Need Some Help	17.8	17	10.2	11	28
Totally Dependent	10.2	13	5.8	3	16
Total		42		24	66

$$\chi^2 = 3.18$$

The Chi Square of 3.18 in the patient statement of self care needs and the Chi Square of 4.70 of the patients' estimates of self mobility as related to the two types of nursing homes approach more closely levels of significance than in any other areas of study. Selectivity of homes by the patients could have bearing on these findings. Other factors could be the meeting of dependency needs and a rehabilitative emphasis of encouragement toward independence in certain types of homes.

This emphasis on independence in self care activities and in total personal functioning is a quality of nursing care that can lead to furthering dependency or to encouraging independence. Evaluation of the quality of nursing care by the patients brought some interesting results.

In the personalized facility of both sizes nursing care was

rated as strongly positive. Table 22 demonstrates that nursing care quality in institutional-type homes received fair ratings from a greater per cent of respondents.

TABLE 22
PATIENT PERCEPTION OF QUALITY OF NURSING CARE
BY SIZE AND TYPE OF HOME

	<u>Personalized Home</u>		<u>Institutional Home</u>	
	100 or more beds	Less than 100 beds	100 or more beds	Less than 100 beds
Good	53.3	68.6	23.1	71.4
Adequate	19.0	22.7	11.7	28.5
Fair	9.5	13.6	35.2	0.0
Poor	14.2	13.6	11.7	0.0

While the above table reflects percentages of patients' perception of quality of nursing care in each type of home, observed and expected frequencies provide a different view of this area.

Table 23 shows that observed frequency regarding patient perception of quality of care in the personalized facility is 1.8 points above the expected frequency and .1 higher on the two positive ratings. In the environment termed institutional where staff attitude was categorized as professionally efficient as opposed to the warm and friendly category of the personalized home, a decided downward trend is visible in the two favorable ratings of care between expected and observable frequencies. Residents rated institutional care as fair in quality 2.5 points higher in observed frequency than expected frequency. Chi Square of 3.1 is not considered a significant level.

TABLE 23

PATIENT PERCEPTION OF QUALITY OF CARE AND TYPE OF HOME

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Good	23.2	25	10.8	9	34
Adequate	8.9	9	4.1	4	13
Fair	7.5	5	3.5	6	11
Poor	5.5	6	2.5	2	8
Total		45		21	66

$$\chi^2 = 3.1$$

The positive observed frequency of the personalized homes could be influenced by the warmth and friendly attitude of staff which could be interpreted by patients as a part of the quality of care. While professional efficiency can contribute to good care, it deals primarily with the physical needs of the patient and the organizational needs of the facility. The findings in this segment of the study demonstrate the importance of meeting the needs of the total person, psychological and social, as well as physical. The personalized nursing homes, as indicated by this area of study, are patient-oriented while the institutional nursing homes could be termed facility-oriented with emphasis seeming to be on standardization rather than humanization of care. That the staff in the institutional home facilities visited far less frequently with patients, according to patient estimates, than those in personalized homes, can also contribute to patient estimate of care quality. The impersonal dehumanizing element of professional efficiency of the insti-

tutional staff could be interpreted as part of the quality of care from the patient's viewpoint.

While quality of care is not directly reflected in the dietetic provisions of nursing home, food quality and quantity relate to the type of services being provided, as shown in Tables 24 and 25.

TABLE 24

PATIENT PERCEPTION OF FOOD QUALITY AND TYPE
OF HOME BY NUMBER OF RESPONDENTS

Rating	Personalized Home Number	Institutional Home Number
Good	17	9
Adequate	9	2
Fair	11	7
Poor	7	4
Total	44	22

TABLE 25

PATIENT PERCEPTION OF FOOD QUANTITY AND TYPE
OF HOME BY NUMBER OF RESPONDENTS

Rating	Personalized Home Number	Institutional Home Number
Good	23	13
Adequate	8	3
Fair	8	3
Poor	5	2
Total	44	22

Seventeen patients perceived food quality in the personalized facility as good, nine as adequate, eleven as fair, and seven as poor. Food quantity in these homes was rated good by 23, adequate by eight, fair by eight, and poor by four.

In the institutional category food quality was rated good by nine, adequate by two, fair by seven, and poor by four. Quantity was rated good by thirteen, adequate by three, fair by five, and poor by two.

Tables 26 and 27 present an analysis of observed and expected

TABLE 26

PATIENT PERCEPTION OF FOOD QUALITY AND TYPE OF HOME EXPECTED AND OBSERVED FREQUENCIES

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Positive	24.7	26	12.3	11	37
Negative	19.3	18	9.7	11	29
Total		44		22	66

$$\chi^2 = .47$$

frequencies emphasize further the importance of food to the younger nursing home resident, as it relates to home types. Positive responses from personalized home subjects were 1.3 points higher in observed frequency than expected frequency and a corresponding 1.3 points lower in the negative reaction to food quality. Institutional setting brought the reverse; positive response was 1.3 lower in observed than expected frequency as compared with negative response correspondingly higher in

TABLE 27

PATIENT PERCEPTION OF FOOD QUANTITY AND TYPE OF
HOME EXPECTED AND OBSERVED FREQUENCIES

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Positive	32.7	32	15.3	16	48
Negative	12.3	13	5.7	5	18
Total		45		21	66

$$\chi^2 = .17$$

observed over expected.

With food one of the basic human needs and meal time in a nursing home considered a punctuation point of a day, this aspect of study should bring an awareness of the importance to the younger resident of food quality and variety. Some respondents who were financially able to do so, mentioned sending out for hamburgers or complete meals of Oriental or Italian food to break the menu monotony. There seemed to be a strong desire for the more highly seasoned foods that they did not get in the nursing home diets. Many were able to afford only an additional candy bar or packet of peanuts from a vending machine in the home to supplement existing diets. In nursing homes flexible enough to permit it, the younger residents sometimes chose to eat on sun porches in small groups of the same age range or in their rooms with roommates in preference to the larger dining areas with the predominantly geriatric population. When transportation was available a trip outside to a drive-in or restaurant, with opportunity for varied

menu selection, was viewed as an eagerly anticipated event by younger residents. Even general morale of the subject population seemed to be influenced by the prevailing food quality, thus emphasizing the importance of food to the total outlook of the younger patients.

Quantity of food seemed less important than quality. A discrepancy appeared between quality and quantity of food in certain homes. In some where food quality was rated fair to poor, residents who chose to do so were allowed additional servings. In others both quality and quantity were limited, according to respondents. Although the Chi Square of 0.17 regarding food quantity and 0.47 regarding quality were insignificant, these two dietetic considerations can be considered important environmental influences on younger residents in both types of homes as indicated by numerical count and comments.

Not only does food influence the general patient outlook, realistic or theoretical expectations of prospective condition of health have a bearing on morale.

Of the total population interviewed, Table 28 indicates 28 (42.4%) predicted realistically or hopefully that it was their expectation that their condition would improve, 29 (43.9%) that it would stay the same, and nine (13.9%) that it would get worse or progress.

Table 29 examines self rating of general health which brought the revelation that, despite the need for nursing home living, 14 (21.2%) rated their general health as excellent, 28 (42.4%) as good, 19 (28.7%) as fair, and five (7.6%) as poor. Many added the comment regarding a positive rating of excellent or good, "except for my disability, my general health is good."

TABLE 28

SUBJECT SELF PREDICTION OF CONDITION OF HEALTH
BY NUMBER AND PERCENTAGE

Prediction for Future	Number	Percentage
Improve	28	42.4
Stay the Same	29	43.9
Get Worse	9	13.9
Total	66	100.2

TABLE 29

SUBJECT SELF RATING OF CURRENT GENERAL HEALTH
BY NUMBER AND PERCENTAGE

Rating of Health	Number	Percentage
Excellent	14	21.2
Good	28	42.4
Fair	19	28.7
Poor	5	7.6
Total	66	99.9

That physical perfection is equated with excellence in health is not necessarily true for the patients. That it is possible to be healthy, though handicapped, is revealed in the comparative expected frequencies and observed frequencies of the patients' self rating of current health and the patients' self predictions of physical conditions, both as

related to the two types of homes (Table 30).

TABLE 30

PATIENT SELF PREDICTION OF PHYSICAL CONDITION AND TYPE
OF HOME BY EXPECTED AND OBSERVED FREQUENCIES

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Expect to Improve	17.1	17	9.8	10	27
Stay the Same	19.7	21	11.3	10	31
Get Worse	5.1	4	2.9	4	8
Total		42		24	66

$$\chi^2 = 1.37$$

While Chi Square of 1.37 shows no significant probability that the two types of nursing homes influence the patients' self predictions of physical condition, some interesting comparisons are evident in the responses. Observed frequency of responses in both types of homes fell within a fraction of a point of the expected frequency by respondents who expected to improve. However, in the other two areas a different view was forthcoming with observed frequency 1.3 higher than expected frequency in the personalized home respondents who predicted their conditions would stay the same, with a reverse trend of 1.3 more points in expected than observed frequencies in the institutional setting who felt their conditions would remain the same. Of those who anticipated that their conditions would get worse, institutional facility residents showed 1.1 more observed frequencies than expected and those in the personalized homes indicated corresponding fewer observed frequencies than expected

frequencies. It appears that the type of home influences residents' predictions of physical condition in the two less optimistic areas of self rating, but to a less degree among respondents who expected their conditions to improve. Some of these self predictions could be a matter of facing reality if the patient knows that he has a diagnosis of a disease such as multiple sclerosis which can be expected to become progressively more incapacitating. A certain euphoria based on faith and the development of a positive outlook toward the future could have prompted some of the more severely disabled to expect improvement.

In the area of general health, as well as prediction of physical condition, the existence of a disability which may remain static does not necessarily constitute illness or poor general health. Table 31 shows that a much higher percentage of respondents from both types of

TABLE 31

PATIENT SELF RATING OF CURRENT HEALTH AND TYPE OF HOME, EXPECTED AND OBSERVED FREQUENCIES

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Positive	27.4	27	14.6	15	42
Negative	15.6	16	8.4	8	24
Total		43		23	66

$$X = .05$$

homes gave positive responses to rating of current health than negative. There was a higher number of observed frequencies among respondents from

the personalized homes who expected their condition to remain the same than expected frequency. While the presence of a disability can bring secondary complications related or unrelated to the disability, the relationship of the existence of a disability and general health conditions offers opportunity for further study.

Health and prognosis influence a patient's overall outlook and significant comparisons were forthcoming in evaluating the subjects' feelings about life, displayed in Table 32. Of 42 respondents from the

TABLE 32
SUBJECT FEELING ABOUT LIFE AND TYPE AND
SIZE OF HOME BY PERCENTAGE

	<u>Personalized Home</u>		<u>Institutional Home</u>	
	100 beds or more	Less than 100 beds	100 beds or more	Less than 100 beds
Constant Challenge	19.0	23.8	11.7	14.2
Interesting	33.3	38.0	23.5	42.8
Rewarding	19.0	14.3	11.7	0.0
Dull	23.8	23.8	35.2	42.8
Not Worth Living	4.8	0.0	17.7	0.0
Total	99.9	99.9	99.8	99.9

personalized facilities, nine (21.4%) found life a constant challenge and 16 (38%) found life interesting. Listing life as dull were 10 (28.5%) from this group with one (2.3%) stating that life was not worth living.

From the institutional category two (8.3%) of the subjects out of 24 from this population, felt that life was a constant challenge, seven (28.8%) found it interesting, nine (37.5%) found life to be dull, and three (12.5%) felt that life was not worth living.

Perhaps the feeling of some subjects who view life with a degree of humor was reflected in the sign that was seen on the back of the wheelchair of a 55-year-old female patient which read, "I'm at the middle age of life--too late for sex and too early for old age pension."

That a greater percentage of the subjects living in the institutional-type setting expressed the more extreme negative outlooks on life than those in the personalized setting could indicate a further need to examine the ecological impact of each setting on its occupants. Further examination of observed and expected frequencies gives added insight into these areas.

A broad spread is evident in the findings of the patients' feelings about life in relationship to the type of home, as shown in Table 33. In the personalized home setting the observed frequency is three points higher on the positive response than the expected frequency and a corresponding three points lower on the negative. In contrast, the institutional setting positive observed frequency regarding feeling about life is four points lower than the expected frequency. The Chi Square of 2.83 is not considered a significant level.

The environmental influence of the personalized home with its flexibility of activity, its warm friendly staff attitude, and the comparative individualized freedom of each patient to live his own life within the scope of the nursing home setting could be an important

TABLE 33

PATIENTS' FEELING ABOUT LIFE AND TYPE OF HOME
EXPECTED AND OBSERVED FREQUENCIES

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Positive	30.0	33	14.0	11	44
Negative	15.0	12	7.0	10	22
Total		45		21	66

$$\chi^2 = 2.83$$

factor in these findings. All of these considerations would contribute to a general positive feeling about life.

Additional comparisons were forthcoming on the Feeling and Outlook scale which consisted of a series of true-false answers reflecting positive-negative reactions to life and self. (See Appendix for positive-negative interpretations.) Feelings about health were strongly negative from respondents in institutional settings with a spread of only three between positive and negative in the larger homes. Strongly positive trends toward health outlook in the personalized setting were evident in both sizes of homes. It is possible that the personalized atmosphere is more conducive to feelings of well-being.

On the friendship satisfaction statements subjects in the personalized setting were much more strongly positive than those in the institutional setting.

Subjects in personalized facilities of both sizes paralleled closely on the positive and negative responses to life outlook, with 51

and 53 positive, respectively, in the larger and smaller homes, and 33 and 32 negative in the same sequence. Such parallels were not evident in the institutional category of responses. A warm emotional climate may be a positive factor in the personalized facilities in influencing life outlook of patients. Flexibility and breadth of activities could be important considerations as well.

Table 34 reveals responses to the feelings and outlooks of

TABLE 34
POSITIVE AND NEGATIVE RESPONSES TO FEELING AND
OUTLOOK SCALE AND TYPE AND SIZE OF HOME

	<u>Personalized Home</u>				<u>Institutional Home</u>			
	100 beds or more		Less than 100 beds		100 beds or more		Less than 100 beds	
	Pos.	Neg.	Pos.	Neg.	Pos.	Neg.	Pos.	Neg.
Attitude toward Health	68	15	56	31	31	28	21	7
Friendship Satis- faction	59	24	60	24	41	19	17	11
Life Outlook	51	33	53	32	38	22	21	7
Family Relations	28	35	47	16	25	20	10	11
Facility for Young Adults	42	21	51	15	36	7	17	4
Sexual Adequacy	26	17	26	16	14	12	7	7

Note: See Appendix for interpretation of positive and negative responses.

the patients. The only strongly negative response in the personalized setting on the Feeling and Outlook scale was in Family Relations. Respondents in both institutional-type homes indicated a degree of satisfaction with family relations. Those in the personalized facility

with less than 100 beds showed strong positive response to the Family Relations segment and were strongly negative in the facility with 100 beds or more.

Strongly positive from all four categories was the desire for a special facility for young adults. There was a strong broad spread toward the positive side over negative. Negative reaction was minimal to this concept and most of the negative responses seemed to come from the older respondents who were nearer the age of the major nursing home population.

In the area of concern about sexual adequacy those in both categories showed almost equal positive-negative reactions. Only a point or two difference was visible in the positive-negative answers to this area. Some of the negative responses could indicate denial of awareness of the problem, a reluctance to discuss this sometimes socially unacceptable subject of sex, or possibly achievement of some degree of acceptance of sexual limitations. Unavailability of sexual outlets might have influenced responses to some degree. Those responding positively answered more vehemently than did the negative respondents.

After viewing the results of the Feeling and Outlook Scale and the effect of the environments of both categories of nursing homes, it seems more apparent that the total ecosystem of a nursing home does have bearing on the residents' lives, particularly the lives of the younger patients. The freedom and flexibility of the Phrase Completion Responses should give added insight into the needs of young disabled adults and how they react to the nursing home environment.

The Phrase Completion section of the questionnaire gave

subjects an open-ended opportunity to complete 45 free-association phrases in an unstructured way. Results are given in Table 35.

TABLE 35
SUBJECT RESPONSES TO PHRASE COMPLETION
SCALE AND TYPE AND SIZE OF HOME

	<u>Personalized Home</u>		<u>Institutional Home</u>	
	Positive	Negative	Positive	Negative
External Intangibles (People Interrelations, World Affairs, Politics)	1.78 %	0.71 %	1.33 %	0.48 %
External Tangibles (Money, Food, Work, Smoking, Drinking)	4.78	1.73	3.47	1.27
Psychological Focus (Family, Sex, Religion, Future, Death)	9.33	7.18	7.66	5.07
Health Focus (Physical Condition, Mental Outlook, Disa- bility Source, Pain)	5.52	7.80	4.54	9.16
Ecological Reaction (Nursing Home, Staff, Patients)	0.16	2.97	0.33	2.87

Responses were divided into five general areas: External Intangibles focusing on such things as interrelationships with people, world affairs, and politics; External Tangibles such as money, food, work, smoking, or drinking; Psychological Focus dealing with feelings about family, sex, religion, the future, or death; Health Focus such as comments on physical condition, mental outlook, source of disability, and pain; and Ecological Reaction dealing with the nursing home environment, staff, or other patients.

This segment of the questionnaire may be evaluated in several ways. A composite view of the number of subjects who focused on health factors could be an indication of preoccupation with physical and mental problems as a result of a loss of feeling of well-being, negative self concept, or too much idle time resulting in a tendency to dwell on health problems. Each category could be analyzed in this manner.

Comparisons by subjects from the personalized or the institutional facilities could give a clue to ecological atmospheres conducive to positive and negative reactions in each general category.

Concentration on positive and negative responses from the same types of facility could show the outlooks and attitudes of the subject population in this type of facility as compared with the contrasting facility.

Analysis of Phrase Completion responses revealed the higher percentage of subjects from the personalized facility focusing on positive psychological areas with 9.33 per cent responding in an optimistic manner which was interpreted as positive. Highest percentage of subject responses from the institutional facilities was in the area of negative health reactions with 9.16 per cent. Another important comparison was evident in the next highest number of responses with a reverse positive-negative trend showing. Negative responses dealing with health from subjects in the personalized facility totalled 7.8 per cent and positive responses from residents of the institutional setting focusing on psychological areas were 7.66 per cent.

While these top percentages gave contrasting reactions to these two phrase completion segments of the questionnaire, another

picture was forthcoming when each category was evaluated within the confines of its own area. Psychological Focus received 9.33 per cent positive or optimistic response from respondents in the personalized setting and 7.66 per cent from those in the institutional setting, and 7.18 per cent negative or pessimistic response from respondents in the personalized facility and 5.07 per cent from the institutional residents.

In the Health Focus area positive responses totalled 5.52 per cent from the personalized residents and 4.54 per cent in the institutional setting, with a contrasting negative response reversing itself with 7.80 per cent negative from subjects living in the personalized atmosphere and 9.16 per cent negative response from the institutional residents.

Other categories of External Intangibles, External Tangibles, and Ecological Reaction of the Phrase Completion section fell into closely parallel positive-negative response patterns.

Diversity of answers to the Phrase Completion segment on specific subjects revealed a wide range of reactions to such topics as "The future . . .," "My body is . . .," "I need . . .," and "Death is . . ."

Samples of response to the phrase beginning "The future . . ." show the prospect to be everything from beautiful to bleak. Some responses to "The future . . ." were:

- is rewarding
- is beautiful
- is unpredictable but good
- looks OK (3 responses)
- looks dreary
- looks to be the same as yesterday
- outside of here, fine
- is bright (6 responses)
- looks good (5 responses)

is questionable
 looks bleak, not too bad but not too bright
 has got to be better
 is peaceful
 is pretty dismal
 is something I look forward to
 is bleak
 of life looks good to me
 is none just now
 is hopeful
 seems quite full
 has very little in store for me
 looks right now like this is the way it has to be and I have
 to make the best of it

Both positive and negative aspects of body image and self concept were revealed in the responses to the Phrase Completion question that began with "My body is . . .". Some completions to this phrase indicated:

Positive body image answers including such responses as "good," "OK," brought 17 responses.
 Negative body image answers including "broke," "dead," and similar answers brought 11 responses.

Other responses were:

not worth a nickle	very unique
crooked up now, was good	weary
pretty well worn out some places	overweight
the only one I've got	what I was born with
half missing	clean
my worst enemy	my own business
wracked with pain day and night	embarrassing
paralyzed (3 responses)	wasting away
full of misery	

More diversification was shown in the responses that began with the phrase, "I need . . .," than with any other. Many felt the need for more companionship and someone who cared. Some stated they needed nothing. Some of the responses to the phrase, "I need . . .," included:

Need for more companionship, closeness, moral support, and encouragement (14 responses).
 Desire for health improvement (6 responses).

Other responses were:

a job (3 responses)	to walk (2 responses)
money (5 responses)	to go home
lots of things I haven't got	more activities
and aren't going to get	to get out of here (3 responses)
nothing (8 responses)	girls
to pray more	guidance
a little more time (3 responses)	transportation
education (3 responses)	coffee

The concept of death was in the Phrase Completion section.

Some saw death as a release, some as inevitable for everyone eventually, and some felt it was a frightening prospect. Some responses to the phrase, "Death is . . .," included:

something that happens to everyone (15 responses)	
can come at any time	
sad	coming close
scary	nothing I study about
something to dread	I'm ready any day
reality	nothing to be afraid of
far out	a way out of misery
freedom	not important
the end	an escape from here
beautiful	terrible
don't know what it is	worrisome
to be dead all over	something I feel like
a long way off	has already happened
black	how do I know, I'm still alive

Death is a part of anyone's future consideration whether or not a disability exists. Outlook for the future is another personal philosophical consideration. In weighing their perceptions of their personal outlook for the future, Table 36 indicates subject response in the personalized setting ranged from 40.9 per cent of the residents in the smaller homes seeing the future as bright, 31.8 per cent as adequate, 13.1 per cent as dull, 13.1 per cent as bleak, and none seeing the future as hopeless. In the larger facilities with personalized atmosphere 42.8 per cent saw the future as bright, 28.5 per cent as adequate, 4.7 per

TABLE 36

SUBJECT ESTIMATE OF OUTLOOK FOR FUTURE AND
HOME TYPE AND SIZE BY PERCENTAGE

Outlook	Personalized Home		Institutional Home	
	100 beds or more	Less than 100 beds	100 beds or more	Less than 100 beds
Bright	42.8	40.9	23.5	42.8
Adequate	28.5	31.8	41.1	14.2
Dull	4.7	13.1	17.6	42.8
Bleak	14.2	13.1	5.8	0.0
Hopeless	9.5	0.0	11.7	0.0
Total	99.7	98.9	99.7	99.8

cent as dull, 14.2 per cent as bleak, and 9.5 per cent as hopeless.

Future outlook in the smaller institutional setting showed 42.8 per cent seeing the future as bright, 14.2 per cent as adequate, 42.8 per cent as dull, and no one in this grouping saw the future as bleak or hopeless. In the larger institutional-type facility 23.5 per cent rated the future as bright, 41.1 per cent as adequate, 17.6 per cent as dull, 5.8 per cent as bleak, and 11.7 per cent as hopeless.

Size of the facility could be an influence on future outlook as indicated by the greater percentage of personalized and institutional residents in the larger homes perceiving the future as hopeless whereas none in the smaller homes of both categories saw the future in this light. Patient outlook for the future is seen in a different light when viewed through observed frequencies and expected frequencies.

The insignificance of the Chi Square of .6 in the patient out-

look regarding the future as related to the type of home is overshadowed by the strongly positive observed frequency of the personalized home setting with a 1.4 upward differential from expected frequency. This is demonstrated in Table 37. Negative response shows a corresponding

TABLE 37

PATIENT OUTLOOK REGARDING THE FUTURE AND TYPE OF HOME BY EXPECTED AND OBSERVED FREQUENCY

Outlook	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Positive	28.6	30	16.4	15	45
Negative	13.4	12	7.6	9	21
Total		42		24	66

$$\chi^2 = .6$$

downward swing in this category. In the institutional setting the reverse is true as to patient outlook toward the future with a 1.4 decline in observed over expected frequency in positive response and corresponding increase in negative.

Psychological atmosphere of the personalized homes could be conducive to a positive patient outlook toward the future. Quality of care might be another factor in the positive-negative contrasts of the two types of homes. Another ecological influence on a nursing home resident's outlook is the opportunity to spend his time constructively throughout the day and evening.

Questions concerning diversional activities, recreational opportunities, and day time utilization of time revealed a great deal

of overlapping information since the three are very similar.

According to Table 38, of all the respondents, 47 per cent stated they

TABLE 38
SUBJECT STATEMENT OF DIVERSIONAL ACTIVITY ATTENDANCE
BY HOME TYPE AND SIZE BY PERCENTAGE

	<u>Personalized Home</u>		<u>Institutional Home</u>	
	100 beds or more	Less than 100 beds	100 beds or more	Less than 100 beds
Yes	61.9	27.2	58.7	42.8
Unable to go	23.8	22.7	29.4	28.5
Keep busy with other things	14.3	50.0	11.7	28.5
No activities	0.0	0.0	0.0	0.0

attended structured diversional activities, 28.7 per cent felt they were unable to go because of being bedfast or too physically limited to participate, and 24.2 per cent stated they kept busy with other things in their rooms or around the nursing home. A few of the younger residents helped in the office and reception area or delivered mail to other patients as a part of their daily activities.

Responses regarding diversional activities on the personalized and institutional settings showed a large percentage in the larger facilities of both personalized and institutional participating in existing diversional activities. Of the smaller homes, the respondents in the institutional setting indicated more participation than those in the smaller personalized facility. A large number, 50 per cent, in the smaller personalized setting kept busy with other things. In contrast,

the lowest percentage of respondents who kept busy with other things, 9.5 per cent, came from the larger personalized facility. The number who were unable to go to diversional activities was nearly equal in all four categories with those in both institutional settings showing slightly higher percentages. Respondents from the larger personalized facilities, 9.5 per cent, indicated no diversional activities at all.

Among the more significant levels of Chi Square at 4.0 is that part of the study dealing with patient participation in diversional activities as related to the two types of homes. Most dramatic spread is the response indicating that the patient keeps busy with other activities. Perhaps the flexibility of the personalized homes with patients encouraged to assist with certain operational functions of the homes accounts for the 3.2 upward spread of observed frequencies over expected in this type of home (Table 39).

TABLE 39

DIVERSIONAL ACTIVITY PARTICIPATION BY PATIENTS AND TYPE
OF HOME BY EXPECTED AND OBSERVED FREQUENCIES

	<u>Personalized Home</u>		<u>Institutional Home</u>		Total
	Expected Frequency	Observed Frequency	Expected Frequency	Observed Frequency	
Yes	19.5	18	10.5	12	30
Unable to go	11.1	10	5.9	7	17
Keep busy with other things	9.8	13	5.2	2	15
No activities	2.6	2	1.4	2	4
Total		43		23	66

$$\chi^2 = 4.0$$

This higher level of significance may be explained by the presence of more bedfast, dependent patients in the personalized homes which could be a factor because these patients are unable to go to diversional activities. This area shows 1.1 fewer observable frequencies than expected. Participation trends show 1.5 fewer observed than expected in the personalized homes, possibly because more are keeping busy with other things or are too incapacitated to attend. Availability of diversional activities probably is not a contributing factor in the divergence since there appeared to be virtually an equal number in both categories of homes responding that no activities are available.

Closely linked to diversional activities is the recreational program of the home. Table 40 shows that recreational programs were

TABLE 40
SUBJECT RECREATIONAL ACTIVITY ATTENDANCE AND
TYPE AND SIZE OF HOME BY PERCENTAGE

Participation	Personalized Home		Institutional Home	
	100 beds or more	Less than 100 beds	100 beds or more	Less than 100 beds
Yes	80.9	57.2	82.3	42.8
No	19.0	33.4	17.7	57.1
No Activities	0.0	9.5	0.0	0.0
Total	99.9	100.1	99.0	99.9

attended by 67 per cent of the respondents, 27 per cent did not attend, and 6 per cent stated there were no recreational activities. Favorite recreation was bingo which received sixteen votes as preferred choice with dominoes second with ten residents preferring this. Chess and

checkers were also among the favorites. Other activities receiving preference were:

records	country and western bands
swimming	jigsaw puzzles
dancing	gardening
cards	bar bells
leathercraft	spectator sports
embroidery	television
singing	church
reading	getting the hell away from here
ceramics	

Recreational activity attendance revealed comparable percentages in both larger facility categories with 80.9 per cent participating in the personalized and 82.3 per cent in the institutional. The smaller personalized respondents indicated a higher percentage of recreational participation with 54.5 per cent than did the smaller institutional who indicated 42.8 per cent participation. Similarities existed in the two larger facilities in non-participation with 19.0 per cent from the personalized and 17.7 per cent from the institutional. Of the smaller homes, institutional showed 57.1 per cent non-participation and personalized, 36.3 per cent, both indicating much greater non-participation than in the larger homes. Only in the smaller personalized setting did respondents indicate no recreational activities and this was 13.6 per cent.

One form of recreation was conversation and visiting which seemed to be a popular pasttime and many subjects listed several preferences. Visiting patterns of patients are revealed in Table 41 and show that most of the subject group, 54.5 per cent, visited with other younger residents most frequently while 42.4 per cent indicated that they visited most frequently with the staff. It is possible that

TABLE 41

VISITING PATTERNS OF PATIENTS AND TYPE
AND SIZE OF HOME BY PERCENTAGE

Most Frequently Visited	<u>Personalized Home</u>		<u>Institutional Home</u>	
	100 beds or more	Less than 100 beds	100 beds or more	Less than 100 beds
Staff	66.6	59.0	29.4	0.0
Younger Residents	61.9	63.6	14.1	42.8
Older Patients	52.3	27.2	46.0	42.8
Family	14.2	4.5	17.7	0.0
Friends from Outside	19.0	18.2	5.8	14.2
Others (Roommate)	0.0	9.1	17.7	0.0
No One	0.0	0.0	5.8	28.5

the staff's being made up primarily of a contemporary age group bringing in news of the more active, outside world accounted for some of this frequency. Visits with older patients were listed by 39.3 per cent of the respondents as most frequent visiting patterns.

The breakdown by types of facilities visiting patterns demonstrated one of the most significant percentage comparisons of the entire study. Both large and small personalized facility respondents listed younger residents as the people with whom they visited most, 61.9 per cent and 63.6 per cent, respectively. By contrast, institutional subjects indicated 14.1 per cent in the larger and 42.8 per cent in the smaller visiting with younger residents. Another sharp contrast was the indication that staff was listed as most frequent visitors in the personalized setting with 66.7 per cent of the subjects listing staff in the larger homes and 59.0 per cent in the smaller. Contrasting figures

showed staff-patient visiting at 29.4 per cent in the larger institutional homes and zero per cent in the smaller institutional types.

The only subjects indicating no one with whom they visited were those from both institutional settings, 5.8 per cent from the larger and 28.5 per cent from the smaller. This could stem from the staff attitude contrasts of warmth and friendliness in the personalized and professionally efficient in the institutional. Family indifference could be a contributing factor also. Type of home could also be partially responsible for the less than optimistic feeling about life that residents in the institutional homes indicated in their answers regarding life, with loneliness one aspect of their outlooks. Closeness with other human beings is an essential ingredient for thriving and for creating the desire to live. Some patients with no family nearby and a professional efficient staff taking care of their physical needs had probably had no affection or human warmth shown them since arriving and possibly even prior to arrival at the nursing home if families were rejecting or undemonstrative emotionally.

Friends and family appeared to be more frequent visitors in the personalized facilities with 14.2 per cent of the visitors being family members in the larger homes and 19 per cent listed as friends from outside. Subjects in the smaller personalized settings listed 4.5 per cent visitors to be family and 18.2 per cent friends. Institutional settings showed subjects indicating 17.7 per cent visitors to be family in the larger facilities and none in the smaller. Friends were listed as frequent visitors by 5.8 per cent of the subjects in the larger institutional-type setting and 14.2 per cent in the smaller.

Interview results have shown that the size of the nursing home has bearing on the patient's outlook, that the personalized setting is more conducive to positive or optimistic views toward psychological considerations such as family, sex, religion, the future, and death, and that the institutional setting prompts negative attitudes toward mental and physical health, disability source or degree, and pain. There appears to be little difference in the impact of either the personalized or institutional environment on such areas as relationship with people, world affairs, money, food, work, smoking, or drinking. Since these are external variables, it is not surprising that the nursing home environment has less impact on the subject population than the more deeply-felt internal areas of health and emotional functioning.

The loneliness expressed by patients in the institutional setting plus the non-involvement at a social level of staff in these facilities brings strongly into focus the influence of the ecosystem on the residents of this special world.

Suggested changes by respondents in the nursing home environment may offer additional understanding of this influence of the nursing home setting on its under-55 population.

Residents were asked about suggested changes in the nursing homes in which they resided. Their responses are given in Table 42. Many respondents checked more than one item, two checked every item, and some made additional suggestions. Highest percentage in all four categories of homes was the desire for more young residents. This result could stem from nursing homes, as they are known today, being basically designed for the predominant population, the geriatric patient. The

TABLE 42

RESIDENTS' PERCEPTION OF SUGGESTED CHANGES IN NURSING
HOMES BY TYPE AND SIZE OF HOME BY PERCENTAGE

	<u>Personalized Home</u>		<u>Institutional Home</u>	
	100 beds or more	Less than 100 beds	100 beds or more	Less than 100 beds
More Visitors	4.8	9.1	17.7	0.0
Group Activities	14.2	18.2	0.0	0.0
Outside Trips	19.0	27.2	17.7	0.0
Meals	19.0	22.7	41.1	0.0
Physical Arrangements	0.0	9.1	0.0	0.0
Recreation	28.5	18.2	5.8	0.0
Younger Patients	61.9	31.8	41.1	28.5
Unspecified Other	19.0	13.6	17.7	42.8
Nothing Changed	14.2	18.2	5.8	14.2

clustering and other responses expressing desire for more activity and suggested changes placing meals high on the percentage of desired changes could indicate an existing physical and operational design that is keyed to the geriatric patient, leaving the younger residents the forgotten population.

Write-in responses regarding suggested changes included: get out of here, learn something constructive, more respect for individual privacy, physical therapy, freedom, administrator, better care, and another nursing home. Suggested changes as indicated by subjects' recommendations plus some of the personal revelations of the cooperating patients about their physical, psychological, and social needs can contribute dramatically to the nursing home industry and to the medical and rehabilitation professions in the future.

CHAPTER IV

DISCUSSION AND CONCLUSIONS

Nursing home residents perceive nursing home living in a variety of ways: the place they go to die, the way to learn to live, a vegetative environment where they may be cared for with the least amount of effort, or a unique world where they can build comparatively independent lives for themselves. Their individual perceptions on arrival and as they settle into their routines in the setting determine, to a great extent, their basic philosophies toward this special environment.

Results of this study based on responses of the younger nursing home residents participating in the research indicate that the nursing home environment has an impact on the young disabled adults residing there just as they create a strong influence on the environment as well. The physical, psychological, and social ecology of this special world affects individuals of all ages residing in nursing homes. Such things as physical well-being, outlook toward life, self concept, and attitude toward the future are affected. The presence of younger patients in homes primarily occupied by geriatric residents makes the environmental web of interrelationships infinitely complex.

There appears to be a strong desire among the younger residents for association with other young adults, for special nursing facilities suited to their needs, and the desire for meals and activities more

appropriate to their age range. Findings indicate that the physical and operational designs of nursing homes are keyed to the geriatric patient leaving the younger residents virtually a forgotten population.

Meals often consist of a bland soft diet keyed to the older resident which includes soups, jello, puddings, and some cassarole combinations that are inexpensive and easy for the edentulous senior citizen to chew. Appetites of the younger residents call for greater variety with more imaginative seasoning. Spaghetti and meatballs, pizza, hamburgers with onions, and an occasional steak with french fries would probably be welcomed by the younger population resulting in re-awakened appetities sparking a new interest in life. The ideal situation would be a snack kitchen or cooperative arrangement in the diet kitchen where they could actively participate in the preparation themselves. Even peeling potatoes or weeping over an onion slicing session holds an intriguing charm if these simple tasks have been off-limits or out-of-reach in a custodial care setting.

Activities are quiet and somewhat passive, often consisting of crafts, bingo, church services, and hymn sings. The younger resident might respond more enthusiastically to discussion groups, more active games, and live rock music more in keeping with his tastes and age level. Wheelchair square dancing and bowling are available in some rehabilitation organizations if arm strength and stamina permit.

Some of the younger residents listed as their favorite recreation weekly trips to a recreation center for the disabled which provides special bus service to and from the center. Since this is a popular diversion for those who participate, regular excursions by special bus

or private car to special events such as ball games, stock car races, rodeos, musical productions, and sightseeing tours could be arranged through churches and other civic organizations so the younger resident would feel a part of the living outside world.

Flexibility of staff attitude in interpretation of policies and procedures plus a quality of caring toward patients in the facilities categorized as personalized has a bearing on the adjustment of the younger patient as evidenced by visiting patterns, percentages of residents who reflect an optimistic outlook toward life and themselves, and by the clustering found among the younger disabled adults concentrated in a few nursing homes. It is this population that has the initiative to find new, more compatible surroundings and this seems to be what the younger residents have done by seeking the homes which best meet their needs and continuing to relocate until they find one. As Goffman (1961b) maintains, significant differences in tone will appear in total institutions, depending on whether the decision to enter the nursing home is voluntary, semivoluntary, or involuntary.

Suitability of the existing nursing homes to the young residents seems in doubt since the sample turned out to be smaller than anticipated. It is evident that the younger residents are making other living arrangements either by hiring nursing attendants privately or, as mentioned by some administrators, marrying one of the nursing staff and moving into living quarters outside the nursing home. It is this population that has the initiative to choose an alternate place to live if not satisfied with present arrangements. The fact that a large number of the sample indicated the desire for a special facility for

younger patients should give impetus to modification of present nursing home philosophies or development of new concepts in special nursing facilities for young adults.

Implications of the findings of this research can provide nursing home owners and administrators with new approaches to meet the needs of the younger patients. Rehabilitation specialists can benefit from many of the responses in achieving a better understanding of the disabled individuals with whom they are counseling.

Nursing home administrators might be more aware of the needs of younger residents in a number of areas. Food selection could be planned to satisfy younger appetites with, possibly, hamburgers, pizza, or spaghetti offered to residents of all ages whose digestive processes can accommodate such diets. Since meals are one of the daily opportunities for diversion and socialization, and food is one of the basic human needs, meal time is among the most important events each day.

Administrators might give some thought to implementing activities that interest and stimulate younger residents both within the homes and outside. A broader range of outside excursions could help the younger residents feel more a part of the world and could motivate certain patients toward developing skills that they had not recognized before.

Proximity to other younger patients seems to be of paramount importance to the feeling of belonging and sense of well-being of young nursing home residents. That the younger residents were found to cluster in a few nursing homes shows the need to be near others in the same age range. Socialization among those in the same age range should

include opportunity to relate with individuals of the opposite sex. This could include dating among nursing home residents with transportation provided to a drive-in movie or other event. One astute nursing home administrator from another area of the state described his efforts to help his senior citizen residents achieve an element of closeness with others by encouraging dates and couple activity outside the nursing home setting. This could apply to younger residents to an even greater degree. In one home where interviews took place, one male subject shyly admitted to feeling a strong attraction toward a younger female resident but seemed to convey that there was some social taboo to his admitting his feelings. Common interests, needs, and problems inevitably draw together those in each home who are among the younger population regardless of degree of mobility or type of disability. With minor modifications of policy, administrators could provide these and other needs of the younger residents.

When viewed in the context of total institutions, nursing homes seem to be the exception to Goffman's (1961b) statement that there does not seem to be a total institution in Western society which provides batch living so completely segregated by sex. Unlike the convents, prisons, military installations, and mental institutions used by Goffman as prototypes, nursing homes do practice heterogeneous room assignments, geographically, although homogeneous roommate arrangements prevail. With co-educational dormitories becoming more accepted on college campuses, it is possible that this trend could spread to nursing homes in the future.

Nursing care is being constantly evaluated and modified

in facilities for veterans of all ages. Veterans Administration health professionals can utilize this material as they set up the plans for the immediate and long range care and rehabilitation of the Viet Nam veterans and prisoners of war. Veterans of the Korean conflict and World War II are within the age range of this study and are in need of treatment and rehabilitative measures resulting from service connected conditions and later accidents and illnesses of their age group. Data gathered in this study could provide information for setting up ambulatory units and rehabilitation facilities by Veterans Administration and other federal agencies.

Currently many disabled veterans are housed in nursing homes under VA contracts. Others are in state and federal veterans' domiciliaries. Some of the latter are keyed to the needs of veterans of younger ages as well as the older veterans. The camaraderie of the service years carries over into Veterans hospitals and other facilities where veterans are served. Yet, many veterans are accustomed to a flexible life style where luxuries and diversions are available. They are able to afford this style of living through their own wages or VA compensation if they are disabled through a service connected injury. This financial security permits a degree of independence whereby they may request and expect comfortable and suitable accommodations complete with diversion and recreation that appeals to them. This study could provide guidelines by which special veterans facilities can make such accommodations available giving the veteran a life style suited to his needs.

According to Rusk (1972) there are 300 million persons in the

world who require some kind of rehabilitation services and are unable to obtain them. The economic factors are equally important in view of the finding in this study that 57.7 per cent of the participating subjects were being supported by state welfare and 31.8 per cent were receiving Social Security Disability benefits, some of these in combination with some other type of support.

Nursing care is necessary but perhaps a modified version of the care being provided in nursing homes would meet the needs of the younger residents more effectively. For example, emphasis should be placed on dressing in day clothes rather than remaining in robes because of convenience to staff. Special instruction in activities of daily living with appropriate adaptive devices would stimulate an approach to independent living. This could include helping the patient learn to dress himself with the help of specially designed closings in clothing, reaching devices for pulling on slacks or stockings, and long-handled shoe-spoons for those unable to reach their feet. Many grooming devices such as special grips on electric shavers, combs, brushes, tooth brushes, and other items make independent dressing possible for those with severe limitations.

A few of the cooperating nursing homes in the personalized category were using younger residents at the nursing desk for such duties as answering the telephone, record keeping, and mail delivery. Morale of these young adults appeared to be noticeably more positive than others, possibly because they were experiencing purposeful activity and feeling that they were contributing something to their environment. Some hoped to utilize the experience they were gaining in this capacity toward

careers in the field of business through training under sponsorship of state vocational rehabilitation programs or veterans administration benefits. Most of these subjects were dressed in some modification of casual daytime clothing and had taken an interest in their grooming. There was an air of optimism about them that others living more in the sick-role area seemed to lack.

Weber and Rusk approach care of the disabled from different viewpoints. Perhaps the personalized homes have been modified in their policies and administrative procedures through the concept that Weber (1947) presents in that "bureaucratization is occasioned more by intensive and qualitative enlargement and internal deployment of the scope of administrative tasks than by their extensive and qualitative increase" (p. 66).

Rusk (1972) comments on care of the disabled:

If I sometimes become impatient at the slowness of total acceptance of rehabilitation needs, it is because millions of valuable lives are wasting away unnecessarily, because at this moment throughout the world millions of handicapped people lying helpless in their beds could be up and about, doing constructive things. It has now been proved beyond question that 90 per cent of even the severely disabled have the capacity if they get proper training, to take care of their own daily needs, and in many cases, to return to gainful employment in a competitive society (p. 295).

In meeting the needs of the younger disabled residents in nursing homes, some environmental alternatives could give impetus to modifying the environmental web toward appropriate satisfying life style. A look at another type of living arrangement could offer alternate possibilities in the care of the younger disabled adult.

One alternative is discussed by Colbert (1969) who gives a

description of a special facility which has been successful in its own right. He explains that various disabled living groups have been attempted in Southern California with apparent limited success. He asked an official of the Paralyzed Veterans Association what he considered the reason for failure. He was answered, "Oh, a lot of these groups have been tried. I do not really know, I guess the fellows would rather be on their own. The only successful place I know is in Guadalajara, Mexico" (p. 19).

Upon investigation, Colbert learned that one of these Guadalarjarian groups is advertised regularly in the Paraplegic News and reads as follows:

Special help and facilities for quadriplegics and paraplegics. Enjoy Guadalajara's perfect year-around climate and colorful living at low cost. Rates include personal care, meals, chauffeur service, laundry, private swimming pool. Accommodations for women" (p. 19).

Colbert took a trip to this southern paradise, to visit a few of these successful living groups. Asked why he had elected to live there, one of the year-round residents answered frankly, "When I had the accident, I did not want to face my family in a wheelchair, so I came down here to live." In sampling the informal conversation, it seemed to Colbert that it centered around Mexican citizens of the female gender. In fact, it seemed to Colbert that two of the cohesive elements of these successful communities were sex and the low cost of alcoholic drinks. "Of course," Colbert comments, "while booze and sex would probably enhance any humanitarian program, they are not as readily available in other locales" (p. 19). Another observer familiar with

that locale indicated that availability and low cost of marijuana contributed to the popularity of this area.

A personal interview with a married paraplegic resident of Guadalajara who was being treated in June, 1973, at the Veterans Administration Hospital in Oklahoma City revealed that he and his wife chose to move to this southern city because of climate and in hopes of finding a small quiet village in which to live. He expressed their amazement that the anticipated village turned out to be a thriving city of two million people with a paraplegic and quadriplegic population of around 450. He planned to return to Guadalajara as soon as his health problems were resolved to resume his activities in a large and dynamic organization called PVA or Paralyzed Veterans Association.

Another approach to modification of the environment to meet the needs of the younger disabled adult brought pertinent facts and figures to the foreground and was done in 1968 in Ohio. Maxwell (1971) explains this study in his statement that in 1968 a group of church, medical, and community professional persons met at Dodd Hall, the Ohio State University Hospital Rehabilitation Center, in response to the need for a creative effort to improve the quality of life for severely physically disabled persons in the Central Ohio area.

Maxwell observes that findings showed that the kinds of assistance most frequently needed included help with transferring in and out of a wheelchair, bed, automobile, etc., dressing, grooming, bathing, bowel and bladder care, and other routine activities of daily living. According to Maxwell, usually the family is able to handle these problems

for a young child with little difficulty. However, as the disabled person reaches adulthood, or if the disability occurs later in life, these tasks become very taxing and, in time, impossible for other members of the family to perform. Moreover, the disabled person recognizes and responds to the physical, emotional, and financial burden he is imposing upon them.

These considerations may account for the fact that the age range of 21-30 in this study accounting for only 10.6 per cent of the subject population, 31-45 age range showing 25.7 per cent respondents, and the 46-55 age group accounting for 63.6 per cent of the population. As the disabled individuals grew older, family members who cared for their personal needs were growing correspondingly older necessitating the need for nursing home care.

Maxwell (1971) maintains that the only alternatives by which this special care assistance can be provided are:

- (1) Placement in an institutional setting, such as a nursing home. This is expensive, isolating, and mentally unstimulating.
- (2) Employment of help in the home. Persons for such employment are practically impossible to find and retain, especially on a part-time, split-hour basis, and they are very expensive on a full-time basis. This kind of attendant help is consistently disruptive to family privacy and living patterns (p. 12).

In addition to these specific findings, Maxwell points out that severely physically disabled persons are a small but steadily increasing minority contained within a larger minority classified as "the physically handicapped" which contains an estimated 22 million Americans. As a minority, the severely physically disabled persons have always

known exclusion--not exclusion from the front of a bus but even from climbing aboard it, he explains.

Maxwell adds that even if these questions could be answered affirmatively, it would still be necessary to evaluate the somewhat intangible, yet real, concept of a "quality of life". For most physically disabled individuals, quality of life is blighted by such problems as independent housing, transportation, recreation, all types of architectural barriers, and the absence of social life. Such problems, Maxwell maintains, are a concern of all who believe in the ultimate rehabilitation and should be a concern for all of society.

Maxwell mentions that certain problems blight the prospects of such planning as that which he advocates. These limitations are a part of any study as are those encountered in this descriptive analysis.

Primary limitation of this study in Oklahoma County nursing homes is the small sample size and whether it is indicative of a pattern of responses that might be forthcoming with a study on a larger scale. It had been anticipated that adults in the 21 to 55 age range would be found in each of the 38 nursing homes in the selected area. Not only were there no suitable subjects in eighteen of the 38, but there were fewer than the expected number in many of the cooperating nursing homes.

Another limitation could be the fact that the study took place only in Oklahoma where middle western philosophies and mores prevailed. Responses of nursing home residents in states on the west or east coasts, or from other locales, could bring contrasting attitudes and reactions. Availability of other types of facilities and other organizational contacts unavailable in Oklahoma could contribute to a differ-

ent pattern of responses in other parts of the United States. A study of nursing care facilities operating for the benefit of specific groups could give additional strength to a descriptive analysis of this type. A number of homes for retired motion picture stars are sponsored by the Screen Actors Guild and other professional theatrical organizations. Among the outstanding homes in the nation are those maintained by Jewish organizations. Other professions and trades provide nursing care and retirement living for teachers, firemen, policemen, and ministers of all faiths. Each of these offers its own philosophies toward productive living for disabled of all ages. Again, most of these are particularly designed for the geriatric patient, the senior citizen with his special needs.

That few of the research categories were significant as to Chi Square probabilities points to a remarkable homogeneity of residents without regard to the type of facility in which they live. The small sample, in all probability, kept the level of significance down.

Further research possibilities could include a broader study encompassing a five-county area surrounding a metropolitan population center or a statewide survey of young disabled adults in all nursing homes throughout the state. Another research area which could benefit administrators and nursing home licensing boards and associations is a more comprehensive study of the educational background, experiential preparation, philosophies, and personal involvement of administrators and other personnel concerned with patient care in the operation of nursing homes.

Many additional facets of patient response need to be studied

with more breadth and depth than this study permitted. Contrary to expectations, subjects were not as concerned with sexual adequacy and availability of sexual encounters as might be expected. Some denial and lack of openness might have contributed to their responses. Lack of available partners and privacy for experimentation may also be a contributing factor. Study is needed in the area of sexual adjustments of the disabled male and female, in body image as it relates to early childhood and current adjustment to disability, mood swings of the younger nursing home resident and the ecological influences triggering the mood swings, and physical and emotional adaptive measures that the disabled resident of a nursing home learns in relating to this special environment. These and many other areas could provide fertile research possibilities that were not accomplished in this study.

Many subjects responded positively to the concept of a specially designed comprehensive care facility for young disabled adults which would offer the necessary care in activities of daily living with special emphasis on activity, rehabilitation, and productive employment. Consideration of the ideal facility will lend a measure of reality to this concept. Because of the need for proximity to jobs and training facilities, the facility should be located in a metropolitan city near public transportation. Those residents who can use public transportation could avail themselves of buses if the stop is nearby, and staffing is easier with transportation available.

Since the philosophy is based on action, independence, and rehabilitation, some variations from the traditional nursing home design should include a large inside and outside recreational area for social

activities, and for such other activities as wheelchair square dancing, bowling, shuffle board, croquet, pingpong, table games, bingo, rock concerts, talent programs, and church services for those unable to attend elsewhere.

Adjoining the recreational area should be a snack kitchen accessible to residents so that snacks and between-meal drinks are available to those not on special diets. This would be in addition to the dietetic kitchen where meals are prepared. A number of small conversation rooms should be provided for visiting with families, forming new friendships, and for structured or unstructured discussion groups.

A music room equipped with piano, stereo, guitars, and other musical instruments would encourage development of music appreciation and participation. Organization of talent groups from among the residents could result in performances at civic meetings and on television interview shows. These performances would serve a dual purpose. They would increase public awareness of the facility, stimulate better understanding of disabilities, and would bring about better adjustment to disability among the performing individuals by helping them to forget their self-consciousness through public appearances.

A sewing and laundry room should be planned for sewing and alterations by the residents. This would provide a setting for development of a business of custom-design clothing for disabled adults who may have fitting problems because of deformities or size deviations. These could be designed and made by the residents themselves.

A woodwork and metal shop would make possible repairs on furnishings and equipment that are inevitably needed with an active group

of young adults. This could also provide equipment for manufacture of specially designed appliances not available through retail supply stores such as a port-a-ramp, sliding boards for transferring to car or bed from a wheelchair, clip-on trays, wheelchair repairs, and other items for which only those who are disabled can know the need and design the item.

A workshop area should be planned for small industrial contracts which could be obtained from industries that use small assembly work. This would provide useful work for those unable to go to jobs outside the facility and would make a contribution to industry as well. A crafts room with kiln and other equipment could adjoin this area so that flow of space will encourage socialization and exchange of ideas.

Physical therapy by a qualified therapist should be encouraged with emphasis on physical fitness in a well-equipped gymnasium. The physical fitness program would build up remaining muscles which must compensate for the loss of others and is an important element in creating a new body image for a disabled individual.

A modern beauty and barber shop would encourage personal grooming and would help in improving self concepts. Special grooming and charm courses could be offered by cosmetic firms, and hair styling for men and women could be demonstrated by qualified experts. This could also provide a training site for those interested in this field if they are unable to attend the private training schools.

No limitation should be placed on disability types other than maintaining a balance between mental or emotional disabilities and physical disabilities. Each problem can complement the other and as

heterogeneous a group as possible will give a more normal distribution of disabilities and contacts.

Age range should be from 21 to 55 because this age group would have compatible interests and activities. It is this group that falls in the most employable category as far as employers are concerned, and these people are more adaptable to change and amenable to training.

Essential qualities necessary for staff along with professional qualifications, are a warm and accepting personality, a genuine enjoyment of young people, a sense of humor, flexibility, innovative ideas, optimistic outlook, and an attitude of understanding encouragement toward independence and rehabilitation. Some of these qualities are an innate part of an individual while others may be developed through in-service training and example.

The psychological make-up of each staff member should be considered, avoiding dependency-creating possessiveness, masochistic martyrs, self-righteous do-gooders, sadistic kidders, and impersonal professionalism. A neurotic staff member can create a neurotic patient. A practical joker on the staff can distort genuine humor into an emotionally-traumatic disaster in a disabled person. An administrator whose primary interest is financial gain can produce an unfeeling, cold staff with a facility full of rejected, fearful, introverted residents.

The public relations aspects of the ideal comprehensive care facility must appeal to the protecting-rejecting desires of the parents and the apprehensive emancipative needs of the young disabled adults. The parents must be reassured that the patient for whom they have cared, either from birth or since the onset of the disability, will have

equivalent or better care than he has had at home. They must know that chaperonage and personal care assistance are adequate and that opportunities for development and learning to make a living are available.

Parents may have guilt feelings about releasing him from their care and fear that he may feel rejected. Therefore, the plus-factors of this move must be pointed out, not in an effort to fill the rooms to capacity but as a humanitarian move that will benefit the disabled individual.

The young adult patient, who may have been spoiled, pampered, and protected, may be afraid that he will be left for hours without help or that adequate care will not be forthcoming when he needs it. He may view his new living arrangements as total rejection by his parents, as a method of "putting him away" for life.

He may see his new freedom as a way to build a life for himself as an adult for the first time. Then again, he may view it as a time to "live it up" by drinking and behaving in self-destructive ways at first opportunity. Either reaction on his part may create apprehension and a threatened feeling on the part of the parents. A carefully selected, well-trained staff can do much to alleviate these ambivalent feelings that the parents and the disabled young adult are experiencing.

Primary purpose in developing a comprehensive care facility for young disabled adults should be utilization of every physical and mental ability to the fullest potential for each individual.

Activity, training, and employment figure strongly into this. In order to encourage this, a number of peripheral services are essential. A referral system to Rehabilitative Services of the Department of

Institutions, Social, and Rehabilitative Services and other special service organizations is of utmost importance. Negotiations should be conducted with DISRS to have special counselors assigned to the facility so that concentrated rehabilitation services such as those provided by that agency may be utilized most effectively. Through these agencies vocational testing, counseling, training scholarships, and other services may be available.

In order to achieve a goal of employment, a special placement office for the disabled applicant should be established as a part of the facility. Under the direction of a qualified person, residents who are unable to work outside the facility but who have suitable skills could handle the clerical, receptionist, interviewing, and telephone contacts needed in the placement office.

This would serve as a placement center for disabled people throughout the state and would serve as a clearing house for employers who have vacancies in their companies that a disabled individual could fill. Constant employer contacts would have to be maintained to keep them aware of the placement center and effort would have to be made to acquaint disabled individuals, many of whom are well trained and well qualified but who have been unable to locate a job, with the services of the placement center. More mobile residents and special staff could make the personal contacts with industry to locate job openings and to diminish resistance among employers toward employing disabled people.

Clerical training and contract clerical jobs could be handled from the facility with adequate equipment in office machines and typewriters provided as part of the program. This is a field where there

is a great need for efficient workers and one that is easily adaptable to employment of the disabled.

Transportation is a realistic problem that must be met if the residents are to go to school or to work. One of the greatest desires and most nagging worries in a disabled person is learning to drive a car. When a disabled individual is behind the wheel of a car he is equipped and qualified to drive, the disability is virtually eliminated and he is provided with a feeling of independence and freedom he seldom experiences on braces and crutches or from a wheelchair.

Driver education with specially-equipped hand-control operated cars should be provided at the facility so that residents may have independent transportation when they can afford a car. Transportation may be provided by car or facility-owned bus for those whose disabilities prevent their driving to work or school. Special help may be needed in passing the driving test and this, too, could be provided as part of the driver education.

The same vehicles could be used for special tours to local and state scenic, educational, cultural, and recreational areas to encourage socialization and breadth of experience for residents, many of whom have been limited in travel either through financial limitations, family disinterest, or extremity of disability.

Since this group has, of necessity, been primarily "takers" rather than "givers" of service as individuals, resulting in a degree of self-centeredness and narrowness of interest, opportunity should be made for residents of the facility to give of their time and energy to helping others. They may serve as volunteers in homes for the aged by

reading or writing letters. They may give an occasional party for a childrens' home or hospital. They may serve as guides or information officers in a pavilion at the State Fair or some appropriate convention such as National Rehabilitation Association. They might take a talent presentation to the County Home and Hospital, Veterans Administration Hospital, or one of the state homes for the mentally retarded or mentally ill.

In this way, they can feel the satisfaction of giving of themselves to others, thus minimizing their own physical limitations or at least putting their own disabilities in a new perspective.

Each disabled person, whether the disability stems from a birth malformation or from accident or disease occurring later in life, must work out his own concept toward himself as a person and toward his disability. Body image plays an important role in this development and in self-acceptance.

Some people with markedly grotesque disabilities develop outgoing, vivacious personalities that virtually eliminate awareness of the deformity in the disabled person and in the eyes of the beholder. Others with less disfiguring problems are severely disabled emotionally because the disability is uppermost in their minds and, consequently, glaringly visible to others.

Many individuals who are severely disabled enough to need a facility of this type have had little opportunity for social interaction. Many have never known a close friendship. Some who have had over-protective parents feel like emotional freaks, incapable of love or marriage.

Most who have lived sheltered lives crave an opportunity for interaction with the opposite sex and a chance for sexual experimentation. Many deny sexual desires, yet secretly yearn for love, marriage, and a family.

Many can have normal marriages and satisfying sexual relations. Those physically incapable of sexual intercourse or reproduction may develop meaningful relationships with marriage partners. Many are unsure of their sexual roles and wonder about female sexuality or masculine virility. Most hesitate to discuss these thoughts and doubts with anyone and have had little opportunity to explore such questions.

As revised self concepts develop in the atmosphere of such a facility, it may be expected that these reservations will diminish. Sexual experimentation may be expected and viewed as a normal outcome of self acceptance. Frankness and openness are essential in dealing with this new self awareness and sexual awakening just as with any other phase of personal adjustment.

Results of the research of this descriptive analysis point up the need for such a comprehensive care facility for young disabled adults. This would be a dramatic departure from the traditional custodial care philosophy that now exists in nursing homes. As indicated in the study, some are modifying their approaches to care of the younger resident with some innovative measures. The younger occupants, themselves, are bringing about some of these modifications.

An ideal environment for the young disabled adult would need to be a progressive, developmental project to meet the changing societal and physical needs of this special population. Drawing from Weber's (1947)

concept, it is not possible to set up a static ideal system of scientific study because of the progressive nature of sociological systems.

In seeking an ideal nursing facility for young disabled adults, Weber's (1947) stand that meaning may be of two kinds, the "actually existing" meaning to a concrete individual actor or the "theoretically conceived pure type of subjective meaning" or "the ideal type" (p. 11). As with the nursing home population, Weber (1947) maintains that the actor is treated not merely as responding to stimuli, but as making an effort to conform with certain ideals rather than actual patterns of conduct, with the probability that his efforts will be only partially successful with elements of deviation.

These deviations in human needs and in demographical demands create philosophical and design problems to establishing an ideal ecological setting for young disabled adults. The ideal type, as Weber used it, is both abstract and general. It does not describe a concrete course of action, but a normatively ideal course, assuming certain ends and modes of normative orientation as binding on the actors.

This descriptive analysis meets the need voiced by Switzer (1969) when she commented, "One of our most urgent needs is to have models, drawn from actual experience, that can stimulate more joint activity in providing services people need, where they live" (p. 28).

Goffman (1961b) presents a contrasting view of meeting the needs of disabled people when he states:

Every institution captures something of the time and interest of its members and provides something of a world for them; in brief, every institution has encompassing tendencies. . . . Their encompassing or total character is symbolized by the barrier to social intercourse with the outside and to departure

that is often built right into the physical plant, such as locked doors, high walls, barbed wire, cliffs, water, or moors" (p. 4).

In the case of nursing homes such barriers include physical entrapment by wheelchair, bed confinement, transportation limitations, and, isolation from family or other caring human beings. The barrier to social intercourse with the outside world, as stated by Goffman (1961b), is dramatically evident among the younger nursing home residents interviewed in this study.

Based on the responses of the 66 participants it appears that some degree of modification is indicated so that the existing philosophy of nursing homes which are geared to the geriatric patient can more nearly meet the needs of the younger residents whose lives are so affected by the total ecology of their surroundings.

In a view that is somewhat different from Goffman's, Rusk (1972) states that ultimately, the success of all rehabilitation depends on the patient himself and to believe in rehabilitation is to believe in humanity.

It is hoped that this descriptive analysis will open the door to new considerations of the needs of young disabled adults in nursing homes and other environments and will provide guidelines which have been unavailable before.

CHAPTER V

SUMMARY

This descriptive analysis of the impact of a nursing home environment on physically disabled young adults between the ages of 21 and 55 years was designed to understand, more fully, the needs and desires of the younger residents in this special environment. The total philosophy of care for the older patient afflicted with infirmities of aging is different from that needed by the young adult patient who might be permanently or transitionally housed in a nursing home. It was expected that the younger adult patient would be positively or negatively influenced by the nursing home environment which is a unique ecosystem of its own.

Sixty-six subjects in the designated age range from 20 cooperating nursing homes of the 38 in Oklahoma County participated in the 30-minute interviews which were conducted over a five-week period. Questionnaires included: a personal data sheet; a check list on reaction to nursing home living to attitudes on life, health, and the future; a true-false scale on feelings and outlook; and an open-ended phrase completion list dealing with self concepts, interpersonal relationships, aspirations, and death.

All 38 nursing homes were evaluated by ecological factors and

the 20 participating homes were categorized on the basis of this evaluation as personalized and institutional, each divided into two sub-categories of 100 beds or more and less than 100 beds. Results of the questionnaire were tabulated by positive and negative responses and comparisons were made according to the four divisions and with Chi Square levels of significance. Results indicate that the nursing home environment has a strong impact on the young disabled adult residing there, especially in such areas as physical well-being, outlook toward life, self concept, interpersonal relationships, visitor patterns, and attitude toward the future. Flexibility of staff attitude plus a quality of caring by the staff was evidenced in the personalized setting with a resultant patient reaction of positive outlook toward themselves and toward life.

There appeared to be a strong desire among the younger residents for: (1) association with other young adults; (2) for special nursing facilities suited to their needs; (3) the desire for more suitable meals; and (4) the need for activities more appropriate to their age range.

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APPENDIX

APPENDIX A

INTERVIEWER'S INTRODUCTORY STATEMENT

I am an interviewer for Marion Davis who is working on her dissertation for her doctor's degree. We are interviewing all patients between the ages of 21 and 55 who live in nursing homes in Oklahoma County.

To Staff: I would appreciate it if you would give me the names and room numbers of your patients under 55 who are alert enough to be interviewed. Then we would not need to bother you further about it. Answers are confidential and will not be seen by anyone except the interviewers.

To Patient: Would you mind answering a few questions for me about how you feel about living in a nursing home and about yourself? It will only take about 30 minutes and would help us a great deal in understanding the younger adults who live in nursing homes and in understanding their needs and thoughts. All your answers are confidential and will not be shown to anyone except the interviewers who will be helping with the tabulations.

Instructions to interviewer: Allow patient to ramble enough for him to feel comfortable. Diplomatically steer him back to the questionnaire at appropriate pause. Ramblings can be significant. Jot down any pertinent points in margin beside question where pause occurred. DO NOT provide answers for him but draw him out with additional questions if he blocks on an answer, especially on phrase completion page. Praise him occasionally so he will feel approval and interest from you. You may need to ask some leading questions to get him to elaborate on his answers enough for desired completion of question. Thank him for his cooperation.

APPENDIX B

OKLAHOMA COUNTY NURSING HOMES

From 1972 Directory of Licensed Rest Homes,
Intermediate Care Facilities and Specialized Homes

State Department of Health

Bellevue Northwest Nursing Center, 6500 N. Portland, Oklahoma City
Bethel Memorial Manor, 225 S.W. 35th, Oklahoma City
Brown's Nursing Home, 627 N.E. 4th, Oklahoma City
Capitol Hill Nursing Home of Oklahoma Inc., 2400 S.W. 55th, Oklahoma City
Colonial Manor Nursing Home, 8016 S.E. 15th, Midwest City
Dalles Nursing Home, 3718 N. Portland, Oklahoma City
Draper Nursing Home, 3300 N.W. 23rd, Oklahoma City
Edmond Nursing Center, 39 S.E. 33rd, Edmond
Evening Star Nursing Home, Inc., 6912 N.W. 23rd, Bethany
Evergreen Nursing Home, 400 S. Scott, Del City
Fairview Lodge Nursing Home, 3233 N.W. 10th, Oklahoma City
Four Seasons Nursing Center, 5301 N. Brookline, Oklahoma City
Four Seasons Nursing Center, 5600 S. Walker, Oklahoma City
Four Seasons Nursing Center, 2900 Parklawn Dr., Midwest City
Godwin's Nursing Home, Inc., 1210 N. Broadway Dr., Oklahoma City
Grayson Nursing Home, Inc., 3000 N.E. 17th, Oklahoma City
Lackey Manor Nursing Home, 9700 Mashburn Blvd., Oklahoma City
Lora Lane Nursing Home, 1214 N. Broadway Dr., Oklahoma City
Lou Len Manor, 505 E. Wilshire, Oklahoma City
Mid-Del Manor Nursing Home, 1401 Crosby Blvd., Midwest City
Morning Star Nursing Home, Inc., 3804 N. Barr, Oklahoma City
Murray Nursing Home, 2520 S. Ranking, Edmond
Northeast Nursing Home, 1215 N.E. 34th, Oklahoma City
Northwest Nursing Center, 2801 N.W. 61st, Oklahoma City
Oak Hills Nursing Home, 1100 West Georgia, Jones
Oklahoma Christian Home, Inc., 906 N. Blvd., Edmond
Oklahoma County Home, 7401 N.E. 23rd, Midwest City
Rosa's Shady View Nursing Home, 1163 E. Madison, Oklahoma City
St. Ann's Home, Inc., 3825 N.W. 19th, Oklahoma City
Sequoyah Nursing Center, 6501 N. MacArthur, Oklahoma City
Southern Oaks Manor, 301 S.W. 74th, Oklahoma City
Southwestern Convalescent Manor, 5512 S. Western, Oklahoma City
Terrace Gardens Nursing Home, 1921 N.E. 21st, Oklahoma City
Watkins, Stephens Skyview Nursing Home, 2200 Coltrane Rd., Oklahoma City
Wendemere Nursing Home, 7000 N.W. 32nd, Bethany
Western Oaks Nursing Home, 7500 N.W. 23rd, Bethany
Windsor Hills Nursing Home, Inc., 2416 N. Ann Arbor, Oklahoma City
Woodside Nursing Home, Inc., 3601 N. Eastern, Oklahoma City

APPENDIX C

PERSONAL HISTORY

This first page is a personal history. The questions are very simple to answer. All of the information is confidential and will be combined with other interviews for an overall picture of the young adult living in a nursing home.

1. What is your name? _____
2. How old are you? _____
3. Sex: Male _____ Female _____
4. Are you married? _____ Divorced _____ Widowed _____ Never married _____
5. How far did you go in school? Less than high school _____ Grade _____
High School _____
Some college _____ How much _____
College degree _____
Graduate degree _____
6. Who are your nearest family members that you see the most? (one or more)

Spouse	_____
Mother	_____
Father	_____
Brother	_____
Sister	_____
Children	_____
Other	_____
	specify
7. What is your primary disability? (check one or more)

Orthopedic	_____	Type	_____
Amputation	_____		
Paraplegic	_____		
Quadriplegic	_____		
Hemiplegic	_____		
Other	_____		
		specify	
8. Source of disability.

Congenital	_____
Accident	_____
Disease	_____
9. How much help do you need in self care?

Totally independent	_____
Need some help	_____
Totally dependent	_____
10. Are you in a wheelchair all or part of the time? _____

Bedfast	_____
Able to walk unassisted	_____
Able to walk with help	_____
Wheelchair part of time	_____
Wheelchair full time	_____

APPENDIX D

Patient's Name _____

INFORMATION REGARDING NURSING HOME LIVING

These questions concern your decisions to live in a nursing home and your activities here.

1. Do you live in a nursing home because: You choose to do so _____
You have no choice _____
2. Do you have relatives who could take care of your personal needs at home? Yes _____
No _____
3. Do you find the nursing care here: Good _____
Adequate _____
Fair _____
Poor _____
4. Are you free to come and go as you please? Yes _____
No _____
5. Is the food quality here: Good _____
Adequate _____
Fair _____
Poor _____
6. Is the food quantity here: Good _____
Adequate _____
Fair _____
Poor _____
7. Do you participate in the diversional activities? Yes _____
Unable to go _____
Keep busy with other things _____
8. Do you like the planned recreational activities? Yes _____
No _____
9. What is your favorite? _____
10. How do you spend most of your time during the day?
Reading _____
Watching TV _____
Group activity _____
Individual hobby _____
Playing cards _____
Sleeping _____
Conversation _____
Other _____
specify

Nursing Home Living--Continued

11. Do you visit most with: Staff _____
 Younger residents _____
 Older residents _____
 Family _____
 Friends from outside _____
 Others _____
 No one _____
12. How long have you been disabled? Less than 5 years _____
 5 to 10 years _____
 10 to 20 years _____
 More than 20 years _____
13. How long have you lived in nursing homes? Less than 5 years _____
 5 to 10 years _____
 10 to 20 years _____
 More than 20 years _____
14. How would you rate your general health? Excellent _____
 Good _____
 Fair _____
 Poor _____
15. Do you feel that life is: A constant challenge _____
 Interesting _____
 Rewarding _____
 Dull _____
 Not worth living _____
16. The decision for you to come to a nursing home was made by: Yourself _____
 Your physician _____
 Your family _____
 Other _____
 specify
17. Do you consider nursing home living to be: Temporary _____
 Permanent _____
18. What would you like to change about your life here? More visitors _____
 Group activities _____
 Outside trips _____
 Meals _____
 Physical arrangements _____
 Recreation _____
 Younger patients _____
 Other _____
 specify

Nursing Home Living--Continued

19. Do you feel that your condition is most likely to:

Improve _____
Stay the same _____
Get worse _____

20. To you does the future look:

Bright _____
Adequate _____
Dull _____
Bleak _____
Hopeless _____

APPENDIX E

Patient's Name _____

FEELING AND OUTLOOK SCALE

These statements can be answered with TRUE or FALSE and concern your feelings about life and about yourself. Answer TRUE or FALSE to the following statements:

	TRUE	FALSE
1. I feel reasonably well most of the time.	<u>Pos</u>	_____
2. If I can't feel better soon, I would just as soon be dead.	_____	<u>Pos</u>
3. My health is constantly on my mind.	_____	<u>Pos</u>
4. I feel miserable most of the time.	_____	<u>Pos</u>
5. I have many close friends.	<u>Pos</u>	_____
6. I have no one to talk to about personal things.	_____	<u>Pos</u>
7. I am lonely much of the time.	_____	<u>Pos</u>
8. I consider my life to be reasonably happy and satisfied.	<u>Pos</u>	_____
9. I am happiest when I have definite work to do.	<u>Pos</u>	_____
10. I have no work to look forward to.	_____	<u>Pos</u>
11. My life is still busy and useful.	<u>Pos</u>	_____
12. My life is empty and useless.	_____	<u>Pos</u>
13. My family tries to make my decisions for me.	_____	<u>Pos</u>
14. I wish my family would pay more attention to me.	_____	<u>Pos</u>
15. I am satisfied with the way my family treats me.	<u>Pos</u>	_____
16. I would like to live a more active life if my physical condition would permit.	<u>Pos</u>	_____
17. I feel that a special setting would help me to be more busy and active.	<u>Pos</u>	_____
18. I would like to live in a nursing home especially planned for young adults.	<u>Pos</u>	_____
19. I feel the need for more opportunity to socialize with the opposite sex.	<u>Pos</u>	_____
20. I worry a lot about my sexual adequacy.	_____	<u>Pos</u>

APPENDIX F

Patient's Name _____

PHRASE COMPLETION LIST

Here is a list of phrases which could be the beginning of a sentence. As I read each phrase in this list, I would like for you to complete the sentence with the first words that come to your mind, no matter how appropriate or silly they seem to be. Be sure to say what first comes to your mind. Please try not to omit any item.

1. I like _____
2. I want to know _____
3. I regret that I _____
4. At bedtime I _____
5. The best _____
6. What annoys me is _____
7. I feel _____
8. My greatest fear is _____
9. I can't _____
10. My stomach _____
11. When I was a child _____
12. My nerves _____
13. I suffer _____
14. The most dangerous _____
15. My mind _____
16. The future _____
17. I need _____
18. I feel best when _____
19. There are times when I _____
20. What pains me is _____
21. I hate _____
22. I wish that _____
23. The only trouble is _____
24. My greatest worry is _____
25. I get angry when _____
26. My health is _____
27. My idea of a good time is _____
28. The best part of my body is _____
29. Death is _____
30. It is not healthy for people to _____
31. The worst part of my body is _____
32. My parents are _____
33. My worst habit is _____
34. It is more important to have _____
than it is to have _____
35. Work means _____
36. I would like to get away from _____
37. What embarrasses me most is _____
38. I can't understand what makes me _____
39. I feel happy when _____
40. My ambition is _____
41. Money is _____
42. I like to daydream about _____
43. My physical strength is _____
44. I am most successful at _____
45. My body is _____

APPENDIX G

NURSING HOME INFORMATION

1. Name of nursing home: _____
2. Address: _____
3. Approximate size:

Under 50 beds	_____
50-100 beds	_____
Over 100 beds	_____
4. Exterior construction:

Frame	_____
Shingle	_____
Brick	_____
Rock	_____
Cement block	_____
Other	_____
	specify
5. Condition of grounds:

Well kept	_____
Moderately neat	_____
Unkept	_____
6. Interior decor:

Carpeted halls	_____
Carpeted rooms	_____
Vinyl floors	_____
7. Room furnishings:

Coordinated	_____
Semi-coordinated	_____
Institutional	_____
8. Housekeeping quality:

Very neat	_____
Moderately neat	_____
Clean, but cluttered	_____
Unsanitary	_____
9. Physical atmosphere:

Fresh air	_____
Stuffy	_____
Antiseptic smell	_____
Cooking aroma	_____
Urine odor	_____
10. Staff attitude:

Warm and friendly	_____
Professionally efficient	_____
Indifferent	_____
Unkind	_____
Other	_____

Nursing Home Information--Continued

11. Name of Administrator: _____
12. Does he own this nursing home? Yes _____ No _____
13. Does he own other homes? Yes _____ No _____
14. Business background, if available:
15. Observable attitude toward interviewer: Cooperative _____
Indifferent _____
Resistive _____
16. Name of Director of Nursing: _____
RN _____ LPN _____
17. Observable attitude toward interviewer: Cooperative _____
Indifferent _____
Resistive _____

APPENDIX H

INTERVIEWER'S EVALUATION

1. Name of Interviewer _____
2. Date of interview _____
3. Time of interview _____
4. Interviewer's evaluation of patient's attitude toward interview:
 - Cooperative _____
 - Helpful _____
 - Interested _____
 - Intrigued _____
 - Bored _____
 - Resistive _____
 - Other _____
5. Side comments of patient which seem pertinent:

6. Physical description of patient:

7. Apparent validity of answers:
 - Highly valid _____
 - Partly valid _____
 - Mainly invalid _____