The Modern Family and Rehabilitation of the Handicapped: A Macrosociological View

(Modernization, medical institution, chronic handicaps, family structure)

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Modernization of society has fundamentally altered the family institution and at the same time has produced a medical institution capable of decreasing the prevalence of infectious diseases, while increasing the prevalence of chronic handicaps. Structural and functional changes in the family resulting from modernization include: smaller size and increased mobility; more women employed outside the home; age segregation and increased longevity of members; higher rates of dissolution; and loss of functions to other institutions in a more specialized society. Changes making the modern family ill-equipped to care for the chronically disabled are discussed, together with implications for rehabilitation.

At the end of the 16th century when Shakespeare described the seven stages of Man, high mortality was taking its toll and only a privileged few reached the oldest stage of "... second childishness and mere oblivion, sans teeth, sans eyes, sans taste, sans everything" (1, p 1). Today's technology allows more persons to reach the last stage, perhaps with some remaining teeth, eyes, and taste. Modernization is a sociological concept describing the basic social change that accompanies "the process of urbanization and industrialization..." and "... touches all aspects of social life: family, religion, politics, education, and others." (2, p 404) The increase in world population, or the demographic transition, is due to the decrease in deaths resulting from improvements in technology, sanitation and hygiene, and medical care accompanying modernization (2, p 421) (see Figure 1). Allied health professionals also are products of these changes: Laurencelle states that "... rehabilitation is a social movement, a social process, and a social revolution" (3, p 330).

Acute medical conditions have decreased in incidence and prevalence. However, people with permanent handicaps are more common. The family institution also has un-
dergone tremendous changes with profound implications for rehabilitation. Beppler (4), Gilchrist and Wilkinson (5), Goodell (6), Litman (7), Nau (8), Schwab (9), and Smits (10) stress family involvement in rehabilitation, but without analyzing structural and functional limitations hampering this participation. McKibbin discusses problems experienced by parents of mentally retarded children, but the focus is therapeutic, not macrosociological (11). Kovell does mention macrosociological factors making home care of the ill difficult, but without analyzing long-term rehabilitation implications in greater detail (12).

Sociologists are aware of the incompatibility of modern family structure with care of the acutely ill. However, they fail to discuss the full implications for rehabilitation of the chronically disabled (13, p 180). An institution simply is a stable, dependable way of performing important social activities, and Bynder and New advocate a “...structural analysis of...institutions and how they impinge...on the disabled...” (14, p 51). They state that:

... if we knew more about the conditions and constraints in society relevant to the disabled, to the professional, and to the rehabilitation process itself, the impact may be greater on the successful rehabilitation of the disabled. (14, p 48)

The family institution has been present in some form in all societies but historically large, specialized, bureaucratic medical institutions are recent. Thus, the two institutions do not always function well together. Effects of large-scale changes in the family institution upon rehabilitation of the handicapped are of specific concern here. Structural and functional characteristics of the modern family will be discussed, followed by implications for rehabilitation.

Structural and Functional Characteristics of the Modern Family

The modern nuclear family, composed of spouses or one parent and offspring, functions as a smaller unit than the preindustrial, three-generation extended family. Reduced infant and child mortality rates and effective contraception mean that couples bear fewer children and can expect them to survive. Also, the reduced fertility that occurs with the demographic transition means that parents often have greater emotional investment in fewer children, whether or not the children are handicapped.

Changing occupational patterns make the nuclear family more geographically mobile (15, p 586), and further sever extended family ties. Thus, individuals with similar handicaps but dependent upon others for economic support often are widely dispersed. For example, delivering home health care to spinal cord injury patients is difficult within “large catchment areas” (16, p 251).

The increasing percentage of women working outside the home has received much attention from social scientists who state that the role of the working woman becomes increasingly complex with her “liberation” (17). It, as Litman suggests, the “...mother...[is]...the main source of comfort and assistance in times of illness” (7, p
Riesman has documented the increasing importance of the peer group in modern society (18). We generally begin life in a nursery with our age peers, and often end it similarly in a nursing home. Age segregation of family members means that many activities formerly conducted within the family, from recreation to education, are now experienced with age peers.

People live longer, but aging does not guarantee higher family status. While early marriage and death before all children left home were common in the preindustrial society, a couple now can survive together "beyond reproductive age" (19, p 33) after the last child leaves home. Thus, "disengagement" (20), or withdrawal from social activities does not characterize the aged in pre-industrial societies but "... appears to accompany modernization" (21, p 323). A handicap can be simply another affirmation of old age that is detrimental to successful rehabilitation in a society where aging no longer brings higher familial or societal standing. Furthermore, a sex differential in mortality rates favors women, who usually outlive men.

The structure of the modern family has become less stable, with divorce rates rising gradually since the beginning of this century (2, p 191). If the handicapped individual is a child, dissolution of the parents' marriage can place the child in the precarious position of being the total responsibility of one adult with other obligations. The consequences of the acquisition of a physical handicap by a spouse are profound; the vow "till death do us part" takes on new meaning when a spouse becomes permanently disabled. One study indicates that the percentage of married male spinal cord patients had dropped substantially two years after injury, partly because of their decreasing sexual drive (22); and another study suggests that married persons disabled at earlier ages, especially under 25, are more likely to experience marital dissolution (23). The consequences of such dissolution are profound for a handicapped individual who may not find another partner.

With "modernization," the family loses basic functions to other large-scale educational, political, and economic institutions. In short, it is simply no longer a dominant societal institution. In an urban society described by such sociologists as Charles Horton Cooley (2, p 138) and Erich Fromm (24) as increasingly specialized and impersonal, neighbors may remain strangers or, at best, casual acquaintances, so that the family with a member who is handicapped cannot always rely upon their neighbors for help. Specialized agencies, such as home-visit teams and transportation services, provide care, but on a somewhat impersonal basis. Furthermore, individuals are "labeled" by prominent physical and social characteristics when social interaction is less intimate, relatively impermanent, and very specialized.

The total education of children to behave as responsible adults, was previously a family function. This function is now being fulfilled largely by other institutions (2, p 181). Handicapped children receive training from professionals outside the home, and with many new categories of childhood disabilities resulting from higher survival rates of "high risk" infants, many families are responsible for care of children with chronic medical conditions. Successful treatment of these children depends upon sophisticated knowledge not possessed by the average family.

While one's family or ascribed status was of paramount importance in determining one's social status in preindustrial society, the modern nuclear family is free to achieve economic success or failure unencumbered by extended family ties. Furthermore, individual family members can attain a job identity separate from the family, and one's occupation, not one's family membership, becomes a primary status variable in modern society.

The family provides one with a name but it no longer is a primary basis for political identity. The terms kinship and lineage imply that the family served important political functions in preindustrial societies where such concepts were very important. Modernization decreases the family's political importance. Social classes, racial and ethnic groups, occupational identities, age categories, sexual preferences, and handicapping conditions claim political allegiance.

Finally, the extended family formerly produced most of the goods consumed by its members, including the provision of medical care. Such goods and services are now provided largely by other bureaucratic institutions outside the home. Because government agencies or third-party payers cover many costs of medical care, rehabilitation often terminates "when the insurance runs out," rather than when the individual is rehabilitated or the family is prepared to assume full-time care. Yet, ironically: "... the family constitutes perhaps the most important social context within which illness occurs and is resolved. It consequently serves as a primary unit in health and medical care" (7, p 495). Thus, a disabled individual's family who no longer produce
most of their own medical care still
must consume these services, often
at the convenience of the medical
establishments providing it.

Discussion and Implications
Smaller family size has many im-
plications for care and rehabilita-
tion of the handicapped. If a child is
physically handicapped, the burden
places additional strain upon the
parent or parents who may have no
other relatives to help (25). If the
handicapped person is an adult, the
spouse and/or children often as-
sume responsibility for the patient’s
care in the absence of other re-
latives. Because more elderly persons
will experience chronic disabilities,
children will have more years to
care for their disabled parents.
Goodell finds that stroke or multi-
ple sclerosis victims often become
handicapped just when their teen-
age children are becoming inde-
pendent (6); and Kimmel suggests
that middle-aged adults frequently
must care for their parents when
their responsibilities toward their
own children are heaviest (26, p
212), finding themselves caught in
the middle of a demographic
“crunch” produced by decreasing
death rates and increased longevity.

LeMasters notes that modern
parents, having come from smaller
nuclear families, often lack previous
child-rearing experience and are inadequately prepared for paren-
thood (27, pp 20-21). Thus, parents
of handicapped children may lack
experience with normal children, let
alone a child with a sophisticated
medical diagnosis. The early social
philosopher Max Weber foresaw
the nature of a modern bureaucratic
society when he stated that person-
nel would be selected for positions
in modern institutions on the basis
of achieved professional qualifica-
tions, not friendship or family rela-
tionship (28). This is especially true
of medical personnel. Yet paren-
thood is thrust upon many without
professional qualifications, and it
is rare, indeed, when parents of
handicapped children are profes-
sionally qualified. Thus, handi-
capped parents may be in “double
trouble,” especially since research
reveals that such parents often call
upon their own experience, rather
than upon professional knowledge,
in child-rearing (29, p 302). Barsch
suggests that a . . . chasm . . . exists
between the extensive body of knowl-
edge in child rehabilitation and the
minimal awareness of this knowl-
edge on the parental front of child
rearing. There is an obvious need
for bridges to be built (29, p 348). He
found that parents of handicapped
children were uninformed about
basic speech problems and basic
methods for reinforcing appropriate
behavior (29, pp 121-122, 143, 280),
and McKibbin similarly found that
parents of mentally retarded chil-
dren had difficulty managing their
behavior (11, pp 126-127).

Child-rearing techniques, right
or wrong, used to be part of the fam-
ily’s folk knowledge and were passed
from generation to generation. Now
such techniques have become a spe-
cialized science, with an everchang-
ing body of knowledge fed by con-
tinuing research. Although parents
of nonhandicapped children can
often ignore this science, parents of
the handicapped cannot. Thera-
piests working with such parents should
never assume that the parents pos-
sess adequate knowledge about
normal child development as a basis
for assessing and facilitating their
handicapped child’s progress. Pro-
fessional occupational therapists
and nonprofessional parents live in
a technologically advanced society,
and research suggests that the former
can best serve the interests of par-
ents of the handicapped by develop-
ing easily communicated ways to
bridge Barsch’s knowledge gap to
increase their skills as parents.

The handicapped can be greatly
inconvenienced as members of mo-
bile families, for a move confronts
the wheelchair-bound individual
with new architectural barriers, or
the arthritic with a new house to
which to adapt. The family, wish-
ing to relocate, may hesitate to move
where suitable schools and/or reha-
bilitation facilities are unavailable,
respecting this job opportunities (30).
While therapists often must judge
their productivity in terms of the
number of hours spent in direct
patient contact, they often can be
more “therapeutic” by arranging
and coordinating other rehabilita-
tion services for a particular patient
who, otherwise, might be lost in the
cracks of large rehabilitation bu-
reaucracies. Furthermore, therapists
must always consider the possibil-
ity of a patient’s relocating. A
female multiple sclerosis patient
likely to change residences might
use a removable wheelchair tray
with a recession bowl, rather than
an entirely new kitchen counter; the
arthritic patient can be given more
than one ulnar deviation splint in
the case one is lost or damaged while
visiting grandchildren; and the
father of a child with cerebral palsy
with a job opportunity in another
region may be informed by the ther-
apist of several alternative facilities
for his child.

Koos describes the pivotal family
role of the mother in illness: “. . .
when the mother became sick, fam-
ily life became disorganized” (31):
Litman states that: “. . . patient’s
hospitalization seemed to have had
the most disruptive effect on the
activities of the wife-mother . . . .
(7, 509); and Poznanski found that
mothers of handicapped children
"isolate themselves with the children" while fathers "isolate themselves from the home" (32, p 325). Although industrialization has fundamentally altered the wife/mother's family role, the basic biological and sociological "differential reproductive burden" (33, p 351) still places much responsibility for raising a child (handicapped or not) upon her.

This burden must be redistributed among all other available family members whenever possible, a task made more difficult by our mobile society's dependence upon the mother to transport children and coordinate services for them, while fathers engage in a full-time occupation. Parents often remain locked into traditional parental roles despite changing occupational patterns, so that therapists must make special efforts to reach fathers (evening or weekend "fathers' days" at therapy centers, well-written home programs, etc.).

It is likely that women's increasing rates of employment outside the home will actually facilitate some rehabilitation. Zimmerman stated more than a decade ago that basic rules for training a disabled home-maker applied regardless of age or sex (34, p 226), but the rigidity of sex-roles sometimes encouraged disabled men to resist rehabilitation to avoid having to do housework (35, p 274). Carpenter suggests that when a male wage-earner is disabled, but not severely, a wife's working in and of itself encourages him to assume home responsibilities (35, p 273).

In modern society, acceptance by one's peer group is a sign of maturity and independence, and the family cannot replace it in the life of the disabled individual. Therapists can make use of peer groups in treatment to help age-mates adjust to handicap limitations, but must do so wisely, recognizing occasions when a handicapped individual should not engage in activities solely with age peers. Many therapists are familiar with the apathy exhibited by members of elderly stroke groups. There are times when the elderly handicapped individual would profit from engaging in activities with younger persons, just as elderly preindustrial family members associated with the young. Younger stroke victims or nonhandicapped persons might serve as more stimulating group companions and not as reminders of the ravages of old age. In other words, therapists can avoid therapy that simply is one more way of categorizing and isolating individuals by age, to the detriment of the patient's welfare.

Loomis suggests assessing a patient's "first-order social roles" for rehabilitation (36). Motivation of the retired disabled patient for rehabilitation can be all the more difficult if he or she has outlived family or occupational first-order roles. For example, rehabilitation personnel can expect to see more older, disabled females without a spouse. Often new roles must be created for the elderly if they are to be sufficiently motivated. This is a difficult task for a therapist, for society itself has created many conditions impeding elderly rehabilitation. If any family or occupational roles remain, therapists must use them to their fullest. The stroke victim might wish to use a phone with adaptive equipment if he or she can speak with his or her grandchildren; or the elderly arthritic might wish to write letters if a splint or typing stick would facilitate it. Special efforts can be devoted to developing functional independence in avocational activities introduced to the older patient as privileges earned with age in a society that, ordinarily, does little to reward its elderly.

One's occupation is a paramount, first-order social role in modern society. Modernization has not created many new family roles; however, numerous new occupational roles and categories appear constantly. Thus, even the most loving family members cannot compensate for the lost occupational status experienced by the newly disabled breadwinner, male or female. It is unfair to ask a family to compensate for this loss, since modern society simply does not function this way. It is all the more necessary for the disabled person to retain or gain a new occupational identity separate from the family, and for the disabled child to proceed with his or her childhood occupational tasks as permitted by the disability. Herein lies the challenge to occupational therapists who are unique among health professionals in their emphasis upon adaptation to a changing environment (37). Facilitating adaptive responses is the key to placing many handicapped persons into the occupational mainstream, but as chronic disabilities become more sophisticated and severe, therapists must provide correspondingly more sophisticated adaptive equipment. This implies the need for more technological education for therapists who must design and construct this equipment.

Social change historically has produced new minority groups. The handicapped are perhaps modern society's newest and most unique political and numerical minority, but their handicaps and ecological disbursement decrease their abilities to organize politically. Nonetheless, occupational therapists and other rehabilitation professionals may find themselves on the vanguard of a social and technological
revolution signalled by the political mobilization of the chronically disabled. In view of this and of the fact that handicapped marriages run risks of dissolution, the therapist can point out to the physically disabled that modern society is characterized by a variety of lifestyles, including being handicapped. For the disabled individual not likely to marry, the advantages of single life can be stressed—many nonhandicapped persons prefer its freedom and independence. A disability may preclude one from participating in many activities, but it does not mean that one has no lifestyle. Handicapped people must develop a new lifestyle. Traditionally, they have been labeled (14, p 46) as handicapped because of their use of adaptive equipment, but use of adaptive equipment is not unique to the disabled in modern society; professionals from doctors to plumbers depend upon it for their livelihoods.

Furthermore, the boundary line between being handicapped and non-handicapped becomes less clear daily. Is the man with the less easily labeled artificial heart pacemaker less handicapped than the boy with a prosthetic right arm? One can easily envision a future society where more than half of its members function by using such equipment and in which handicapped peer groups flourish.

Koos and Fulcomer have described the adjustment of family roles following events such as a family member's disability, as follows: crisis—disorganization—recovery—and reorganization (38). Every social movement, including rehabilitation, involves the development and learning of new roles and the alteration of basic institutions, including the family. Medical technology has made it necessary for families of the handicapped to learn new roles, and therapists can facilitate this. An example is Malpass' orientation meetings developed to teach family members to play the roles of family of a handicapped person by exposing them to other families with similarly disabled members (39). Especially desirable at such sessions would be good male and female role models for newly disabled career men and women who now must assume some responsibility for household tasks.

Two family functions of special concern in a discussion of the relationship between the family and physical rehabilitation are the provision of 1. long-term physical care, and 2. long-term emotional support for the chronically disabled family members. These functions are fulfilled by a smaller family unit and place more of a burden upon the fewer people comprising it. Thus, teaching the handicapped to meet emotional needs of other members can be an important part of Koos

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Figure 2
Summary medical kinship analysis form

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Please indicate additional relatives by age and sex, where appropriate

Please indicate children by age and sex

List additional potentially helpful relatives and/or pertinent information:
The family must be allowed to produce as much as possible of its own medical care for the handicapped at the convenience of its members, rather than at the convenience of large medical establishments. Again, this often means that therapists must spend less time in direct patient contact and more time preparing easily understood home programs, and so on. Home rehabilitation monitored by telephone can minimize costly hospital visits for families capable of this approach. Home health care personnel can maintain home contact and inform the therapist when direct or phone contact with the family is necessary to help overcome what Jones and Jones term high risk factors associated with the home resettlement process (16, p.251). Administrators might be persuaded to credit therapists for such telephone time if it can be shown to decrease patients’ rehabilitation costs and increase rehabilitation success.

Therapists must give family members dealing with the handicapped an opportunity to teach themselves. Several months after rehabilitation has begun, a simple questionnaire requesting areas about which the therapist did not inform family members adequately or correctly might be given to family members to complete. Also, therapists must evaluate a patient’s family situation just as they evaluate muscle strength in a quadriplegic person or range-of-motion in an arthritic person. For ease of information and standardization of information, a medical kinship analysis form (developed by the author) or summary family tree resembling those developed by anthropologists to analyze cultural kinship structures (see Figure 2) might be completed by the therapist for his or her own use. This information might aid in the following matters:

1. The therapist can easily and graphically assess a client’s family situation (i.e., do things look good or relatively bleak for home rehabilitation?). Specifically, what first-order family roles remain to be used in therapy, and what roles are now precluded by the disability?

2. If the disabled individual has an intact, supportive family, all efforts can be made to keep it that way. Shepard and Barsotte describe a transitional health care program for adult patients and their families who spend one or several nights in an apartment near medical assistance. Giving toileting assistance to and repositioning the handicapped individual several times at night caused major family disruptions, and professionals aided family members in performing these functions before the family returned home, to forestall home crises (40).

3. If the patient’s home situation is relatively bleak, the therapist can begin arranging for appropriate substitutes for home health care early in treatment, rather than waiting until the patient is ready to return home to an undesirable situation.

4. The therapist can identify those nuclear and, if possible, extended family members who would be good home therapists so that they can be instructed in home care early in treatment. Therapists also can attempt to distribute responsibility for care of the handicapped among as many family members as possible (especially to ease the burden that generally falls upon the wife/mother).

5. Therapists can ascertain whether any nuclear or extended family members not living in the home live close enough to help out occasionally. If so, it would be worthwhile to involve them in patient care and provide home programs for them—their help can make for much greater rehabilitation success.

6. Perhaps most important, the therapist can pinpoint those family interaction patterns most likely to be strained by an individual’s disability. For example, a male quadriplegic and his wife most likely will require sexual counseling from a qualified person. A teenage daughter may be asked to help in home care, but with the realization that she soon will leave home and may resent being asked to assume too much responsibility for her father’s care. The astute therapist may learn whether or not any family members are working against rehabilitation and, if so, why this is the case.

7. Finally, Litman lists several areas of family rehabilitation requiring further sociological research (7, pp.511-512). Data arising from consistent use of such a form can be of considerable value to researchers investigating the relationship between the modern family and rehabilitation of the handicapped.

Conclusion

The social stigma experienced by the disabled often stems from physical disabilities (14, p.46). The entire family of a disabled individual also can be stigmatized by society because
of their “sociological disabilities” based upon results of both rehabilitation research and sociobiological analysis. It is here argued by the author that many of these family limitations stem from innate structural and functional characteristics of the modern family, not from shortcomings of particular families or of particular family members (13, p 180).

Modern medical technology has extended the lives of victims of formerly fatal conditions; however, when chronic disabilities remain, the disabled often return to families that, by their very nature, are ill-equipped to care for them properly: ... the common medical assumption of universal family understanding and preparation for home care would seem to be in need of considerable reassessment: ... (7, p 507).

Many of the therapeutic suggestions discussed above are likely already part of many occupational therapists’ treatment repertoires. However, tremendous knowledge gaps can exist between personnel of highly specialized medical institutions and nonprofessional family members of the disabled because of the innate structural and functional limitations of the modern family, whether or not its members are supportive of the disabled family member. How well particular families with a handicapped family member cope may depend upon the help of therapists who realize this.

REFERENCES

27. LeMasters EE: Parents in Modern America, Homewood, IL: The Dorsey Press, 1974