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Helping Couples with Neurological Disabilities: A Job Description for Clinical Sociologists

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ABSTRACT

This essay applies insights from data gathered in a previous study on divorce and disability to suggest contributions clinical sociologists can make to ease the human condition. Intensive interviews were taken of couples one of each of whom was afflicted with multiple sclerosis, a demyelinating neurological disorder. Given the elevated divorce rate among MS couples, the previous study specified some conditions under which the chances of divorce could be reduced. Clinical sociologists can serve in six basic functions, perhaps more distinct in theory than in practice: 1) teacher; 2) forecaster; 3) metaphysician; 4) sociotherapist; 5) facilitator of interaction; and 6) reformer.

This paper is a foray into clinical sociology, in the belief that a humanistic sociology does not just study people—it helps them. The ultimate justification for our knowledge is its practical utility in improving the human condition. This paper is a partner piece to a study reported earlier (Ventimiglia, 1983). Whereas the purpose of the first was to gather data to achieve understanding, the purpose of this one is to apply insights emerging from those data in order to advise and intervene. Going from research to practice, this paper makes recommendations to clinical sociologists as to how they might help couples, one partner of whom is afflicted with MS, a degenerative neurological disorder.

This article was adapted from a paper presented in the Clinical Sociology session of the Annual Meeting of the Mid-South Sociological Association, Little Rock, Arkansas, October 25, 1985. Correspondence to: Joseph Ventimiglia, Department of Sociology and Social Work, Memphis State University, Memphis, TN 38152.

MS—THE CRIPPLER OF YOUNG ADULTS

Multiple sclerosis is the most common demyelinating disease of the central nervous system, afflicting an estimated half-million persons in the United States. It most often strikes young adults between the ages of 20 and 40 and women two to three times more often than men (Weaver, 1974). It causes long-term incapacity and shortens life expectancy by about 15%. Neither contagious nor curable, the disease attacks the myelin sheath around the message-carrying nerve fibers in the brain and spinal cord. Where myelin has been destroyed, plaques of hardened tissue (*sclerosis*) appear in multiple places.

Symptoms vary according to the part of the nervous system affected. They include weakness, tingling, numbness, impaired sensation, lack of coordination, disturbances in equilibrium, double vision, involuntary eye movements, blindness, slurred speech, alterations in mood, tremor, stiffness or spasticity, clonus, weakness of limbs, and loss of bowel and bladder function (Wasserman, 1978). Significantly, impotence eventually affects more than half of the men (Masters et al., 1985), and anorgasmia, nearly as many women.

Though like many other chronic conditions, MS lends itself peculiarly well to a study of stress. It shortens lives, but unlike cancer is not terminal. Patients eventually die of complications, typically arising from pneumonia. It handicaps the sufferer, but the handicap does not stabilize or localize as it does for an amputee. Even a mastectomy is spatially localized and temporally stabilized. MS is progressive, but the course is not precipitous and linear like that of alateral sclerosis. The sexual function is disturbed but probably more intermittently and less extensively than for the spinal cord-injured patient. Like alcoholism, it disrupts family life, but MS lacks the same prospect for recovery.

What is most distinctive of MS is its variability—with respect to site, severity, and progression. Variability makes for uncertainty, which is inherently stressful. One patient may be blind, another lame. Some may sink fast, others hold their own for years. Any given patient may be ambulatory one day, bedridden the next. Other chronic conditions like rheumatoid arthritis show fluctuation, but "none approaches the vagaries of the natural history of MS that never cease to surprise the neurologist" even after a lifetime of practice (Matthews, 1978:25). The protean nature of MS retards coming to terms with it—much like shooting at a moving target. For many, however, the course involves a series of acute exacerbations, partial or complete remissions, slow progression and periods of stability. As a rule of thumb, one relapse is expected every 2 or 3 years for the first 10 years and one for every 5 years thereafter (Brown, 1977).

This uncertainty creates role confusion between the sick role¹ and the spousal role for the ill spouse and between the caretaker role and the spousal role for the well spouse. In the asynchrony characteristic of MS, a wife may resign

herself to the sick role before the husband has accepted the role of caretaker, or else the wife may enact the role of caretaker while the patient still aspires to perform the role of husband. The role partnership is thus off balance.

Among the respondents interviewed, sexual activity was almost invariably curtailed, above and beyond the decline usually expected over the duration of marriage. Although performance of the sexual role was compromised in the couple with MS, one must take care not to overstate impairment of sexual function with multiple sclerosis. First, intercourse is not so difficult for the female patients as it is for the male patients. The challenge of erection seems more formidable for the inserter than lubrication seems for the insertee (Singh and Magner, 1977). Second, while most male patients become impotent, some are spared. Third, even the spinal cord-injured (Knight, 1986) can have erections by reflex, "phantom orgasms," and sexual response through stimulation of some nongenital erogenous zone, such as ears, neck, or nipples. Society arbitrarily overemphasizes intercourse as the proper form of sexual expression between partners. Alternatives to intercourse (Masters et al., 1985) include fellatio, cunnilingus, kissing, massage, cuddling, and the use of a vibrator. Renegotiating alternative forms of sexual expression makes for a sex life which is an improvement on abstinence. Society also prejudicially regards the disabled as asexual, whereas both the spinal cord-injured and those with MS still have the desire to perform, however limited their ability to do so. Zola (1982) calls attention to this insensitivity of society. He participant-observed for a week in a community of disabled people in the Netherlands and poignantly chronicled living with a disability. He believes that the able-bodied make for invalids by invalidating the humanity of the disabled. Denied are not only their personal potentials and their expressions of anger but also their very sexuality.

THE PRIOR STUDY

The data base for the prior study comes from a wide range of experiences, primarily research, secondarily counseling. The principal investigator has known a large network of patients as acquaintances over the past 10 years, has participated in three local chapters of the National Multiple Sclerosis Society, has sat on the executive board of a local chapter, has interviewed three chapter directors, has consulted three physicians, and has observed two self-help groups of patients, in addition to doing research. This research culminated in some 16 intensive interviews of respondents from couples one of each of whom had MS. The interviews ranged from 3 to 7 hours in length and elicited detailed life histories, amounting to clinical case studies. Respondents varied by gender, marital status (currently married or not so), and health (well vs. ill). They were recruited in two states by a process of judgment and snowball sampling, and over 85% of those approached agreed to an interview.

The point of departure of the prior study was the impact of disability on divorce. Divorce rates among MS couples are two to three times those in the general population (Weaver, 1974). It appears that the bias among many marriage and family counselors is to save the marriage, but not at any cost. If the marriage fails, intervention can turn to divorce counseling. Divorce was seen in the study as a bane for the ill spouse, if not necessarily a boon for the well spouse. The ill spouse seldom if ever initiated the divorce proceeding; the disabled spouse would have to be very altruistic, indeed, voluntarily to free the well spouse. Practically speaking, the well spouse is the rejector and ill spouse the rejectee. Therefore, the bias toward marital stability here assumes that the ill spouse has more to lose than the well spouse has to gain.

Yet divorce could be a last resort in some circumstances. One of the respondents provided the analogy of an overcrowded lifeboat. Cruel as it seems, one partner had to be put over the side, or else both would perish as if by drowning. The spouse filing for divorce thus makes a "Sophie's choice" which cuts losses but instills a guilt potentially handicapping in its own right. Divorce becomes a matter of survival, not the pursuit of happiness.

The prior study identified some of the unifying and alienating forces in MS couples. By way of summary, the study hypothesized that a relationship might be preserved or prolonged under the following conditions:

1. If the case of MS is light in severity and does not progress much.
2. If the couple enjoys whatever other insulating factors normally protect against divorce, such as an abundance of economic resources.
3. If the marital contract is satisfactorily renegotiated or the relationship re-defined.
4. If the spousal roles that maintain intimacy and that cannot be easily reallocated, i.e., sex and therapy, are performed satisfactorily.
5. Failing this, as a temporary solution, if tolerable substitutions are made, e.g., oral sex for intercourse, third parties as confidants.
6. When the well spouse is the provider and the provider values work over family, if the ill spouse makes a critical contribution to the livelihood of the well spouse or at least does not interfere with it.
7. If some sense is made of the tragedy.
8. If an external rather than an internal attribution is made of the incidence of the illness as well as of the patient's emotional reaction.
9. If the self-esteem of the ill spouse is relatively high and that of the well spouse is relatively low.
10. If the personality of the well spouse is prone to nurturance (or an agapic love style [Lee, 1975] or playing the martyr in marital transactions) and/or the personality of the ill spouse is prone to succorance (or a manic love style or playing the victim in marital transactions).

11. If a clinical sociologist or other helping professional intervenes to support the relationships involved.

In general, the findings set aside the commonsense idea that the marriage vows (“in sickness and in health”) are binding. To the extent they are taken seriously, inconsistent actions presumably generate uncomfortable cognitive dissonance (Festinger, 1957) which people strive to avoid. Although many people nowadays probably regard these words as pro forma ritual, by no means does everyone take them lightly. Consider, for example, the protest from feminists who demand replacing “to obey” with “to cherish” and who deplore the reference to women as the “weaker vessel.” The data also set aside the symbolic interactionist implication that the sentiment of love cannot be reduced to the principles of exchange (Shibutani, 1961). However altruistic, love cannot indefinitely flout the Law of Distributive Justice (Homans, 1961). Certain crucial roles, even in a primary relationship, must be performed.

This research utilized a typology of marital roles adapted from Nye et al. (1976). Economic provision (1) and homemaking (2) are the traditional roles. Sexual (3) and therapeutic (4) roles maintain physical and psychic intimacy, respectively. The therapy role in marriage should not be confused with psychotherapy. Nye describes therapy as untrained counseling, stroking, building up the ego, and reassuring the worried spouse. Parenting (5) may be divided into (a) bearing, (b) caring for, and (c) rearing children. Finally, a rather amorphous recreation/companionship role (6) is emerging.

MS critically interferes with the sexual and therapeutic functions. Other functions, like economic provision or housekeeping, can be allocated to a surrogate structure like the state, or hired out to a domestic, but to open a relationship sexually, or even therapeutically, is to import a Trojan horse. Sex and therapy are virtually nonreallocatable. Oftentimes, the physical sequelae of the disease interfere with the performance of the sexual function, and the emotional sequelae with the therapeutic function.

An Illustrative Insight

If a partner joined his or her spouse in achieving a *superordinate goal* (Sherif and Sherif, 1969), the marriage could be prolonged. Such a goal is essential for survival and requires the coaction of husband and wife. Three cases serve as examples.

Anna M, a victim of MS, is a songwriter cohabiting with her bandleader-lover. She will not marry for fear of losing benefits like SSI, food stamps, and Medicaid. Their relationship began as a working relationship. Reputed to have a genius IQ, she contributes a keen business sense and ideas for songs to their enterprise. “He wants so much for me to be a part of it,” she mused. Their

relationship has so far survived her incontinence, but she acknowledges the possibility of separation given a substantial worsening of her condition.

Robert K is a drywaller who owns his own small business. His disabled wife helps him with bookkeeping and answering phones. An essential part of running the business is bidding for jobs—a task which he finds difficult, but which his wife does quite efficiently. Without her, he says, he cannot manage the business. He dotes on his wife but misses their sex life which has declined by 70%. Having consciously chosen family over career, he passed up a lucrative job opportunity which would have interfered with family life.

Reverend R, now a widower, institutionalized his wife for four years in a nursing home. He spent between \$75,000 and \$100,000 and still owes \$25,000. He called her “baby,” she called him “Reverend.” He said he had rather commit suicide than divorce his wife, but

It wounded all of us. My son's [age 25] academics were disrupted. The youngest [a 15-year-old girl in psychiatric care] lives in a world of her own. It damaged me sexually. I begged the doctor to give me something to eliminate the desire.

He refused to divorce his ill wife, but preserving the marriage nearly ruined the family psychologically and financially. He saw his mission as that of a moral example for his congregation, and the disgrace of divorce would have made his professional identity untenable.

THE CONTRIBUTION OF A CLINICAL SOCIOLOGIST

The clinical sociologist can function in a variety of ways to help the couple distressed by MS. 1) Teacher. Clinical sociologists can disseminate information from the corpus of sociological theory; for example, clients can have concepts like role, function, resources, exchange, social contract, etc., explained to them. Clinical sociologists can also act as clearing houses, relaying the typical experiences of respondents surveyed to other patients and their families. 2) Forecaster. Especially those recently diagnosed need an orientation to what lies ahead. Physicians do not deal with changes in man-woman, husband-wife, and parent-child relations. To the extent that these changes are threatening, clinical sociologists can sound the alarm—“forwarned is forarmed.” 3) Metaphysician. In particular, clinical sociologists can influence clients' worldviews. They can persuade clients to reinterpret reality, to redefine the situation, and to reattribute causes (Shaver, 1975). They can substitute more adaptive beliefs about God, life, justice, the individual, the system, etc. 4) Sociotherapist. Clinical sociologists can help patients and partners adjust to the social forces with which they must cope, to accept what they cannot control, by acting as agents of resocial-

ization. Attitudes could be modified, now lowering levels of aspiration, now clarifying values. Care can be shown, giving comfort to the patient and conciliation to the partner. 5) Facilitator of interaction. Clinical sociologists can facilitate: (a) dialogue, as discussion leaders in groups of patients or caretakers; (b) decisions, by delineating alternative choices, e.g., among coping methods, marital statuses, and so on; and (c) agreements, as mediators in renegotiation of the marriage contract. 6) Reformer. Strictly speaking, clinical sociologists are not advocates or activists (Glassner & Freedman, 1979). Yet it seems only fair, having emphasized adjusting the couple to fit the situation, to raise the possibility of changing the situation to fit the couple. The prior study on divorce and disability suggested innovations in divorce law and in forms of marriage, but these changes may not be feasible for many reasons. These six contributions are variously illustrated below.

Clinical Sociologist as Teacher

The clinical sociologist can detail the strategies, resources, and facilities available for coping. Patients can be referred to compassionate physicians accustomed to dealing with chronic conditions. They may be urged to follow the guidance of nutritionists to conserve what health remains. Physical therapists are helpful in preventing muscle atrophy, and occupational rehabilitation may forestall retirement.

The earlier study reported specific coping devices of patients. The clinical sociologist can relay such information. One woman used yoga to relax and find inner peace. Others used humor as an antidote to depression. Several became more religious; faced with a problem too big for them to solve, they found value in surrender. Some engaged in values clarification, trying to separate the wheat from the chaff. They determined that what was left was more important than what was lost. The best adapted appeared to treat their disease as a *learning experience*. They tried to find meaning in an essentially meaningless disease, to see order in chaos.

Useful concepts from sociology can be explained to clients. A working knowledge of roles, functions, norms, resources, exchange, and contracts implicitly recognizes the clients' rights to think for themselves. At the same time an educated client should be easier for clinical sociologists to work with in their roles of facilitator and sociotherapist. The information-dissemination functions of forecaster and metaphysician are basically spinoffs from the teacher role.

Clinical Sociologist as Forecaster

The clinical sociologist can warn the couple of role changes likely to take place and of the differential impact of the illness depending on which spouse is ill.

In general, the ill spouse suffers a loss of roles, and the well spouse suffers role overload. If the worker becomes ill, government or insurance benefits may help compensate for the financial loss, but the well spouse may have to look for work. If the homemaker becomes ill, the tasks of housecleaning and food preparation have to be assumed by the well spouse, delegated to the children, or farmed out. Childbearing is often contraindicated for prospective mothers with MS. As for the care of small children, the well father participates even more than before the onset of the illness, and the well mother spreads her childcare attentions thinner. Since rearing tends to be relatively shared by parents, the ill spouse's share tends to be transferred to the well spouse or perhaps neglected.

The recreational role is severely limited when MS strikes, though perhaps more so when the husband is ill, as it is often necessary for the well spouse physically to support or carry the ill spouse. Some recreation is simply foregone, with an accompanying loss of quality of life. The alternative is to seek companionship in recreation elsewhere; this requires no adjustment for already sexually separatist couples,² but for others it opens the relationship psychically and threatens marital stability further.

MS also seriously impairs intimacy in marriage. If the wife is ill, her responsiveness in lovemaking is reduced. If the husband is ill, his performance is impaired. One goes outside a closed system for intimacy at grave risk to the relationship which may continue but be irrevocably altered. The sexual role is *nonreallocatable*. The other intimacy-maintaining function on which marital satisfaction depends is therapy (Nye et al., 1976). In traditional relationships, the impairment is not so great when the husband is ill as when the wife is ill, for then it is wives who bear the burden of emotional support, while the task of economic provision falls to the husband. Even among today's dual-earner families, husbands earn the major portion of the family income. All functions are taxed in an MS couple, but perhaps the therapeutic function most.

Clinical Sociologist as Metaphysician

Like theoreticians, laypersons seek to determine causality. In everyday interpersonal relations, this translates as blaming individuals for events. The clinical sociologist can guide causal attributions away from such fallacious reasoning. For example, MS patients are often irritable; irritability causes them to find fault with those around them. Instead, it may be realized that complaints may reveal more about the person complaining than the person complained about. A second cognitive error is to hold oneself responsible for the disease—for not properly exercising, sleeping, eating, in short, not living right. Middle-class individuals who feel that they are the captains of their fates are prone to such self-blame. They are like the mother of the Sudden Infant Death Syndrome casualty who asks, "What did I do wrong?" If there is something a person can do to prevent

MS, it is not known. A low-fat diet, for example, only helps one live with the disease, not prevent it.

Another fallacy to which patients are prone is anger with God for the cross they must now bear. They are as perplexed as Job in the Bible who wrestles with theodicy. As Rabbi Kushner (1981) writes in *When Bad Things Happen to Good People*, the problem lies in their conception of God. If God is all powerful, He cannot be all good; and if He is supremely good, there are limitations on His power. The secular version of this fallacy is known to psychologists as the “just world phenomenon” (Lerner, 1980), whereby people believe that the good are rewarded and the evil are punished for their actions, impressive evidence to the contrary notwithstanding. Rational-emotive therapy (Ellis, 1973) calls it an “irrational belief” to think that justice inheres in the world. An alternative view is that justice be carefully nurtured and vigilantly protected by moral agents with social power.

To remedy such cognitive errors, the clinical sociologist can encourage external attributions. Where problems seem unsolvable, external attributions are adaptive. Families in crisis are more disorganized by unemployment, for example, if the cause is internal, e.g., excessive drinking, than if the cause is external, e.g., economic depression. The blame for MS should be directed at no person at all, not self, not spouse, not physician, but in the words of attribution theory (Shaver, 1975), at the “environment”—dumb luck, blind chance, mad randomness. A religious conviction may be a helpful coping device just because it permits an external attribution (“It’s God’s will” and “Ours not to reason why”) for a problem people find overwhelming. It seems the mission of religion to suggest answers precisely where science cannot ascertain them. Subjects in the prior study who surrendered seemed better adjusted, with the exception of fundamentalists who clung to the belief that a wrathful diety visited vengeance upon them for their sins or the sins of their forebears.

The unique view of sociology, the “sociological imagination” (Mills, 1961), allows for a system to have effects unintended by its participants—emergent effects—as illustrated by Mills’ conceptual leap from personal troubles to social problems. Thus, patients and their families can be made to understand, among other things, that they have companions in their misery—they are not alone; that they are subject to laws of individual psychology and interpersonal dynamics that make their experience more or less predictable; and that they are free only within legal and cultural constraints, like laws that disallow MS as grounds for divorce and family forms that restrict sexual and psychic intimacy to the monogamous relationship.

Clinical Sociologist as Sociotherapist

Sociotherapists often try to resocialize patients and families into new perspectives, to make the best of a bad situation. If one’s circumstances cannot be

changed, perhaps one's attitude can be adjusted. First, the clinical sociologist can focus on the patient's time perspective. In the pit of despair, the patient can be reassured that the mood will pass; almost anything can be endured briefly. Confronted with an apparently hopeless future, the patient's time perspective may be truncated—life can be lived "one day at a time." Second, although attributions of cause should be external, the patient may be encouraged to turn inward (a difficult task for the anti-intrceptive personality type). Yoga, religion, psychotherapy, and rapping about feelings help in this regard. Third, the patient can do exercises in values clarification, to help distinguish the important and the trivial. As an ill breadwinner's central life interests shift from career to family, for example, the shift may be legitimized. Fourth, most important, in the process of contract renegotiation, the patient's level of aspiration can be lowered. As with the dieter who must now survive on 1500 calories a day, the quality of life may be reduced if the quantity of life is to be conserved. There is no guarantee that the patient and family will accept the lower quality of life, i.e., that the quality will not fall below minimum standards. Indeed, some patients may prefer euthanasia. Finally, clinical sociologists can teach clients the self-teaching perspective. Life can be construed as a process of intellectual quest and growth. Patients do best who ask themselves, "What can I learn from this experience?" and "How has MS made me a better person?" As patients seek wisdom, they grow in depth of character and administer therapy to themselves.

Emotional Sequelae. The sociotherapist can serve an emotionally supportive "defense" function (Mechanic, 1978) as patients show stress from a variety of typical emotional reactions. No one knows to what degree these reactions are the result of (a) the physiology of the disease, (b) the neurological loss, (c) psychological stress, or (d) situational accommodation. Clearly, the clinical sociologist can intervene more effectively if the causes are social or psychological than if they are physiological or neurological. Whatever the cause, the clinical sociologist can do yeoman's service by sounding the alarm.

One of the emotional sequelae of MS is *denial*, inadvertently conspired in by physicians reluctant to make and announce the diagnosis. Typically, respondents saw more than one doctor over a period of several months before the diagnosis was made. Physicians' admitted reluctance is justified on the grounds (a) that there is no positive test for MS, (b) that the case could be benign, or (c) that the announcement could be traumatic, like handing down a death sentence. Not wishing to be the bearers of bad news and admit to a condition beyond the power of modern medicine, they often procrastinate, waffle, or refer to other specialists. Specialists not schooled in holistic medicine or practiced in bedside manner give the patient short shrift, fail to tease out the social psychological ramifications of the illness, and promote defining the problem as the physical condition of the victim rather than the psychosocial stress on the marriage or

family group. Denial works for those lightly affected and for a brief period, but the disease eventually demands that the inevitable be faced.

A second reaction is intermittent bouts of *euphoria* shored up by occasional remissions and in particular by false hope of imminent miracle cures. With optimism and in desperation, patients travel to Florida, Mexico, and Germany for snake venom, hyperbaric oxygen, and sea kelp. Every huckster with snake oil is bound to get an audience from patients and well-meaning spouses who, in their futile search, may drain the family of time, energy, and money. On the other hand, a case could be made for the placebo effect (Frank, 1961) of some treatment or therapy if the cost is not prohibitive. The alternative of sitting idly by and wasting away in abject resignation is no better than tilting at windmills. Patients steer a delicate course between accepting and succumbing to their limitations.

A third emotional reaction is *bitterness*. In a world believed to be just, victims ask, "Why me, Lord?" They curse their fate. The afflicted sometimes feel that they are being punished by a wrathful deity for some sin or otherwise hold themselves personally responsible for precipitating their condition. Bitterness takes the form of anger with God or "catastrophizing" about injustice (Ellis, 1973).

A fourth reaction is *self-pity*. By rights, the afflicted have legitimate complaints which make self-pity understandable, but protracted self-pity can displace adaptive responses. It can contribute to the fifth sequela—*egocentrism*. Patients become autistically preoccupied with self, *their* fatigue, *their* temperature sensitivities, *their* pain, striking the observer very much like children in Piaget's experiment who cannot take the role of the other. Egocentrism is pernicious, not so much because of the attention paid oneself, as because of the attention diverted from one's spouse and children. It may contribute to the sixth reaction, a kind of *demandingness*. Just when patients are contributing the least, they often act as if the lives of others must revolve around them. These reactions go hand in glove with an oft-reported irritability which taxes the tolerance of family members.

Another emotional sequela is heightened *sensitivity* to social *stress*. In adjusting to life, molehills become mountains; routine irritants—the job, the budget, the kids, the in-laws—threaten to potentiate symptom severity. This has unfortunate results—the well spouse adopts a pretense or walks on eggshells so as not to upset the patient and evades conflict or normalizes everyday problems that should be confronted. The spouse shelves them for an appropriate time which never seems to come. To spare the health of the patient, then, the relationship suffers from dishonesty and neglect.

The patient's self-esteem plummets from an *erosion of body image*. Muscles atrophy from disuse, grooming suffers from the inability to use one's hands, bellies protrude from sagging posture and lack of exercise, and even symptomatic

treatment with steroids produces a side effect, the appearance of a moon-face. These do not enhance one's aesthetic appeal, and one begins to connive in one's own "denial of sexuality" (Zola, 1982).

Finally, patients have trouble striking the right balance between *independence and dependence*. They may fall and hurt themselves when they should have reached out; they may insist on being babied when they should care for themselves. All this creates ambiguity in the minds of well-intentioned partners who fear helping too much or too little and are not sure whether to play the role of spouse or the role of caretaker.

Clinical Sociologist as Facilitator

To keep the marriage intact, a pivotal concept of which to persuade the couple is that of marriage as a social contract, which should be arrived at by bargaining. Couples resist this argument because of a popular bias toward the notion of romantic love. Contracts sound bloodless, clinical, legalistic, and impersonal compared to the mystique and heady limerance (Tennov, 1979) of romance. Even classic symbolic interactionists have assumed that the principles of exchange do not apply to a love relationship; to suggest that love can be exchanged like money seems to reduce marriage to prostitution!

Yet Walster et al. (1978) cite some evidence to demonstrate the operation of equity (exchange) processes even in romantic and marital relationships. Foa and Foa (1974) also show that exchange applies to primary as well as secondary relationships but that the commodities actually traded—love, services, status, goods, information, and money—differ. Reconciling love relationships with principles of exchange only requires minor adjustments in exchange theory, such as (a) a loved spouse is allowed to incur a larger debt and to take a longer time to repay; (b) commodities like goods and money are zero-sum phenomena whereas exchanging love or status tends to multiply love or status; and (c) love may be treated variously as a cost, a benefit, or an investment. In the last analysis, even relationships between altruistic lovers are utilitarian at their core. Already "utilitarian" couples (Cuber and Haroff, 1965) may resist the contract perspective the least, but relatively "intrinsic" couples may weather the crisis of the disease longer before resorting to renegotiation.

If every relationship is ultimately utilitarian, the idea of a marriage contract³ not only helps make sense of breakups but also may point the way toward preventing them. The contract can be consciously renegotiated so that the ill spouse accepts more without feeling guilty, and the well spouse gives more without feeling angry. Realistically, the level of aspiration would be lowered, for that data showed no evidence for overall improvement of a relationship from the disease, i.e., for reorganization of the system at a higher level of functioning.

In practice, the clinical sociologist can lead discussions between marital

partners concerning the fate of the role functions previously discussed (provision, homemaking, lovemaking, therapy, recreation, and bearing, caring for, and rearing children). A decision may be reached whether the well spouse shall assume a given function, whether the ill spouse shall surrender it, whether the couple shall delegate it to another member of the family, whether it shall be reallocated to a surrogate, or whether it shall be simply malperformed or foregone.

Whereas the ill spouse is the target of medical intervention, now the well spouse becomes the focus of the contract negotiation, for his or her minimum standard must be met to prevent defection. For the mediator interested in preserving the marriage, the challenge becomes how to convince the well spouse to stay. The greater the relative resources of the well spouse to those of the ill spouse, in toto, the greater the temptation to defect, and, given sex differences in our society, for the male, the gap becomes a bigger and bigger incentive as the couple passes through the life cycle. In the marriage market, well spouses may have high "comparison levels for alternatives" (Thibaut and Kelley, 1959), no matter how their "comparison levels" (levels of aspiration) are manipulated. Low self-esteem can, however, mute the well spouse's comparison level for alternatives by causing an underestimation of marketability. For preservation of the marriage, the best combination is low self-esteem in the well spouse and high self-esteem in the ill spouse; the well member is more likely to be able to accept requests for aid and the ill member to lodge reasonable requests without apology. The worst combination is an ill spouse with low self-esteem and a well spouse with high self-esteem. The latter will be tempted to defect, and the former will lack the robust ego needed to cope.

Counseling may be available in self-help therapy groups either of patients or of significant others (caretakers). Integrating the two groups tends to inhibit freedom of speech. Family therapy is more appropriate than individual therapy in the case of MS; many a well spouse, for example, said, "We have the disease." Clinical sociologists can not only do marriage counseling but also facilitate "support groups" of patients or of caretakers. In their ministrations, clinical sociologists are theoretically eclectic but appreciate the importance of social location, sociotypes, social facts, and the sociological imagination (Mills, 1961). The construct of sex role,⁴ for example, fine-tunes an understanding of the impact of MS, an experience which interacts with gender. Clinical sociologists are catholic in their methods but favor the use of group processes, sociodrama, and grounded encounter therapy (Swan, 1984).

Clinical Sociologist as Reformer

Strictly speaking, clinical sociologists are not advocates or activists (Glassner & Freedman, 1979). Yet it seems only fair, having emphasized adjusting the

couple to fit the situation, to raise the possibility of changing the situation to fit the couple. The prior study suggested some social changes which could alleviate the stress of the MS couple. Two such proposals are including MS as actionable grounds for divorce and extending the conjugal couple to include at least one or two other members, for example, well husband/ill wife plus ill husband/well wife. MS seems at least as debilitating as alcoholism or mental illness, which constitute grounds for divorce in many states. Allowing MS as grounds for divorce may spare the well spouse but sacrifice the marriage. Apparently, what is helpful at one structural level may be harmful at another.

Extending the family in the direction of group marriage would likewise ease some burdens but not others. The conjugal family with its delicate equilibrium of one husband and one wife hardly has personnel to spare. If one participant fails, the system tends to grind to a halt. Nestling the troubled couple in a communal living arrangement, whether a multilateral marriage, a family cluster, a cooperative, or just a communal neighborhood, provides built-in helpers for the allocation of otherwise malperformed functions. In a group marriage even the sensitive functions of sex and therapy could be shared. They are nonreal-locatable only under the closed system of monogamy whose norms these days may be honored more in the breach than in the observance. Yet group marriage requires that the participants openly violate monogamous norms, that they adopt a collectivistic attitude uncommon in our culture, and that they have the organizational acumen to manage jealousies and hostilities. Such instabilities are liable to arise in groups larger than and not divisible by two.

SUMMARY AND CONCLUSION

Based on a prior interview study of couples one of each of whom was afflicted with multiple sclerosis, a degenerative neurological disorder, this paper has sought to apply research to practice in the belief that a humanistic sociology does not just study people but helps them. Clinical sociologists can help such couples as teachers, forecasters, metaphysicians, sociotherapists, facilitators, and reformers. These roles outline a job description for the clinical sociologist in the case at hand.

NOTES

1. For a quarter of a century, medical sociology has concerned itself with the ideal type of "sick role" introduced by Parsons (1951). Its norms call for the sick person to be excused from normal duties, not to be blamed for the sick condition, to desire to get well, and to seek competent help to do so. Yet the concept of the "sick role" seems inappropriate to multiple sclerosis, an apparent exception to this ideal type in almost every respect. A critic, Freidson (1962), for example, notes that handicaps may not involve the attention of the physician, the motivation to recover, or the exemption from normal activities. No help is competent enough to cure the incurable, but Parsons

was never farther from the mark than when he suggested the norm of exemption from normal responsibilities. As therapists with the severely handicapped (Kir-Stimon, 1977) advise, it is a fallacy for the patient to believe that he or she will be absolved of responsibility because of illness or for the therapist to believe that the patient should be paternalistically treated as a "sick person." MS is a chronic, not an acute, condition. In all fairness to Parsons, however, he has recognized (1975) that recovery may be impossible, whereupon the goal becomes to minimize incapacitation.

2. Sexual separatism may benefit working-class couples with MS. Research (Komarovsky, 1967) suggests a blue-collar pattern in which husband and wife move in different social circles. Compared to middle-class couples, they spend more time with same-sex friends and kin. The ill wife in one of the better adjusted couples in the prior study, for example, had excellent rapport with her blue-collar husband, primarily by sparing him details of her MS. Instead, she leaned heavily on a support system of mother and grandmother who lived nearby.

3. A preoccupation with social exchange, i.e., with counting how much you are giving and how much you are getting, may be symptomatic of a decaying relationship (Brehm, 1985). "Keeping score" bespeaks a basic lack of trust. If this is true, then contract renegotiations may only forestall rather than prevent marital dissolution. Renegotiation is also precarious because it entails so-called "serial polygamy to the same person" (Jourard, 1976). The robust individual married years earlier may bear little resemblance to the hapless spouse transformed by MS. Renegotiation, therefore, resembles matchmaking.

4. The impression prevailed among the directors interviewed that the well wife is more likely to remain in the marriage when the husband is ill than the well husband when the wife is ill. Assumptions that women are more loving or devoted may be exaggerated. When the husband is ill, the wife simply extends her caretaker role to cover her spouse. The well husband may have to delegate caretaking to extended kin, eldest daughter, visiting nurse, etc. As a matter of fact, there is *less net change in the system* when the husband is ill than when the wife is ill. If the wife is ill, change is required in four of the six roles: therapy, sex, parenting (particularly bearing and care), and home-making. If the husband is ill, change is required in but three: therapy, sex, and economic provision. Moreover, if, as in traditional marriages, women report less interest in sex and do more therapy than their husbands, then disturbance in the nonreallocatable functions of sex and therapy has a more deleterious effect when the wife is ill.

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