Managing Chronic Illness at Home: Three Lines of Work

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ABSTRACT: Problems of managing chronic illness at home are addressed in terms of the concept of "work:" what types and subtypes of work, entailing what tasks, who does them, how, where, the consequences, the problems involved. Three types of work and consequences of their interplay are discussed: illness work, everyday life work, and biographical work. Theoretical concerns of the sociology of work are addressed as well as the substantive issues of managing chronic illness.

This paper addresses some of the problems of managing chronic illness at home. It does that in terms of the concept of "work." Examination of work means a close inspection of its many facets: what tasks, who does them, how, where, the consequences, the problems involved. We shall focus on three types of work and on the consequences of their interplay. They are (1) illness work, (2) everyday life work, and (3) biographical work. These types of work were the salient ones in our data, as described below, while others that appeared are subsumable under one or another of them. We think of this paper as contributing both to the substantive area of the sociology of health/illness and as addressed to the theoretical concerns of the sociology of work.

As is now generally recognized, the chronic illnesses have supplanted infectious and parasitic diseases as the prevalent disorders in the more developed nations. At the same time, technological advances in their diagnosis and treatment have made the work of managing chronic conditions increasingly specialized and complex. So, when the ill are sent home from the hospital after acute phases, they are often accompanied by much technology—procedures, drugs, machinery—and some direction in how to utilize this technology (Fischer, 1982). But management of an illness in the home is not accomplished without difficulty and a great deal of effort, unless the

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regimens are relatively simple and do not greatly interfere with the normal flow of life.

Our paper begins with a look at what is involved in the work of managing illness and daily life, touching only secondarily on their relationships with biographical work. From there it will move into an examination of the structural context within which management takes place. Then it will look at the phenomenon of relative equilibrium which the actors seek to maintain given the demands of the three lines of work. Next, it will explore why that intent is so difficult to carry out. Finally, it will explore strategies most likely to produce desired outcomes.

The data for this paper come from a study of the work done by *the chronically ill and their spouses* in managing both the illnesses and their lives. Unless the ill live alone, it is the spouses who share the burden of the work of managing the illness. Our data consist of intensive two- or three-hour interviews with 60 couples, interviewed mostly at home but with some interviews done at a VA hospital in the San Francisco Bay area. The interviewees suffered from a wide range of illnesses, but principally from cardiac diseases, cancer, stroke, and illnesses attending paraplegic and quadraplegic injuries. The interviewees tended to be middle aged or older, except for the accident victims, and they came from lower-, middle-, and upper-middle income populations. Additional data came from a number of autobiographies of people making comebacks from severe chronic illness or dying from it, and a relatively few biographies came from spouses written after ill mates had died.

Trajectory and Everyday Life Management

Rather than use the medical term of "illness," we shall use the sociological concept of *"illness trajectory"* (Glaser and Strauss, 1968; Strauss et al., 1985). This concept refers not merely to (1) the course of an illness, but (2) to all the related work, as well as (3) the impact on both the workers and their relationships that (4) then further affect the management of that course of illness and the fate of the person who has it (Schneider and Conrad, 1983). The concept gets us focused analytically on the social context for work as well as on the social relationships affecting the work.

Trajectory and everyday life management in the home means that there are two basic lines of work to be performed daily, weekly,

monthly—*illness-related work* and *everyday life work*. Each line of work is made up of different types of work. For instance, illness-related work consists of regimen work, crisis prevention and management, symptom management, and diagnostic-related work. Everyday life work refers to the essentially daily round of tasks that keep the household going. It includes housekeeping and repairing, occupational work, marital work, child rearing, sentimental work (Strauss et al., 1985), and activities such as eating. Implicated in each of these two main types of work are interactions with spouse, children, friends, health professionals and others in the gathering and dispersing of information, expressions of concern, caring, and the division of tasks. Together these types of work make up the total range of work to be accomplished over any specific period of time.

Of course, each type of work consists of clusters of tasks that must be sequenced between and within the types. For example, regimen work for a respiratory condition may include taking medications four times a day and performing respiratory hygiene three times a day. If the purpose of a prescribed medication is to make secretions more liquid, then it must be taken before the respiratory hygiene in order to increase its effectiveness. And the respiratory hygiene must be fit into the daily routine of going to work, running errands, cleaning house, and cooking meals.

The work, whether it be in the service of trajectory or everyday life management, is performed under conditions that can vary from routine to unusual. Treating insulin shock would be an example of a crisis task, whereas injecting the morning insulin is a routine task (Beneloil, 1975). Since trajectories and everyday lives can differ from day to day, the work to be performed each day can vary in amount, degree of difficulty, time it takes, and consistency with which it must be done. So overall there is a great deal of variation, not only in the total types of work to be done for each line of work but also in the properties of that work. One usually goes to work each day, prepares perhaps two to three meals daily, yet vacuums only once a week. Medications may be taken three times daily, whereas physical therapy may be required only three times a week. Some tasks, such as doing a requisite exercise, may be flexible; others, such as taking one's heart medication, are not. And some tasks require a great deal attention to detail and busy work, whereas others can be done simply and by rote, requiring very little time and energy.

Moreover, each time there is a change in the trajectory or everyday life, there may be a corresponding change in the type and nature of the work. For instance, after a comeback from a stroke, it may still be

necessary to take one's medications for hypertension, but one may no longer need frequent occupational, speech, or physical therapy sessions. With the improvement and extra time, the person may now be able to take on more of the household chores or return to a job. On the other hand, with arthritis a person may be required to spend time each morning just slowly and painfully moving the stiff joints to loosen them sufficiently in order to perform the most basic of life's daily activities, such as dressing and eating breakfast. ("I get my coffee sitting on the edge of the bed. Then I take my pills and begin to move all my muscles, while my husband listens to the groans.") Then, too, other tasks that are part of an occupation or household managing or both may now take longer, because of pain and stiffness and because they must now be done in perhaps more tolerable but less efficient ways (Wiener, 1975).

The Management Context

Our discussion of the management context will center around two main structural conditions impacting upon the management process. Their meaning is captured by the terms: "structure in process" and "reciprocal impact."

Structure in Process

The structure under which management takes place is a fluctuating and changing one—hence the phrase "structure in process." (This concept was first put forward in Strauss, 1959 (republished, 1969; also Glaser and Strauss, 1968).) The consequences for work performance are manifold and call for scrutiny of the various dimensions underlying that structure.

The home. Unlike hospitals designed for efficient care of the ill en masse, each home is individualized to meet needs and suit the tastes of those who live there. When someone acquires a chronic illness—with its accompanying physical, social, and emotional aspects—his or her relationship to the home setting will change, sometimes slightly but sometimes drastically, depending on the nature of the home and the type and phasing of the trajectory. For instance, if there are stairs to climb to the bedroom and bathroom areas and the

capacity to climb stairs is lost, as with severe Parkinson's disease, then a dining room may have to be changed into a bedroom and a closet turned into a bathroom. If quiet and rest are essential to recovery during or after acute episodes, the activities of children and others may be constrained or redirected. With every major change in trajectory phasing, different structural aspects of the home are brought into play to meet the changing needs of trajectory management. For example, as a stroke victim recovers, he or she may be able to climb the stairs to the bedroom but may still require a space downstairs into which to retreat when overcome with fatigue. Furthermore, the amount of daily work to be done in the management of the home may increase, at times significantly, because of trajectory related work like preparing special meals and making frequent trips to health care facilities. Meanwhile the ability of the ill person to participate in the usual shared division of labor may decrease, shifting the responsibility for the work onto the other family members.

Everyday life work. Another important feature of trajectory management is that it takes place within the context of everyday life work. The management of everyday living, like the management of a trajectory, requires that certain tasks be carried out through a complex division of labor. While the everyday tasks of living can be held in abeyance while a person is hospitalized, these tasks can be held off or shunted onto others only for so long. Once the person returns home, temporary arrangements must give way to permanent ones and new ways of performance must be discovered and rediscovered with each major change of performance ability.

Moreover, since everyday life itself is never at a standstill, the work involved in its management is always moving, changing. Even the most routine and repetitious of everyday tasks can vary in the manner in which, the time at which, and the person by whom they are performed, according to the tasks to be done and contingencies that arise—such as flu or a death in the family.

Trajectory and its Work. In examining the structural context of management in the home, we must also consider the nature of trajectory and its associated work. The types and nature of this work vary with the severity of the illness, the type of trajectory, and its phasing within those types. With each phase, different tasks are required for trajectory management and different resources are necessary to perform those tasks.

A trajectory may be routine or problematic, and thus, too, its management. A person may have a single illness or multiple ones: while managing one illness may be complicated, the management of two or more can be much more so. This is especially so since drugs tend to interact and cause sometimes quite severe and unanticipated complications, and physical incapacity from one illness may interfere with the management of another. It is difficult to give oneself an insulin injection if one's dominant arm is paralyzed from a stroke. Also some persons are prone to crises or complications, making management that much more complex. And when changes upward or downward suddenly occur in the course of an illness, the routines of household managing can also be thrown into disarray, further complicating the trajectory management.

Even relatively stable illness states can become unstabilized to some degree because certain changes affect them. For instance, a quadraplegic with a high level injury may develop severe respiratory complications if he or she catches a cold or the flu, because of decreased capacity to cough and expel mucus from the lungs. Hot smoggy weather may increase breathing difficulties in those with respiratory conditions because of their decreased lung capacity. And pregnancy can complicate the management of diabetes by increasing the need for insulin, which then makes the woman more prone to episodes of hypoglycemia. Each change in illness conditions not only brings about changes in trajectory management but also affects the management of everyday life.

Implications. What "structure in process" adds up to is that the conditions under which trajectory management takes place are to some degree *always* changing over time (Glaser and Strauss, 1968). Sometimes the change is radical, at other times it is very subtle and almost imperceptible, unless viewed from a longer temporal perspective. Of course the home, the illness, or everyday life are not in a constant state of flux, for often there are long periods of relative stability. Yet even during the most routine and stable periods of an illness or everyday life, there are variations and fluctuations that bear on the management of either.

Even slight changes in the routines of everyday life can have important consequences for trajectory management. Changes in the timing and content of a meal can be disastrous for a diabetic who must keep a balance between food intake and insulin injections. And dinner at a restaurant or in the home of a caring but unknowing

friend can overextend the sodium limit of a person on a low sodium diet. An exciting and stimulating discussion with a colleague in the morning can severely limit the energy available to a cardiac for teaching a class in the afternoon. Of course, the ideal context for illness management would be a controlled environment in which change and contingencies could be minimized. That is a difficult ideal to realize.

Reciprocal Impact of Trajectory and Biography

Another major contextual feature of trajectory management is the tendency for a change in the status of the trajectory (or for work done for the purpose of managing it), or the ill person's biography (or the *biographical work* necessitated by the continual or occasional reconstruction of his or her life) to have consequences for each other. These consequences in turn impinge upon and give direction to the management process. We refer to this tendency as "reciprocal impact."

For example, it is not unusual for a severe disability or illness to bring about all sorts of consequences for the ill person's biography, some small and some large (Fischer, 1982; Strauss and Glaser, 1970; Riemann, 1983; Schneider and Conrad, 1983; Schuetze, 1981; Zola, 1982, 1982). For instance, the writer Cornelius Ryan tells us:

> There is a communications breakdown between my mind and my hand. Is it me or is it the book that's stalling out? I have to get some straight answers about my health.... I think if I could put cancer behind me I could come to grips with the book research.... The monotony of not being to write is terrible. But the constant fear of cancer which inhibits my ability to work is becoming unbearable.... It even invades my sleep. (1979:276)

Conversely, it is not unusual for biography and the associated biographical work to have an impact on steps taken to manage the trajectory, and so, ultimately, on the status of the latter (De Mille, 1981; Madruga, 1979).

> I have been praying lately, something I don't think I consciously did for years. I want time to finish this book. There is so little else I can do for Katie and the kids. It is so very hard to accept the fact that my sexual desires are now nonexistent and harder, still, to know that my manhood is eroding away each time I take a female hormone. If I didn't have the book and the family I don't think I would have taken the estrogen at all

> after Willet told me the cancer had invaded the bones. If I'd been alone, with no commitments, I would have allowed the disease to take over. (Ryan, 1979:292)

Reciprocal impact of trajectory and biography is ongoing. It is not limited to an initial impact at time of onset; rather, it occurs throughout the course of the trajectory. So, any change in the status or phasing of either trajectory or biography can lead to drastic consequences, with implications for the management of either. Thus, as one man in our study said, "The next attack was two years after the first. They let me know, after I had recovered sufficiently, that I would be put out to pasture." Now, this man not only must do the biographical work of coming to terms with the loss of his job but must also rearrange his finances and discover new ways of finding fulfillment and occupying his time.

While changes of trajectory often have strong impacts on biography, biographical changes can also strongly affect the trajectory management and so an illness itself. For instance, pregnancy in a woman, diabetic since childhood, may provide just the incentive to keep her blood sugar within acceptable limits, something she had found difficult to do while growing up because of her fierce competitive desires. How it is important to do so not only to safeguard the health of her fetus, but so that she might live long enough to see the child grow up.

However, the relationship of trajectory and biography, although reciprocal, is not necessarily mutual. The consequences of one for the other may not be felt at the same time and to the same degree. Rather, they may be felt immediately or they may be delayed. The impact may vary in intensity or permanency. The impact may be beneficial or detrimental to the course or management of the other. Finally, though the trajectory consequences are felt primarily by the ill person, biographical consequences may also be experienced by the spouse and other family members.

In its extremes, as when the illness is out of control because of an acute or crisis situation, there is a tendency for biographical concerns to be disrupted (Bury, 1982; Dingwall, 1976). Control over these may also be lost unless considerable effort is exerted then to counteract the disruption. Conversely, when biography is out of control—as in a crisis brought about by divorce, a spouse's death, sudden unemployment—then considerable effort must be directed at trajectory man-

agement to keep it also from going out of control. A not unusual situation is for symptoms to increase, complications to develop, the progression of a downward trajectory to accelerate, or for reversal in an otherwise progressive comeback trajectory to occur as a result of stress associated with biographically related problems or crises (Isaac, 1974).

Summary

In summary, what makes the structural context under which trajectory management takes place so important is its implications for the work of managing. "Structure in process" means that there are changes and fluctuations in both the trajectory and everyday life. In turn, that means creation of new sets of management conditions. Reciprocal impact indicates that changes in either the trajectory or biography, or actions taken to manage either or both, can have an impact upon the other. These consequences also create a change in the management conditions for one or the other, and so also for everyday life. While some change in conditions can be anticipated and planned for, others are quite unexpected. Expected or not, fluctuations and a change in conditions bear upon the number and type of tasks to be performed, who does them, when, the kinds of negotiations over this division of labor, and the resources needed for their performances and the potential success of management outcomes (Freidson, 1976; Strauss, 1985).

Relative Equilibrium

> I have one schedule for during the week and another for weekends. My insulin dosage for weekends is different because of a difference in schedule. You just have to work it out according to what your life style is. If you work with it, it is easy enough. You just have to feel and adjust. You have to continue living. You can't make the world go around depending upon how much insulin you have taken. Life goes on. Like I wouldn't go out to a restaurant and gorge myself without taking an additional shot.

As this woman tells us, even though you have a chronic illness, life goes on. You can't stop living, though some lives become greatly

constricted because of it. But how do persons continue to hold onto life despite illness and the demands of its management? A clue may be found in the above quotation: It takes a great deal of balancing of the trajectory management demands against those of everyday life and biographical concerns, and then furthermore the development of an action plan that will satisfy all three sets of demands.

Trying to satisfy them all is like walking on a tightrope (Charmaz, 1983). Some sort of relative equilibrium must be maintained among them in terms of effort and other resources—time, energy, money—invested in the management of each. Unless a relative balance is maintained, effort and resources may be usurped in the management of one, leaving little or none for the management of the other. If all of one's effort, time, energy, and money are absorbed in the trajectory management, what happens to the quality of one's life?

However, any equilibrium achieved is relative. The ratio of effort and resources appropriated among the three lines of work can vary considerably in accordance with the various management needs. For example, an illness may be completely out of control in the sense that treatment is no longer effective in containing its progress, meaning that death in the near future is inevitable. Yet pain and energy depletion are sufficiently amenable to control, so that in such a case the ill person is enabled to complete biographical closure and have meaning in his life in the remaining days. That is, there is a relative balance between effort and resources expended in the trajectory management (pain and energy control) and the completion of important biographical work (closure), even though the ratio may be weighted to one side or the other, depending upon how difficult the pain is to control or on how great the need is to complete closure and with whom.

This ratio may be subject to temporary or permanent changes because of the progressive nature of chronic illness and biographical changes or the variability of everyday life. With a change in the phasing of trajectory or biography or if complications occur in everyday life, effort and resources may be shifted from one or the other, disrupting the balance between them. When control is regained, the balance may restabilize at a higher or lower level of the person's functioning than previously.

Our interviews suggest that even under the most routine conditions of illness and everyday life, but even more so during critical periods of the illness, there is a tug-of-war between the requisites of trajectory management and those of everyday life and biography. A

person will follow a regimen, keep a doctor's appointment, undergo needed surgery—but also need to maintain at least a little bit of normalcy in life, like that morning cup of coffee. Maintaining a state of relational equilibrium, regardless of the struggle put forth, is not easy. There is a tendency toward an instability of the balance. Below we will examine why.

The Interaction of Structure and Process

From attempts to control the illness and maintain some quality of life within the home context, there flows a set of consequences. These consequences may be thought of as outcomes arising out of the interaction between structure (context) and process (management). Each consequence is capable of upsetting the relative balance among trajectory, biography, and everyday life. Unfortunately the consequences rarely occur alone; rather, the occurrence of one tends to lead to the occurrence of the other. So, often the combined impact of all working in unison create conditions tending more toward instability than relative equilibrium.

Competition for Resources

One consequence is the competition for resources among different lines of work. ("Competition" is ordinarily thought of as competition among persons or organizations, but we have employed this useful term in the special sense just noted.) These resources include manpower, equipment and other forms of technology, energy, money, and space; also spouses or children to provide physical and emotional sustenance to the ill and, in turn, someone to sustain the spouses so that they can continue to sustain the ill partners.

The number and type of resources needed for each line of work varies with the type, degree of difficulty, amount, and consistency of the work to be done. Thus the more severe the illness and the greater the physical disability, the greater is the number of resources needed to keep the illness under control and to provide for the physical, social, and emotional needs (Schneider and Conrad, 1983). Or the more complicated the household—for instance, one including young children and illness or infirmity in the spouse—the more resources

are needed to keep everyday life under control. Naturally, during acute phases or complications with the trajectory, biography, or everyday life, more resources are needed to bring about and keep control.

Often the resources are inadequate. This leads to a competition among the lines of work, so that priorities must be established to determine how the limited resources will be distributed. The ill person or couple must decide where their time, energy, money, etc. will go. Sometimes the trajectory is given priority, sometimes daily life or biographical concerns. Inevitably, one or another is short-changed. Ultimately, all are affected by *that* situation, because one set of consequences unfortunately has a way of becoming a condition for still another set. If not interrupted, the chaining of consequences can continue until almost every aspect of life is affected.

Competition for resources is most likely to occur when the need for resources is high, as when an illness is severe but the proportional availability of resources is low. For example, many women in our study were the sole caretakers of their husbands, not through choice but because they simply did not have money to hire outside help. They lacked the finances for several reasons. Outside help is expensive. Many of the ill are retired and living on a fixed income. Often, the husband, who was the sole or main source of financial support, is no longer able to work or is working in a considerably lower level position than before the illness or the well spouse has had to quit her job in order to be able to care for her sick husband. Sometimes, even when attendant aid is possible, the spouse will provide for the caretaking needs of her mate, not only because she is consistently available but because the couple needs extra money to survive or resents the intrusion upon its privacy.

The total financial and emotional costs of illness are often difficult for the uninitiated to imagine (Charmaz, 1982; Suczek, 1975). Illness can rapidly drain away money that a couple had kept in reserve to live on in their final years. More than one spouse expressed considerable concern about what would happen to them after all their savings had been used up in caring for the sick partner. Illness can also drain energy. The caretaking spouse, for instance, does not have a diet kitchen to prepare the requisite special diets, a housekeeping department to wash her husband's dirty bed linen, or time off for holidays and vacations. The responsibility is the well mate's, 24 hours a day, seven days a week.

Unbalanced Workloads

Another potential consequence of illness management is an unbalanced workload or what some persons refer to as a lack of equity in the distribution of tasks. Whether their division of labor is based on traditional or more modern forms of task allocation, when the ill mate can no longer perform his or her share of the division of labor then somebody has to take up the slack. That somebody is usually the spouse, unless unable or unwilling to do that.

This means that a husband in addition to his regular outside job may now have to take over the grocery shopping, cooking, and other household chores. But the taking-on of tasks extends sometimes beyond normal household tasks. Often a spouse is called upon to perform for the ill partner the most personal and basic of self-care tasks. For example, a husband must get out of bed in the middle of the night to put his arthritic wife on the bedpan because she is unable to walk to the bathroom on her own. However, while some tasks are simply unpleasant, others make the well partner feel inadequate. For instance, the wife of a quadraplegic said, "I was almost paranoid about getting up on the roof when he wanted me to do something with his antenna. I was scared half to death. I was frustrated with myself because I wasn't a man." On the other hand it is just as frustrating and difficult for the ill to relinquish to another their self-care or the tasks once considered part of their domain.

Much of the time, couples are able to work out a new division of labor between them to keep workloads more evenly balanced. Often ill mates take on alternative tasks to lighten the spouses workload, like dusting, peeling vegetables or driving children to appointments. Although these are small tasks, when their number is totaled that they do help becomes apparent. Other strategies include flexibility in the timing of tasks, the differentiation of needs from what is merely wanted, and provision for occasional relief from the work so that couples can socialize together or have time away to renew themselves. Without such strategies, spouse fatigue, frustration, resentment, and even illness begin to build up. In time, even the most committed of spouses discover they can no longer carry the loads.

> We used to talk that some day I might have to put him in a nursing home. Then last October after 24 years, I realized that I just couldn't handle it anymore. I had had it. Making the decision was the hard part. I went through a lot of grieving with that. It would have been much easier just to lose him completely.

Sometimes keeping the work load within the spouses' limits of tolerance is a matter of setting priorities among the total range of tasks to be performed and of eliminating those that are not essential or can be deferred or done by others. Occasionally, ill mates will push the boundaries of their limitations and discover abilities to perform certain tasks, thus lightening partners' workloads.

Workloads tend to peak during episodes of acute illness or when complications develop either in the illness or daily life, while the performance ability of the ill person stays the same or decreases. It is not unusual for a spouse to feel overloaded under these conditions. Often, however, overload is the result of the culmination of an unbalanced workload that has continued year after year. Understandably, the point at which overload occurs will vary depending on level of tolerance and opportunities for relief from the work.

Distribution of Workflow

While here the work of management is routinizable in varying degrees, the routines are often intruded on by contingencies flowing from the nature of illness, biographies, and daily life that disrupt the normal flow of work. Such a disruption may be minor or extensive, temporary or permanent, and occur infrequently or frequently. Minor, temporary, and infrequent disruptions can usually be accommodated without undue difficulty, and routines reestablished as soon as the underlying cause is resolved. But even temporary disruptions can cause management to become problematic. For instance, one can readily conceive of how difficult it is for a diabetic to adhere to a specified caloric intake during the holiday season or adhere to meal schedules while traveling or for a wife to awaken every two hours during the night to turn her quadraplegic husband while she herself is ill with the flu.

Genuine crises can also interfere with work flow because then the work will cease being routine. However, unless the crisis is prolonged or allowed to progress into a downward cycle, it too passes and routines can be reestablished. When the disruption is permanent or extensive, then new work patterns must be established. That means repeating the cycle of work routinization by determining what tasks are to be done, how, and by whom. Also, the couple must reacquire task competency; and rediscovering the problems, they must work out their solutions all over again. When permanent and extensive disruption takes on the added dimension of frequency, one can read-

ily see why frustration, stress, strain, fatigue, and gaps in the total range of work occur. Since there is no routine, there is a constant expenditure of time, energy, and perhaps money and manpower. Sooner or later a family's resources may be used up.

Conditional Motivation

Money, prestige and satisfaction are among the usual conditions motivating work. However, trajectory management is not your usual kind of work, nor are money and prestige the usual motivations for it. Rather, motivation rests on another set of conditions: namely, having trajectory and biographical schemes, hope, and commitment, with all of these conditions usually working together to motivate the couple.

To do trajectory work persistently one must have a projection of what lies ahead and some idea of how to get there (the latter we term a "trajectory scheme") (Strauss et al., 1985). Visualizing the illness course and some of its attendant medical work is usually the physician's task. But the patient and spouse will have to discover all that is really entailed in carrying it out. Just as important is a biographical scheme, for one must wish to live, even if just long enough to put closure on life. That means carrying out those particular trajectory related tasks that will enable staying alive long enough to achieve closure, like saying goodbye and making a will. Also, having a biographical scheme means that to some extent individuals must have come to terms with their illness, their limitations, and the potential outcomes of their illnesses.

Hope is another condition for work performance. Trajectory and biographical schemes are useless unless one feels that with the performance of certain necessary tasks, those schemes are attainable. Thus, without the hope that chemotherapy will cure or at least provide relief from pain or other symptoms, there is no reason to undergo this potentially debilitating therapy.

Commitment (Becker, 1960; Charmaz, 1982) is still another important condition: that is, commitment to carry out trajectory and biographical schemes, and for spouses' to do so for each other. Interestingly, it is not always love in the traditional sense that sustains the spouses' commitments to carrying out the tasks necessary to fulfill their trajectory and biographical schemes. Many times, a spouse's love, at least in the romantic sense, has been lost over the course of time and it is a strong sense of duty or obligation that

underlies the work performance. One woman in our study even took back her sick husband after being separated from him for ten years and cared for him until his death.

Nevertheless, it is difficult to keep motivation high unless there is some payoff. For example, some illnesses bring about drastic personality changes, and then the well partner finds that caretaking activities require continuous output and that the other can give very little or nothing in return. The love between them dissipates through lack of reciprocity and commitment turns to duty. Finally, the well mate becomes so overwhelmed by the work demands that the sense of duty or obligation breaks down. In the end, he or she may seek custodial care for the spouse but with feelings of guilt and a sense of having abandoned the other.

If there is a great deal of uncertainty about conditions, then the maintenance of biographical projections and up-dated schemes is problematic. How can you plan when you have only vague definitions of what the future will bring. Will I (he) come back? How far will I (he) come? How much longer do I (does he) have to live? How disabled will I (he) become? Will there be a flare up of the disease, complications? If so, when? What will bring it on? Why continue with the work when there seems to be no gain?

The Domino Effect

As one can see, the many consequences flowing from the interaction of structure and process in illness management are like dominoes leaning unstably against one another. If a downward spiral of consequence is not interrupted it can lead to a loss of control over management outcomes. Competition for resources, unbalanced workloads, disruption of work flows, and decreased motivations lead to fatigue, overwork, overload, episodes of acute illness, resentment, anger, and a widening of the marital gap. These consequences may eventually lead to a loss of the relative and delicate equilibrium among biography, trajectory, and everyday life. In turn, its loss may lead to work deficits or gaps in either or all lines of work, and so to a loss of control over them.

The key element in this downward spiral is that the consequences keep ricocheting off one another, bouncing back and forth until the relative balance is so upset that it leads to major gaps in the work and to irreversible loss of control over one or another line of work. The only means of preventing the irreversibility of a downward spiral is to

check it in its early stages. The longer it continues, the more difficut is reversal of the consequences.

How then can one keep the consequences in check and maintain a state (and a sense) of relative equilibrium under conditions tending to produce instability? That is not an easy matter at best, but the more severe, complicated or changing is the illness or daily life, the more difficult it is to keep those fateful consequences under control.

Management in Process

Maintaining relative equilibrium calls for a type of management that we shall term "management in process." This involves strategies and techniques for control which are adjustable and changeable, in response to various contingencies that arise. Like any other type of management, it requires an understanding of the work required, a planning and coordination of tasks, an anticipation of problems, a resource pool to draw from, and a motivated workforce. It differs from other management processes in how its basic strategies are carried out: that is, always with an emphasis on adaptation to change. The basic strategies include: 1) calculating resources, 2) maintaining fluid boundaries in the division of labor, 3) maintain articulation work, and 4) mutual sustaining.

Resource Calculating

Under conditions that tend toward competition for resources among the different lines of work, the maintenance of a relative balance in their distribution and utilization involves an ongoing process of resource calculation (Gerson, 1976). This can be broken down into four steps. The first involves calculating the degree of need within each line of work. This means legitimizing or authenticating the claim by demonstrating the type and degree of need. It also means giving priorities to the most immediate and important needs. From this one can estimate what resources are needed, for what uses, when, for how long, and so forth.

The second step involves calculating the degree of availability of resources that can be apportioned among the lines of work. In calculating that, consideration must be made of attrition, exhaustion, conservation, and how resources can be combined or recombined or simplified. One must consider how utilizing a given type of resource

allows amplification of others, for example, how a medication or a technological resource can raise energy levels or improve upon ability to perform, thereby increasing the self as a resource, decreasing the need for others as resources, and increasing others' time and energy for the accomplishment of other tasks. Calculating the availability of resources, however, may also involve a search for resources not otherwise immediately available, although more people turn out to be extremely "resourceful" at discovering resources that previously they would not have dreamed existed unless forced by their worsened circumstances to find them among friends, kin, public, or private services.

Matching need with availability is the third step. When demand meets availability, a match may be said to exist. In such a match, the problem becomes one of building, maintaining, and renewing the resource pool. The relevant issues then become the degree of resource deficit and whether needed resources can somehow be acquired, recruited, or trained to fill in the gaps. That means looking at options, establishing priorities, juggling resources, calling upon backstopping agents, and negotiating various agreements. Considerations in making decisions about resource utilization when resources are scarce or lacking include: ethics—that is, the quality of life and the right to live or die; legislation which supports programs for the disabled; availability of social security and other third-party payment systems; community programs; the structural make-up of the home environment; and the state of technology.

A fourth step is the actual allocation of resources among the major lines of work in a ratio determined by need. Resources are moved into and out of the work arena in accordance with the demands. Moving resources flexibly increases maximum efficiency and prevents depletion of the resource pool.

Maintaining Fluid Boundaries in the Division of Labor

There are many different means by which tasks are usually divided in the home, according to tradition, efficiency, ability, desire, safety, availability, and so forth. There are daily variations in those divisions, depending upon conditions such as boredom, fatigue, acute illness, vacations, and biographical phasing. When trajectory work is added, it not only creates new work demands but brings about a situation calling for more variation and fluidity in how tasks are

divided. As needs attending the illness change, or performance ability increases or decreases, major shifts will be required in who does what tasks, and when and how.

"Management in process" means that the following conditions exist in the division of labor. First, there is a clear understanding and acceptance about how tasks are divided, even when conditions persistently vary. Second, there is a perceived mutuality between the partners: the perception that each is doing a fair share, or at least all that each is capable of doing under the given conditions. Hence workloads are as balanced as possible. In extreme cases of disability, perceived mutuality may be difficult to maintain; however, some active involvement of the ill and some degree of reciprocity, even if it is a only a "thank you," helps to maintain the perception of mutuality.

A third condition is following through with task performance. Here we get into the issues of responsibility and the taking-on and letting-go of tasks, as well as the power to determine who does what tasks and whether and how well these are accomplished. A fourth condition is flexibility in who does what tasks and when. Being flexible means shifting with daily cycles of fatigue, acute illness, and fluctuations in symptoms. But being flexible also means being alert for and making reallocations of tasks at times of overwork, having reached limits of tolerance and overload. Of central importance is how the allocation is established and the work performed, how shifting is brought about, how disagreements arise and are settled, how power struggles and the issue of responsibility are handled (Strauss, 1985).

Ongoing Articulation Work

Any endeavor requires planning and coordination if the work is to proceed smoothly and to completion. That work we shall refer to as "articulation work" (Strauss, et al., 1985), to denote the planning and coordination necessary to operationalize *any* associated set of tasks. Articulation of trajectory and everyday work takes place at three levels. The first is the task. Each type of work is made up of bundles of tasks that occur sequentially or simultaneously. For example, insulin must be drawn out of the vial and into the syringe before it can be administered. Then, too, before the administration of insulin, the urine or blood is usually checked for glucose level. The second level of articulation is between lines of work. Both must be planned for and

coordinated around each other, if gaps or omissions are to be avoided in either or both. Early morning urine testing and insulin administration must be worked into the daily routines of getting up and dressed for work. Sometimes priorities have to be established about what task or type of work is given preference. For instance, the urine should be checked before the insulin is injected, and the insulin should be injected before breakfast is eaten.

The third level of articulation is that of resources. They must all be planned for and coordinated among tasks and lines of work. If regimen work calls for two people working together, as in percussion to induce coughing, but no one is available to do the percussing because the spouse is working at his or her place of employment, then, although in this case coughing might occur anyhow, it may be less effective a means of getting up the phlegm than if preceeded by percussion, which would require the help of another person.

Since the working conditions may not always be routine ones, keeping lines of work going calls for constantly assessing the status of one or another. For their effective management, this assessment must be followed by a rearticulation of the plan as based on identified need. For example, during a crisis it becomes important to assess the intensity, the amount, and the complexity of work; also the amount and types of resource necessary to manage the situation; also how other types of work will be affected by this shift to crisis action. After this assessment, tasks are prioritized, resources rechanneled, and other aspects of life temporarily frozen until the crisis is resolved.

If one asks couples how they manage to keep some balance between the illness and their daily lives, and at the same time keep both the illness and their lives under control, usually they cannot answer precisely. But our interviews with them suggest that their management of an illness trajectory is very similar to operationalizing a line of work in a factory. It too involves a set of organizational and coordinating tactics aimed at keeping the workflow smooth and eliminating gaps in the total range of work. These tactics include:

1. Making arrangements, as with a laboratory, to have blood drawn for testing twice a week or month.
2. Securing, allocating, and maintaining resources, like money for an attendant or respite care.
3. Managing time, including its planning, scheduling, pacing, fitting together; and the juggling of tasks, like timing one's vacation and chemotherapy treatment so that the peak ben-

efits of the chemotherapy are reached, while major side effects will have passed by the time of the vacation.
4. Establishing routines by scheduling tasks, equipment, and people, by becoming familiar with the work, and by streamlining the work to eliminate busy work.
5. Doing information work including networking, scouting out, coaching and training, providing and clarifying instructions, distinguishing between needs and wants, searching for people, places, and necessary things. For instance, calling a restaurant ahead of time to determine if salt-free food is available or if there are accommodations for a person in a wheelchair.
6. Tending to details, such as filling out forms for Social Security or insurance payment.
7. Making choices among options: "Do I want to undergo this form of treatment?"
8. Prioritizing and reprioriting tasks: sometimes the trajectory work is given priority and sometimes daily life.
9. Devising: coming up with new or modified ways of performing the work or devices to assist with work performance, like the placement of railings in the hallway to assist with walking after a stroke.
10. Troubleshooting: being on the lookout for potential problems and complications such as overload, recognizing one's own and others' limitations, preventing or handling situations of conflict.
11. Distributing tasks, responsibility, and rewards among the workforce, and equipment and other resources between the two lines of work.
12. Monitoring work performance and work flow: Are regimens being followed? Is there time for recreation and other forms of renewal work? If not, why?

Mutual Sustaining

As we have noted, in order for persons to continue putting forth effort to manage trajectory, biography, and daily life there must be some perceived payoff for managing them. But sometimes the payoff is not apparent, as in a progressively downhill trajectory. No matter how assiduously one works at controlling it, the trajectory continues downward. The salient feature of mutual sustaining is that couples

keep each other going *despite* conditions such as overwork, decreased confidence, increased dependency, and lost dreams.

What is it that they sustain in each other? They sustain a common definition of the situation: that is, mutual trajectory and biographical projections and schemes, as well as shared understandings about their everyday work. They sustain hope and commitments to each other and to their joint work. Finally, they help each other to sustain cherished identities.

Arriving at and maintaining mutual projections, schemes and understandings requires that couples share approximately the same levels and types of knowledge and information—not only about the illness but also about their respective needs, wants, and expectations. This calls for open communication. If one partner holds back relevant information, it is nearly impossible to work out mutual visions held about the illness or life, and to make and carry out the plans for achieving those visions.

Talk, talking about, and talking through are all required to keep the lines of information flowing, in order to set and clarify goals, to negotiate divisions of labor, and to resolve conflict. Also required are a mutual setting of priorities and the spouses' willingness to revise and update their vision of the future and their plans, whenever a major change in either the illness or their lives occurs. Sustaining hope means that they help each other to realize their shared visions and to believe that their goals are attainable. Sustaining commitment to the shared work is knowing when to take on or relinquish tasks, and when the boundaries of tolerance have been reached. Sustaining mutual commitment also means keeping the marital relationship going. This includes finding ways to enjoy intimacy and feeling for each other with or without sexual relations. And sustaining cherished identities is a form of "sentimental work" (Strauss, et al., 1983, 1985), accomplished by making the other feel important through sentimental acts like encouraging participation in family decision-making and child disciplining and also by letting the other know that he or she is needed and loved despite the illness and its imposed restrictions, that even limited contributions to the major lines of work are important.

A Final Note

In analyzing our data, we have found the perspective elaborated in this paper to be useful for interpreting the words and actions of the

chronically ill and their spouses. It analytically illuminates those who speak in our interviews and those who speak through their published autobiographies, as well as those who appear in biographies after they have died. It is important that the problems which are entailed in carrying out their lives in the face of illness be understood in analytic terms. This is especially so since health care systems in the United States and probably everywhere around the world, dominated as they are by medical perspectives and ideologies, do not offer much by way of assistance for the chronically ill aside from hospital, clinic and physicians' offices, and rather inadequate support services given by associated agencies (in the United States, the Visiting Nurses' association, meals on wheels, public health agencies, etc.). This is why the ill are thrown back on whatever resources they can generate and maintain.[1]

Reference Note

1. Beyond the substantive import of this paper, we have continuing theoretical concerns. These also have been addressed here through substantive materials to further develop a particular perspective for dealing with work. This perspective has been developed earlier in a monograph titled *The Social Organization of Medical Work* (Strauss, et al., 1985; also Strauss, 1985) as well as in closely related research using the same perspective with the work of scientists (Gerson, 1983; Gerson, 1984; Star, 1983; Star, 1985). The effort has been to look closely at work itself, and at its associated work processes, rather than, as is usually in the sociology of work and occupations, to focus almost exclusively on substantive work or (as is especially frequent in studies done in "the Chicago Tradition") focus mainly on the occupations themselves along with the work done by members of various occupations.

References

Becker, Howard
1960 "Notes on the concept of commitment." American Journal of Sociology 66: 32–40.

Beneloil, Jean
1975 "Childhood diabetes: The commonplace in living becomes uncommon." Pp. 89–98 in Anselm Strauss and Barney Glaser (eds.), Chronic Illness and the Quality of Life. St. Louis: Mosby.

Bury, Michael
1982 "Chronic illness as biographical disruption." Sociology of Health and Illness. 4: 167–82.

Charmaz, Kathy
1983 "Loss of self: A fundamental form of suffering in the chronically ill." Sociology of health and illness 5: 168–95.

Dingwall, Robert
1976 Aspects of Illness. London: Martin Robertson.

De Mille, Agnes
1979 Reprieve: A Memoir. Garden City, New York: Doubleday.
Fischer, Wolfram
1982 Time and Chronic Illness: A Study on the Social Constitution of Temporality. Habilitation thesis. University of Bielefeld, Bielefeld, West Germany.
Friedson, Eliot
1976 "The division of labor as social interaction." Social Problems 23: 204–13.
Gerson, Elihu
1976 "On quality of life." American Sociological review. 41: 793–806.
1983 "Scientific work and social worlds." Knowledge, 4: 357–77.
1984 "Qualitative research and the computer." Qualitative Sociology 7: 61–74.
Glaser, Barney and Anselm Strauss
1968 Time for Dying. Chicago: Aldine.
Isaac, Betty
1975 A Breast for Life ... New York: Exposition Press.
Madruga, Lenore
1979 One Step at a Time. New York: McGraw-Hill.
Riemann, Gerhard
1983 Biographieverlaufe Psychiatrischer Patienten Aus Soziologisher Sicht. Kassel: University of Kassel, inaugural dissertation.
Ryan, Cornelius and Kathryn Ryan
1979 A Private Battle. New York: Simon and Schuster.
Schneider, Joseph and Peter Conrad
1983 Having Epilepsy: The Experience and Control of Illness. Philadelphia: Temple University Press.
Schuetze, Fritz
1981 "Processstruckturen des Lebensablaufs." In Johannes Mattes et al., Biographie in Handlungswissenschaftliche Perspektive. Nuerenburg.
Star, S. Leigh
1983 "Simplification and scientific work: An example from neuroscientific research." Social Studies and Science. 13: 205–28.
1985 "Unvertainty and scientific work." Social Studies and Science 15 Forthcoming.
Strauss, Anselm
1985 "Work and the division of labor." Sociological Quarterly. Forthcoming.
Strauss, Anselm, Shizuko Fagerhaugh, Barbara Suczek, Carolyn Wiener
1982 "Sentimental work." Sociology of Health and Illness 4: 254–278.
1985 The Social Organization of Medical Work. Chicago: University of Chicago Press.
Strauss, Anselm and Barney Glaser
1970 Anguish: A Case History of a Dying Trajectory. Mill Valley, Ca.: Sociology Press.
Suczek, Barbara
1975 "Chronic renal failure and the problem of funding." Pp. 108–118. Anselm Strauss and Barney Glaser (eds.), Chronic Illness and the Quality of Life. St. Louis: Mosby.
Wiener, Carolyn
1975 Pp. 71–80 in "The burden of rheumatoid arthritis." In Anselm Strauss and Barney Glaser (eds.), Chronic Illness and the Quality of Life.
Zola, Irving
1982 Missing Pieces: A Chronicle of Living with a Disability. Philadelphia: Temple University Press.
1982 Ordinary Lives: Voices of Disability and Disease. Cambridge, Mass.: Applewood.