IMPACT OF CHRONIC ILLNESS ON THE PATIENT’S SPOUSE

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The spouse of a chronically ill person can experience a variety of undesirable reactions, such as anxiety, self-blame, or anger. Using a case example that involves Alzheimer's disease—a presenile condition—the author explains how social workers can help clients cope with and adjust to the problems created by a spouse's illness.

The spouse of a chronically ill person is likely to experience any or all of a wide range of reactions, such as sadness, pity, anger, guilt, shame, fear, depression, helplessness, anxiety, self-blame, worry, or loneliness. The role of the social worker or other practitioner with the spouse should be to help him or her understand these reactions, to reopen and clarify communication between the spouse and patient, to help in planning the patient's care, and to help the spouse maintain a sound balance between serving the patient and respecting his or her needs. The primary purpose of this article is to elaborate on these ideas and to elucidate the needs and concerns of the spouse of the chronically ill person.

The discussion will center on a case example that encompasses many of these issues and provides a dynamic framework from which to discuss them. The example involves Alzheimer's disease, a chronic, deteriorative, neuropsychiatric disorder that accelerates the aging process. Its etiology is unknown. It is characterized clinically by rapidly progressing mental deterioration and multiple neurological symptoms; pathologically it involves severe brain changes of the senile type. There is a gradual decrease of the patient’s higher intellectual functioning and a steady regression to profound mental deterioration, with an invariably fatal conclusion. No specific treatment is known, and symptomatic and environmental measures are the sole relief that can be offered.

Although little is known about Alzheimer's disease, it is not rare. It may account for from 1 to 10 percent of all psychoses of later life. However, the disorder may often go undiagnosed because of similarities between it and other neuropsychiatric disorders. The average age of onset of Alzheimer's disease is approximately 54 years. It generally occurs earlier in life than senile dementias (psychoses) and has a more rapid course. Occasionally, the disorder begins in a person's 40s, though it may also appear in the early 60s, where it is easily confused with organic dementias of senility. Estimates as to the duration of Alzheimer's disease vary between two and ten years and sometimes more. Another text notes that death usually occurs from one to four years after the onset of symptoms.
The first stage of this disease is characterized by (1) deterioration of reasoning, comprehension, and perception, (2) loss of memory, (3) temporal and spatial disorientation, and (4) lack of spontaneity. Patients undergo alterations of speech—forgetting words, finding pronunciation difficult, and exhibiting poor comprehension of spoken language. The second stage generally involves progressive loss of memory, aphasia, agnosia, apraxia, a tendency to wander off aimlessly, and addiction to such repetitive movements as tapping, lip-sucking, or chewing. Patients exhibit seriously disturbed speech patterns; they may become unable to complete a sentence, and their articulation may become so poor that it is difficult to understand them. The functions of reading, writing, and the understanding of spoken words are gravely impaired, though some understanding does seem to remain.

A patient with Alzheimer's disease may be depressed, restless, hyperactive, emotionally distressed, or agitated. In spite of the loss of memory, patients often have a distressing awareness of impending insanity. Also, because cortical cells have been destroyed, socially acceptable behavior may be replaced by more primitive behavior, and patients may be assaultive without realizing what they are doing. The terminal stage of the disease usually lasts no more than a year, with patients becoming particularly susceptible to bronchopneumonia, which is the most common cause of death. The following case illustration exemplifies some of the problems associated with the disease.

Case Illustration

Mrs. R, who was 57 years old at the time of the intervention described here, was a Jewish woman who lived with her 61-year-old chronically ill husband in a borough of New York City. They had three grown children who lived away from home. Mr. and Mrs. R had been married for thirty-five years. Mrs. R was working as a clerk, and her husband had worked as an engineer for over thirty-five years. Four years prior to the social worker's intervention, Mr. R had retired after being diagnosed as having Alzheimer's disease. He then began to receive a pension and social security disability benefits. In the fourth year of his retirement, Mr. R's deterioration became increasingly pronounced. According to Mrs. R, her husband had been an intelligent, well-informed man prior to his illness.

Mrs. R called a sectarian family agency because she felt she needed help with her problems. The social worker had eighteen meetings with Mrs. R, including three home visits in which Mr. R (and once their older daughter) was also present. At first, the worker encouraged Mrs. R to bring her husband to the office, but weather conditions and Mr. R's physical difficulties repeatedly prevented this. For the last six months of the period that this report covers, a housekeeper cared for Mr. R while his wife was at work. Eventually, Mr. R was hospitalized with pneumonia.

Mr. R was a pale-skinned, feeble-looking man who appeared considerably older than 61. He displayed the following symptoms of Alzheimer's disease: confusion, short-term loss of memory, time disorientation, and disturbed speech. He fluctuated between periods in which he was lucid and responded intelligibly and periods in which he was confused and responded inappropriately. He could recall events of the past well and even spoke as if he were in the past sometimes—imagining, for example, that he was still working as an engineer. Mr. R was losing control of his excretory functions. He had some "psychotic episodes" in which his behavior was irrational and assaultive and in which Mrs. R was not able to control him. Once he wandered away from the house. A neurologist prescribed Thorazine for Mr. R, which his wife gave him as necessary. Mr. R had increasing difficulty walking and moving around in the months before his hospitalization, and he had fallen twice. His body had become rigid and spastic, and he eventually lost the ability to move from place to place by himself. These symptoms as well as the anorexia and shaking that later developed were seemingly indicative of the terminal state of the illness. During the social worker's home visits, Mr. R spoke about additional changes that he was experiencing, including cataracts, difficulty in hearing, inability
to lift things, and pain in his back. He was distressed, frightened, and confused about these changes.

Mrs. R was a small, chubby woman who walked sluggishly and had a sad, slightly disheveled appearance that made her seem older than her age. She was an intelligent woman who expressed herself articulately. She was extremely upset about her husband's deterioration and cried frequently when she talked of or thought about the possibility of his death. She had difficulty sleeping and eating, and she indicated that she was not able to concentrate or think too clearly sometimes. She was taking tranquilizers to help with her nervousness and with her insomnia.

**Communication with the Patient**

One issue that emerges frequently in families with a chronically ill person is the question of how to tell the patient about the illness. For example, Mr. R's doctors and wife had told him relatively little about Alzheimer's disease. This made the changes he experienced that much more frightening and perplexing to him and helped account for the paranoid feelings he sometimes expressed. The worker tried to help Mrs. R understand this. Mrs. R said that she had to protect her husband by not talking with him about his diagnosis, though she realized this also represented her own inability to deal with his illness. Through discussions and exploration of her behavior, Mrs. R began to recognize that she and her husband were "playing a game" with each other by not confronting what was happening.

It is often the case that the physician tells only the patient's spouse about the seriousness of the illness. The spouse is then left to decide how much, if any, information to convey to the patient and other members of the family. The patient and his or her spouse may lack the courage to share with each other knowledge that they both have about the illness and its meaning to them. Occasionally, as with Mrs. R, the spouse may be able to face the reality when talking with other people but may deny the reality in front of the patient. "The tendency is, unfortunately, to hide feelings from the patient, to attempt to keep a smiling face and a front of make-believe cheerfulness which has to break down sooner or later." Also, the patient and the spouse may wish to protect each other, preserving the roles and relationships that existed between them through the years.

When the spouse and the patient begin to share their awareness, however, they may be relieved that they no longer have to play a deceitful game. Furthermore, instead of increasing their alienation and isolation, they may be able to reach a greater closeness and understanding. Patients need to hear that their spouses are aware of the seriousness of their condition and are able to accept this reality. As Kübler-Ross has stated, genuine emotions on the part of a member of the family are much easier to take than a make-believe mask which the patient can see through anyway and which means to him a disguise rather than a sharing of a sad situation.

Patients need to see and feel the compassion, caring, and love of a spouse as well as to release their own emotions. The encouragement, understanding, and support of communication in the family is one of the goals the social worker should adopt in intervention with the spouse of a chronically ill patient.

**Planning the Patient's Care**

Families of chronically ill persons must eventually become involved in planning for the patient's care. There may be an initial period, varying from weeks to years, in which the patient is ambulatory and able to care for himself or herself at home, using the medical services of a nearby hospital or clinic on an outpatient basis only. If the patient's condition worsens, a decision may have to be made about whether the continuing care of the patient will take place at home or in a nursing home. Mrs. R, for example, began to think of having her husband enter a nursing home when she perceived his increasing need for professional care. She was having considerable difficulty handling him and was being physically and emotionally drained by the increased demands of his care. However, although rationally she knew he should be...
in a nursing home, emotionally she was reluctant to have him enter one. She felt that since she herself would rather be in her own home that her husband would also prefer that arrangement. Mrs. R felt that allowing her husband to enter a nursing home would mean she was shirking her responsibility to him and that she was sending him to a place to die. She supposed he would view life in a nursing home with fear and hostility.

A spouse's emotional reactions often block his or her ability to make an adequate plan. In deciding that the patient should remain at home, the family may fail to consider the physical strain they will undergo in caring for the patient and the emotional strain they will experience in watching him or her deteriorate. The family may attempt to avoid the sense of finality that planning for terminal care precipitates and the anxieties that arise in considering care outside the home. In deciding to have the patient enter a nursing home, the family may avoid the meaning this has for the patient and the feelings of guilt it produces for themselves.

The social worker can help the spouse and other members of the family make realistic plans for the patient's care. After assessing the physical and emotional needs of the patient and family in regard to the choice between nursing-home care and in-home care, the worker should offer reassurance about the course of action chosen and should provide concrete assistance in making and implementing plans. With the worker's encouragement, the spouse can begin to discuss planning with the patient. This not only lifts a burden from the spouse—letting her or him talk about the issue and thus alleviating some guilt about keeping secrets from the patient—but it gives the patient a chance to verbalize feelings about his or her illness and nursing-home care and to feel he or she has a role in deciding about the future. "Involving the patient in decision-making allows him to assume an adult role of shared responsibility, which can help to extricate him from a feeling of self-devaluation." Also, it is important for the spouse to feel involved in what is happening to the patient. "Seeking information about the disease and its likely course and participating in the patient's care serve to bolster [the] sense of mastery and usefulness."!

**Financial Concerns**

It is frequently the case that a person who has a chronic illness also has severe financial problems. Families with little or no money may receive help from programs such as Medicaid, public assistance, or Supplemental Security Income. Middle-class and upper-middle-class families, on the other hand, generally do not qualify for these governmental programs under current income eligibility restrictions, but are often not affluent enough to meet the financial costs of chronic illness. A family requires a huge sum of money to maintain the patient in a dignified manner, even without the cost of seeking improvement in the patient's condition. It is clearly a difficult situation if the patient's spouse or family has to take out a loan or spend money they were saving for their retirement in order to afford such care.

For example, the financial realities that would have confronted Mrs. R if her husband had gone into a nursing home made her feel distressed, angry, and helpless. Her husband was not eligible for Medicaid, and although he was eligible for Medicare, that plan would not pay any substantial amount for the cost of skilled nursing-home care. The cost of nursing-home care would eventually "pauperize" her. This situation infuriated her, and she spoke angrily about the inadequacies and injustices of the medical care system in this country. However, this opportunity to express her anger to the social worker appeared to serve a number of positive functions for her. It appeared, for example, that her financial situation was a more acceptable outlet and focus for her angry feelings than her husband and his illness, because she felt no accompanying guilt. Also, it gave her the opportunity to look into different possibilities and arrangements for her husband's care—which helped her feel she was doing something for him.

Mrs. R's alternatives were limited though. She could (1) pay for nursing-home care until her resources were practically depleted and her husband qualified
for Medicaid, (2) get a divorce so she would not be financially responsible for him, or (3) arrange for professional home care so he did not have to be in a nursing home. The social worker discussed these options with Mrs. R and tried to help her and the family arrive at a realistic, workable plan. Mrs. R found it encouraging to know that the burden she was facing was recognized and understood and that she should not expect to find simple solutions to the problem.

Guilt and Anger

Guilt and anger are two of the most common and painful emotions that the spouse of a chronically ill person deals with. A spouse can feel guilty for many real or imagined reasons, including the belief that one is to blame for the illness, that one was unable to prevent the illness, that one has not done enough to help, that one has angry feelings toward the sick person, that one is in good health and is enjoying oneself, or that one wishes the patient a quick and painless death. Preexisting guilt further complicates the situation by causing the spouse or other family members to feel the need to compensate for past inadequacies, to punish themselves, and to regard their behavior negatively, in terms of abandonment and rejection. The spouse's guilt may result in a need to withhold information from the patient or in overattentiveness to the patient.

Anger is another commonly experienced emotion for the spouse of a chronically ill person. Mrs. R, for example, was angry at her husband for getting sick and thus abandoning her. She was enraged that her husband could no longer take care of her, that she had to carry this burden herself, and that she felt she no longer had a partner in decision-making. She was also angry at her fate and believed her husband was robbing her of the good years they could have shared. She became annoyed, impatient, and resentful over his being a nuisance and making it difficult for her to go out and do things.

Mrs. R felt guilty about her anger, feeling sorry for her husband and knowing he could not help being as he was. She used the threat of the nursing home as a weapon of punishment sometimes, which then reinforced her guilt feelings concerning her desire to get rid of him. She felt guilty because she resented having to take care of him but thought she should not be feeling this as his wife. She frequently felt she had not done enough for her husband, though rationally she realized that she could not have done any more.

The spouse's increased worries and concerns about the patient and the added work and responsibility make the spouse resentful—which may lead to further feelings of guilt. The spouse may perceive that the expression of anger toward the patient is unacceptable and may instead direct hostility toward medical staffs and medical care systems or may direct it inward, thus fostering depressive feelings.

The goal of the social worker should be to help the spouse express these angry and guilty feelings and begin to accept and deal with some of them. The spouse can be helped to see that most people have such feelings. Furthermore, the social worker can help relieve the spouse of unrealistic self-reproach by pointing out the natural tendency of people in this situation to wonder if everything possible has been done. Whenever it is appropriate, workers should assure the spouse that he or she did whatever was possible to obtain help. By using such supportive techniques as understanding, reassurance, and universalization, the social worker gives the spouse permission to have feelings that might otherwise seem unacceptable. As Kübler-Ross has stated: "When anger, resentment and guilt can be worked through, the family will then go through a phase of preparatory grief. The more this grief can be expressed before death, the less unbearable it becomes afterward."

Conflicting Needs

Sometimes the illness of one family member activates illness in other members. A patient's spouse may become exhausted and depressed and find he or she no longer possesses the emotional and physical resources to face each day. A study by Klein, Dean, and Bogdonoff confirms that somatic symptoms—most frequently nervousness and fatigue—in-
"Family relationships undergo changes in response to a member's chronic illness. The relationship of the patient and spouse may become closer, or it may become more distant."

creased to some extent among patients' spouses. Mrs. R, for example, did not get enough sleep or rest and did not always eat properly. She cried a lot, was forgetful, and sometimes had difficulty concentrating. She disregarded her own physical and emotional needs in favor of caring for and worrying about her husband. She did not feel she should make things easier for herself or enjoy herself. It was as if Mrs. R were helping to assuage her guilt by punishing herself. She may even have had an unconscious wish to get sick herself so that she would not be able to take care of her husband and would have to put him in a nursing home. On a rational level, she knew that not taking care of herself would not help her husband or herself, though it was still hard to alter her behavior.

The social worker should encourage spouses to verbalize their thoughts and feelings and to "maintain a sound balance between serving the patient and respecting their own needs." Although the patient's spouse should not, for example, be urged to seek personal pleasures when he or she is not yet ready, the social worker can help the spouse to rediscover his or her own needs and to differentiate such needs from those of the patient.

Serious illness is certain to bring about changes in the family household. For example, there may be a reversal of roles. The husband of a sick woman may have to concern himself more with children, school, meals, and clothing than previously. The wife whose husband is ill may have to get more involved in business matters and financial affairs. Mrs. R, for example, appeared to have been rather dependent on her husband. She perceived her husband as being the strong one in their relationship. Now she tried to be strong but did not always feel successful and felt she was not functioning well under the increased pressures and demands. In general, it is likely that any spouse will find it difficult to adapt to and accept the changing roles, the shifting responsibilities, and the new demands necessitated by illness in the family.

It is helpful for the social worker to provide practical information and encouragement to the spouse who is taking on new duties and responsibilities. The practitioner should also give the spouse the opportunity to discuss his or her responses to the increased responsibilities. In addition, an assessment should be made of the family situation to determine if additional resources are necessary.

Anxieties and Fears

Chronic illness in a family stirs up many anxieties and fears. A spouse may feel anxious and threatened by the loss of security and the end of dependence on his or her partner. There is considerable anxiety when plans and dreams of a future that included the patient must be given up. Mrs. R was afraid of being alone, frightened regarding money and her own health and care, and afraid that her husband might deteriorate further and become totally dependent.

The social worker can give the spouse an opportunity to share painful, frightening feelings and can offer encouragement and support. The worker can also explore with the spouse the feelings attached to past relationships and experiences that may have been reactivated by the present circumstances. The practitioner should acknowledge and reinforce the spouse's abilities and strengths. The client can also benefit from reassurance that he or she will not necessarily face an unhappy future.

Family relationships undergo changes in response to a member's chronic illness. The relationship of the patient and spouse may become closer, or it may become more...
distant, isolated, or antagonistic. The spouse may either move too close to the patient to obviate feelings of guilt and loss or may withdraw from the patient as a means of minimizing the sadness of losing an important part of one’s life. Relatives and friends may become more considerate and attentive—possibly to the point of being patronizing and excessively concerned—or they may become neglectful. The family sometimes feels helpless, and particular members may expect others in the family to furnish emotional support or to help with family functions and labors. If such assistance is not forthcoming or takes on forms that are strange and unacceptable, resentment and dissatisfaction may follow. This decreases the effectiveness of the joint effort that is essential if the family is to be successful in coping with the situation.

In the case example being considered here, Mrs. R felt she had some friends on whom she could depend and that her younger daughter cared about her a lot, but there was disappointment with and anger at her other two children. She felt her older daughter was a cold, selfish, and inconsiderate person who never went out with her mother or took care of her father. Mrs. R also seemed to feel neglected by her son. On the one hand, Mrs. R was annoyed at both her older daughter and her son for offering to help with the costs of a housekeeper and nursing-home care and on the other hand, she was annoyed with the children for not giving her money. Mrs. R thought she was a failure as a mother, and she experienced doubt about how her children would treat her when she was older. She also questioned her trust of them.

Social workers should be aware of the need to have joint interviews with various combinations of family members. In this way, the members’ involvement in the family situation can be fostered, their significance can be acknowledged, and their individual needs can be assessed. Also, practitioners should give the spouse the opportunity to discuss his or her feelings about family relationships. As communication is facilitated, family relationships improve, and all the family members, including the patient, benefit.

Social Worker’s Role

In working with the spouse of a chronically ill family member, the social worker must evaluate the adaptive as well as maladaptive coping responses. Adaptive patterns need to be supported, and maladaptive patterns must be explored, clarified, and understood so that they may eventually be lessened. The social worker needs to be aware that coping demands and responses vary over the course of the illness. For example, immediately after the diagnosis, the spouse may exhibit denial—not believing the diagnosis and shopping around among doctors. However, if this denial persists, it should be gently but resolutely probed. The spouse may also seek isolation for fear of aggravating the patient and other members of the family. Later, anger may be the more obvious response. This may be directed at doctors, hospital personnel, bureaucrats, “the system,” the patient or family, or a variety of other possible targets.

Social workers must also be aware of and understand their own reactions to chronic illness and to the spouse’s stresses and behavior. They must confront their own feelings about such topics as death, illness, aging, their relationship to their own parents, and nursing-home care. In other words, the worker “must identify and come to terms with his [her] own experiences so that they do not interfere with his [her] attempts to understand the client’s perspective.” For example, the social worker may react to the client’s situation with many of the same feelings that the client is having. By recognizing these emotions though, the social worker can help guarantee that the quality of care he or she delivers to clients will not be adversely affected.

In summary, the social worker can help the spouse of a chronically ill person by sharing and understanding the spouse’s feelings of anguish, grief, fear, pity, sadness, or resentment. And the worker can attempt to encourage and clarify communication in the family, to assist in planning the patient’s care, and to help the spouse maintain a healthy balance between serving the patient and looking after his or her own needs.
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Notes and References


Is clinical social work different?

Toward a Definition of Clinical Social Work

Patricia L. Ewalt, Editor

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• What is clinical social work? How is it different from other fields of social work practice and the other helping professions?
• What knowledge and skills do clinical social workers need? Are these the same for all workers?
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