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Community care and deinstitution-alization: a review

Steven P. Segal

After one hundred years the family is once again being asked to assume its major function as care-giver for the long-term mentally ill. Is the family able to support chronic mental patients? Is it willing to assume responsibility for these patients? This article addresses these questions, as well as others, and discusses the implications of family policy for community care.

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THE POLICY OF RETURNING mental patients to their own communities assumes that the family will support individuals who can barely take care of their personal needs. However, few attempts have been made to specify the joint functions of the mental hospital and the family in providing care in the community for the mentally ill. Furthermore, little effort has been made to cite the responsibilities delegated to the family in the context of community care. Finally, there have been few attempts to elaborate on the social policies of community care and deinstitutionalization. This article addresses these issues, reviews the research related to the family as a helper in community care, and makes suggestions as to what the policies should be with respect to the family's role in this vital area.

GOALS AND FUNCTIONS

The concept of community care is an old one. It was reintroduced in the early 1930s as an adjunct of state hospital care. One of the goals of community care is to shift the responsibility for the care of patients from the institution to the community, with the institution acting in a supportive role to local mental health and social agencies, recreation and police departments, and the like. These community agencies coordinate their efforts to support the family in providing the care needed by the released patient. During the late 1950s and early 1960s, innovative state hospital programs such as that implemented by the Dutchess County Unit of Hudson River State Hospital in Poughkeepsie, New York, maintained as many as two-thirds of their inpatients in the community. This unit instituted an easy-in and easy-out policy through which the hospital supported but not necessarily housed the patients. Its major goal was to help patients maintain their social role in the family.

Another goal of community care is to prevent chronic disabilities that are attributable to prolonged periods in locked wards of understaffed and poorly run mental institutions. In the 1960s and early 1970s, however, this

goal became confused with the policy of deinstitutionalization, which involves the removal of the mentally ill from mental institutions. Although the goals of deinstitutionalization are to prevent chronic disability, protect patients' rights, and reduce the cost of care, hospitalized mental patients have been moved to communities without the provision of supportive networks in the community. For many of these released patients the cost of leaving the mental hospital has not been as great as the negative impact of the institution itself; for others costs have been considerable. The latter individuals have often been placed in communities in which they are unwanted and consequently become more isolated from social relationships than they had been in the hospital.

Gruenberg (1970) outlines the following functions of the mental hospital in providing short-term treatment of the mentally ill: (1) to use treatment procedures that require continuous observation, (2) to protect patients who endanger themselves or others, (3) to remove persons temporarily from an environmental stress during a period when they cannot cope with the stress, (4) to provide temporary relief for those who manage to live with patients, and (5) to establish communication between patients and the hospital.

In addition to these functions, the mental hospital has served as a primary provider of long-term mental health care to the aged, as maintainer of the physical and mental health of the chronically mentally ill, and as a supportive social community (often with many negative factors associated with it) for the chronic population. These responsibilities, however, have been shifted back to the family, leaving primarily those functions outlined by Gruenberg (1970) to the mental hospital.

In considering the responsibilities delegated to the family in the care of the mentally ill, these questions must be raised: What is the readiness of the family to accept these responsibilities? What is the impact of these responsibilities on the ongoing relationships in the family and on the long-term ad-

justment of the patients to the community? In view of these questions, the supportive role of the family can be examined in terms of three levels of prevention: primary, secondary, and tertiary. The author discusses each level, starting with the third.

TERTIARY PREVENTION

Tertiary prevention includes community and family planning that leads to prevention of long-term chronic disability and "institutionalism," that is, dependence on and total orientation toward the mental institution. Research has shown that it is possible to achieve these two goals (Segal, 1978). However, is the family ready, able, and willing to provide support for the chronic mental patient? To answer this question, the author will consider the following: (1) the current availability of family support for chronic mental patients, (2) the willingness of the family to assume the additional responsibility for the patient, (3) the impact of assuming these responsibilities on the family, and (4) the relationship between the placement of patients in a family context in the community and the prevention of chronic disability and institutionalism.

Availability of Family Support Although only a small proportion of all admissions to mental hospitals in any given cohort of admissions is isolated or has little family support available to it, this proportion becomes the large residual population of chronic mental patients in the mental health system. Each progressive cohort of returns to a mental hospital has a larger percentage of people in the cohort who have no family support or who have a limited amount of interaction with family members (Miller, 1965; Pasamanick, Scarpitti, and Dinitz, 1967; and Davis, Dinitz, and Pasamanick, 1974).

In a study of former mental patients, aged 18-65, living in community-based sheltered-care facilities in California, Segal and Aviram (1978) found that 52 percent of the patients rarely, if ever, had access to family members. In addition, 60 percent had

never been married, 35 percent had dissolved their relationships, and only 5 percent were married. When examined by sex, these figures revealed that 73 percent of the men as opposed to 44 percent of the women had never been married, 22 percent of the men and 50 percent of the women were either separated or divorced, and only 4 and 5 percent of the men and women, respectively, were married.

These figures reflect a pattern that is characteristic of the population who require long-term institutional care. As any given cohort becomes increasingly involved with the mental health system, its marital status begins to approximate those described previously. Given these statistics, the question must be raised as to the extent to which the family is available to meet the needs of the truly chronic patient.

Willingness of the Family to Assume Additional Responsibility To some extent the attitude of family members toward the ex-patient reflects their willingness to assume responsibility for a relative returning after a prolonged hospitalization or several short hospitalizations. Previous studies have shown that the attitudes of family members toward released patients seem to be significantly more positive and accepting than those expressed by members of society as a whole (Philips, 1963; Schwartz, Myers, and Astrachan, 1974; and Swanson and Spitzer, 1970).

Another indicator of a family's desire to assume such responsibility is its expressed willingness to accept the discharged relative back in the home. Research on this subject addresses three aspects. The first aspect relates to the family's attitude toward the return of the patient from the hospital; the second, to the family's attitude toward the former patient after he or she has been living in the home awhile; and the third, to the psychological, financial, economic, and social burdens placed on the family by accepting the relative back in the home.

When looking at the first aspect, Rose (1959) observed an increasing reluctance on the part of families to

accept discharged patients in the home as the number of years of hospitalization increased. In addition, Evans. Bullard, and Solomon (1961) reported that less than 50 percent of the families they interviewed favored the release of their relatives who had been hospitalized for five years or more. On the other hand, Freeman and Simmons (1963) reported that 95 percent of their family members wanted the patients to live in their household. And Wing and his associates (1964) found that no family members refused to take back their discharged relatives, although 13 percent actively opposed their return and 21 percent were doubtful about it.

Three related factors influence the family's willingness to accept the former patient: the severity of the patient's symptoms, pessimism about the ability of the patient to recover. and stressful conditions in the environment that are related to lower social-class status. Findings reported by Doll (1976) revealed a relationship between the rate of rejection of discharged patients by family members and the onset of severe symptoms. For example, although 83 percent of all the families studied said they wanted the discharged patients to come home, 58 percent of those with severely disturbed relatives opposed their return. In addition, 71 percent who wanted to exclude discharged patients from their social lives were living with severely disturbed former patients. Moreover, Swingle (1965) indicated that half the families of a group of mental patients believed that the patients could not recover from their illness and thus were unable to return home. In addition, Hollingshead and Redlich (1958) found that members of the lowest social class were most unwilling to accept their discharged relatives in the home.

When faced with the actual responsibility of having a discharged relative in the home, however, families seem to respond better to the patient. Barrett, Kuriansky, and Gurland (1972) found that of 85 families whose relatives had returned home following a hospital strike in New York State, 60 percent expressed pleasure about their

return. In addition, Brown and his associates (1966), in their study of 251 families, found that five years after the relatives' discharge, 75 percent of the families welcomed the patients in the household, 15 percent accepted them, and only 12 percent wanted them to live elsewhere.

Cost to the Family for Being a Caretaker The key issue as reported in several studies on this subject is the extent to which the former patient actually places a burden on the family. For example, Grad and Sainsbury (1963a, 1963b, and 1968) noted that 81 percent of the families who rejected their discharged relatives had economic and social problems, whereas only 62 percent of those who accepted the former patients had such problems. Moreover, Barrett, Kuriansky, and Gurland (1972) reported that when patients placed no burden on the household, they were more likely to remain in the home and thus stay out of the hospital. However, in his study, Doll (1976) found that 67 percent of the family members interviewed were ashamed because they had a severely disturbed relative living at home.

In view of the cost to the family for housing a former patient, family members seem to tolerate a great deal of disruption. Hoenig and Hamilton (1969) reported on 179 families who lived continuously with a former patient for four years prior to the research interview. These researchers compared the "subjective" reports of burden made by families with the "objective" rating of burden made by a social worker. They concluded that there was a great deal of subjective tolerance in view of the objective rating of a heavy burden experienced by families. Although 90 percent of the families in the study were sympathetic toward the patient, 56 percent of them expressed relief when the relative was admitted to the mental hospital.

Prevention of Chronic Social Disability and Institutionalism Research shows that the family plays a role in prevent-

ing as well as contributing to the development of long-term chronic social disability and institutionalism. For example, a study by Barrett, Kuriansky, and Gurland (1972) demonstrated a significant relationship between the attitude of family members toward discharged patients and the amount of time patients remained in the community. Results showed that 57 percent of the relatives of the patients who did not require rehospitalization were initially pleased with the patient's release and that only 7 percent of the relatives of those who were rehospitalized responded in this way.

In addition, a study by Greenley (1979) showed that discharged patients were more likely to be rehospitalized if their families expected them to have few friends outside the family, to create a childlike situation in the home, or to exhibit severe psychiatric symptoms. Greenley hypothesized that two types of dependent relationships existed between ex-patients and their families: the ambivalent and inconsistent and the ineffective and rejecting types, both of which involve a basic dislike and rejection of the patient. This hypothesis is consistent with the clinical observations of Stein and his associates (1975) who reported that repeated hospitalizations were a result of a pathological relationship between the patient and family. To deter such a relationship and prevent rehospitalization, these researchers are in favor of separating the patient from the family.

Other researchers also revealed that a relationship exists between the family's interactions with former patients and the readmission rate. For example, Brown and his colleagues (1958, 1962, and 1972) explored the emotional arousal hypothesis. This hypothesis suggests that some environments, which include the mother or wife, are too emotionally stimulating for ex-patients. Therefore, former patients living with their mothers or wives may have a higher readmission rate than those living with siblings, with distant kin, or in lodgings. Findings not only supported the hypothesis but also indicated that there was an optimal level of emotional arousal

above which patients were more likely to return to the hospital.

Early studies by Freeman and Simmons (1958 and 1959) generated the tolerance-of-deviance hypothesis. This hypothesis assumes that families with a high tolerance will continue to accept former patients even when they fail to perform tasks related to work and housekeeping. These researchers found that fewer relapses occur among patients living with families that have low expectations regarding patients' performance. But later studies by Freeman and Simmons (1963), Angrist and her colleagues (1968), and Michaux and his associates (1969)failed to demonstrate a relationship between tolerance of deviance and the amount of time a patient spent in the community.

However, the results of a study by Greenley (1979) supported a hypothesis concerning families' tolerance of symptoms. It was found that former patients who were rehospitalized at a faster rate than others lived with families that had a low tolerance for the expression of symptoms. Although further research is needed to replicate the findings of these various studies, there is reason to believe that a properly selected family environment can contribute to the length of time a patient spends in the community and thus to the prevention of long-term chronic social disability.

Factors that may contribute to the development of institutionalism are social isolation and the limited housing options available to a person. Institutionalism is not necessarily confined to the mental institution. Segal and Moyles (in press) reported that a significant proportion of the mentally ill residents in community care facilities developed a dependence on these facilities. In addition, Brown and his associates (1962) observed that discharged chronic patients who lived with their families were totally isolated in the home and evidenced behaviors associated with institutionalism. Thus, internal aspects of the family as well as the institutional environment are crucial in preventing the development of institutionalism among ex-patients.

SECONDARY PREVENTION

Secondary prevention seeks to reduce the negative effects of mental illness by early diagnosis and treatment. The family can help patients by maintaining its role structure, thereby shortcircuiting any attempts to exclude and thus deprive patients of performing normal family roles. As discussed previously, prolonged hospitalization is related to the increasing reluctance of a family to accept the patient in the home. In addition, researchers have offered other explanations for the reluctance of family members to accept patients. Pitt (1960), for example, argued that former patients exhaust a "reservoir of good will" toward themselves. And Dunigan (1969) concluded that there is a critical point at which the family's expectations of the patient's performance and the family's tolerance of deviant behavior change. Men coped well with one or two hospitalizations of their wife or mother. But with more than three hospitalizations, they tended to withdraw from their female relative, lower their expectations, and make more permanent changes in their household to allow for continued functioning without the presence of the female (Kreisman and Joy, 1974).

Mills (1962) pointed out that when the stress of having a mentally ill relative in the home became too great, families turned to the hospital for relief. Rehospitalization was often followed by a deterioration of the relationship between the patient and his or her family. Myers and Bean (1968) found similar results in their follow-up study, noting that the deterioration of relationships following rehospitalization was true in lower-class families.

Visiting is a crucial element to consider when examining the involvement of the family with hospitalized patients. Rawnsley, Loudon, and Miles (1962) studied records of 230 private patients. They found that 20 percent of the patients had no contact with their families outside the hospital. In addition, the key factor in determining rates of visitation was the length of time patients spent in the hospital. The longer the patients spent in the

hospital, the less they were visited. Sommer (1958 and 1959) also found that those patients who were hospitalized longer had fewer visitors and less correspondence with their family. Furthermore, Myers and his associates (1959 and 1968) reported less visiting and gift-giving among lower-class families.

It is unclear whether family members' failure to visit and their rejection of the mental patient are synonymous. In some studies they are (Alivisatos and Lykestos, 1964; and Myers and Bean, 1968). In others they seem to be independent (Gillas and Keet, 1965; and Rose, 1959). However, visiting and the family's involvement with the patient are related to negotiating the patient's release from the mental hospital, for it is the family who often negotiates the discharge.

An indicator of the restructuring of the family to exclude the ex-mental patient is the divorce rate of former mental patients. Adler (1955) found that divorce and separation rates among mental patients were three times higher than the national average. In addition, in a study of Puerto Rican couples, Rogler and Hollingshead (1965) noted that fewer spouses of schizophrenics said that they would remarry the same person to which they were currently married than did spouses of "normals."

These findings suggest that patients will have problems when trying to maintain their position in society and in the family. Thus, the absence of patients over time is crucial in determining their slow exclusion from the ongoing family process in which they were previously involved.

PRIMARY PREVENTION

From the perspective of primary prevention, the family is delegated two roles: that of helping to define illness and that of providing the social supports necessary to protect individuals from stressful conditions in the environment that can contribute to the development of mental disorders. Often, the family is reluctant to define the relative's problem as mental illness and consequently does not make

the initial diagnosis. The crucial element here in relation to the family's functioning is the attempt of the family to explain the relative's behavior in a normal frame of reference. It is unclear, however, what the consequences of the normalization process are. Although this process may delay treatment for many serious cases, it may also serve as a supportive device for milder cases and as a preventive measure in the labeling of patients. Therefore, much more research is needed on the role of the family in the normalization and diagnostic processes.

"Social margin" refers to the set of skills, resources, and relationships one draws on to survive in society. It is one's "social bank account" that enables him or her to cope with stress. The family is one's major and enduring source of social margin. It is the source of one's biological inheritance, interactional skills, and significant others who function as a support system to help

the individual mobilize his psychological resources and master his emotional burdens, share his tasks, and provide him with extra supplies of money, materials, tools, skills, and cognitive guidance . . . [Caplan, 1974, p. 6].

Loss of a family member through death or divorce, genetic predisposition, and intrafamilial patterns of interaction have all been implicated as factors affecting one's risk of developing a psychological disorder.

More specifically, with respect to the role of the family in providing social support, the longitudinal study of Kellum, Ensminger, and Turner (1977) are most important. These researchers delineated as many as eighty-six family structures on the basis of different combinations of household members who lived in an urban area in Chicago. They pointed out that these different combinations were able to provide different levels of support for their children and therefore were differentially able to insulate them from the environmental stresses related to mental disorders. Furthermore, they noted that children in single-parent families faced greater threats to their psychological well-being than did those in other familial structures. The former encountered more threats because of the limited availability of social supports. However, in families in which the presence of a second relative served as an enabling or protective resource similar to that of the traditional nuclear family, the risks for mental illness were significantly reduced.

In addition, Robins found that

children raised by both their own parents were more often well than other children, and children for whom responsibility was vested outside the parents were least often well [1966, p. 1741.

Although this finding was attributed solely to the virtual nonexistence of an antisocial father in cases in which children were reared by both parents, it raises questions about the importance of support systems in the maintenance of psychological well-being. However, little is known about the role of the family as a support system in helping individuals to cope with the precipitators of mental disorders.

IMPLICATIONS

Policies That Support Tertiary Prevention The original study of Pasamanick, Scarpitti, and Dinitz (1967) demonstrated that mental hospitalization could be prevented by administering antipsychotic medications to discharged patients. However, it was conducted with individuals who had intact families, not with long-term chronic patients who were often without family support. This suggests the need for the development of substitute family units, along with accompanying service supports, as an alternative for long-term chronic patients. Such substitute environments as small group homes and long-term care facilities that do not resemble institutions but are more family oriented should be organized and funded. To accomplish this, Section 8 of HUD (Housing and Urban Subsidized Housing Development) Programs could be expanded.

In addition, a true system of community care is needed rather than one that simply emphasizes the moving of people out of institutions into the community without proper social supports. The planning of activities for discharged patients should be an essential element in the system. Such planning could be conducted in coordination with a mental hospital or with a local community mental health center.

An implication of research on community care relates to the amount of burden absorbed by families who take on the responsibility of their chronically mentally ill relatives. For these families, options related to respite care must be considered. In the past, as previously noted, the hospital served as a temporary relief for patients who could not cope successfully with stressful conditions in their environment and for family members who lived with patients at significant cost to themselves. Either the hospital could again be used in this way, emphasizing an easy admission and easy discharge policy, or "crisis houses" in the community could be set up to fulfill this function. Crisis houses would probably be more desirable because of their location in the community and the nonmedical label attached to such facilities. The latter might be most helpful in preventing the occurrence of any iatrogenic effects associated with being in the hospital.

Another implication related to the reduction of burden on the family suggests the need for the development of a sound supportive social work program. Grad and Sainsbury (1963a, 1963b, and 1968) compared a traditional hospital program with a community care program. They observed that relatives of patients in the community care program experienced many more burdens than relatives of patients in the traditional hospital program. In addition, the major factor that influenced the amount of burden experienced by the family was the regular visits made to the home by the social work staff of the traditional program. It thus seems that a community care program that provides supportive social work services can be effective in reducing the amount of burden placed on the family.

In considering institutionalization, the problem of sheltered-care facilities or family households as community

back wards should be addressed. To cope with this situation, policies are needed that aim at creating educational programs for community care workers and relatives of chronic mental patients. These programs should emphasize that social isolation in sheltered-care facilities or the family could lead to the development of the same type of dependencies experienced in the mental institution and could have negative effects on family life. They should further emphasize that the high expectations of workers and family members would enable former patients to fulfill their maximum potential.

In view of the emotional involvement of patients with other family members, someone should determine whether patients would function better in a sheltered-care facility than in the family unit. A social worker could make this determination and help the family work through its own needs and involvements with the former patient. This suggests, therefore, the need for a strong locally based unit of social workers who would develop optimal placements and provide supportive services to chronic mental patients living in the home or in community care facilities.

Policies That Support Secondary Prevention To prevent the exclusion of former patients from the family, the hospital and other supportive facilities such as crisis houses should function as short-term resources in providing community care. Patients who return to these facilities for brief periods of time should not be viewed as failures but as persons who want to cope with their illness in an institutional setting. Without doubt the easy-in and easyout policy being advocated here places a burden on the family, especially in the area of work and social activities. Therefore, the family should receive supportive community services during the initial stressful periods of brief hospitalization.

Unfortunately, some patients may be unable to resume their previous level of work and social-role functioning. In this case, supports should be offered to other family members in

meeting the demands of some of the roles previously performed by the patient. For example, work training programs could be offered to the wives of released patients who have experienced repeated hospitalizations and who seem to be suffering from a more or less permanent or total disability. This type of program might help the family maintain its commitment to the former patient and reduce the amount of pessimism and disillusionment often associated with helping the long-term chronic patient. Although a change in roles can create a significant amount of stress for individuals in the family, people often rise above stressful situations and maximize the potential of these situations for their own growth.

In addition, as part of the general

orientation toward community care,

social workers should help family

members understand the fine line be-

tween maintaining realistic expecta-

tions and maintaining a "high expecta-

tion environment." The former pre-

vents the disillusionment of family

members; the latter prevents patients

from drifting into chronic dependence

and enables them to fulfill their poten-

tial. Although these may seem to be

contradictory goals, the "fine tuning" of the balance between them is crucial to enhanced patient outcome. **Policies That Support Primary Preven**tion Further research should examine the role of the family as a diagnoser of mental illness, especially the

family's attempt to normalize all behavior before recognizing the presence of illness. In addition, education programs that promote a positive understanding of mental disorder should continue to be sponsored by federal agencies. These programs should include materials that illustrate the importance of the family in supporting the mentally ill. Finally, the social

perhaps serve as an extended family. After one hundred years the family is once again being asked to assume its

supports necessary to prevent the de-

velopment of psychological problems

should be provided. These supports

should include child care and pro-

grams that enable single parents to

exchange supportive activities and

major function as care-giver for the

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