The role of social work in contemporary home care planning[1]

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Patients on home care are increasingly being required to assume responsibility for sophisticated medical technology. Social changes, such as deinstitutionalization, and financial trends, such as prospective reimbursement, serve to fuel the momentum of home care. Trends affecting the American family, such as increased mobility and changing women's roles, contribute to stress in the face of increasing responsibilities for home care. It is the role of the medical social worker to find creative solutions in coordinating transfer of the patient from a hospital-based team to a multiplicity of nursing agencies, vendors, and social service agencies providing care in the home. Counseling the patient and family in making temporary or permanent adjustments is essential in the preparation for home care. There is an acute need for further research on the psychosocial consequences of sophisticated medical care in the home.

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The role of the social worker within the context of burgeoning home medical technology needs to be defined, and in particular, those social trends which complicate home care planning and obviate the need for pre-discharge counseling should be defined. The social worker serves as a liason between hospital and home care teams and plays an important part in facilitating the patient's return to family and society and redefining his or her roles therein.[1] This concept of re-entry requires further research into definition of the quality of life for the home-bound patient who is dependent on medical technology. The effectiveness

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of the social worker in adjustment counseling and discharge coordination also needs to be assessed.

Social trends

During the past century, the focus of medical care has shifted from the home to the hospitals as they emerged in the 1920s and 1930s and now once again to the home. Medical social workers became involved in the rise of hospitals early on as partners of physicians and nurses in easing the patient's transition to the home setting.[2]

Technological developments and social trends gave impetus to the movement toward home care in the past decade. Home birth and hospice care gave rise to self-help movements which emphasized taking responsibility for one's own health. The trend toward decentralization and deinstitutionalization has driven many back to their homes as the center of their lives. Naisbitt explains this trend as "disillusionment" with institutions and return to self-reliance.[3]

More recently, the trend toward prospective pricing as a means of reducing health care costs has served as an incentive for early discharge and resulted in greater emphasis on medical care in the home. Technological advances, such as permanent central venous catheters and continuous ambulatory perioneal dialysis (CAPD), have made home care both safe and effective. At the same time, changes in the nature of the American family have complicated home care planning. Traditionally, adult women have been responsible for home care; but with more women employed, fewer are available for care of an ill spouse, parent, or child. With families in the 1980s increasingly mobile, often an extended family is not available to assist in treatment,[4] while at the same time more sophisticated care is being demanded of the family.

In response to these trends, hospitals developed home care teams to specialize in areas of new medical technology in the home setting. Social workers have been part of these teams since before the mandate of the End-Stage Renal Disease (ESRD) Medicare Amendment passed in 1972.[5] The role of the social worker is to sort out the ways in which these social forces affect a given family and to enhance the ability of both patient and family to cope with the practical technological realities of day-to-day home care.

Deciding on home care

With the emergence of the self-help movement, patients and their families are more informed and more active in medical decisions. The social worker enhances the patient's self-determination and assists him or her in making the transition from a passive role to self care.[6]

Gutheil et al reinforce this point, noting that informing the patient establishes a "therapeutic alliance" which gives him or her a greater degree of control and hope in spite of the uncertainties which lie ahead.[7] Coulton et al note that lack of involvement in post-hospital planning can have negative consequences for the patient, including depression, dissatisfaction, regret, and even a higher mortality rate than those given a choice.[8] It is apparent from these findings that the social worker must inform the patient of options for post-hospital care, give him or her adequate time and support for the decision-making process, and enable him or her to be realistic and hopeful about his or her choice. The effectiveness of social counseling in enhancing patient autonomy, strengthening the alliance with the physician, and supporting compliance requires further study.

Support during home care training

Dependency fostered by repeated hospitalization inhibits the training process but is not in itself a contraindication for home care. Long-term hemodialysis at a medical center appears to promote such dependency for most patients; even transplanted patients return to "hang around" the dialysis center.[9] In our clinical experience, some total parenteral nutrition (TPN) patients who have had several operations have adapted so well to the passive-dependent role that the prospect of self care is met with anger and resentment. Families may accept without question the fact that the patient requires their attention, further inhibiting the patient from taking responsibility. In TPN, particularly, we insist on an adult assuming most of his or her own care, finding better compliance and fewer medical complications with this approach, as reported also by Hughes et al.[10]

As the day of discharge approaches, the patient experiences strong ambivalent feelings. His or her enthusiasm for the return home is tempered by a fear of separation from the team and the safety of the hospital and insecurity about assuming total responsibility for his or her own care. In our experience, the family of the chronically dependent patient may have doubts about their ability to assume total care of the neurologically impaired or ventilator-dependent patient. Reas-

surance that they will not be abandoned helps to allay their fears; and encouraging them to phone about even minor problems or concerns is essential, particularly during the first two weeks of independent care. A 24-hour on-call system available through the hospital and vendor is a must. The family can enhance their ability to cope by setting up the home (including most of the necessary equipment) the week prior to discharge. Rooming with the patient for 24-hour periods prior to discharge clarifies their expectations of home care.[11]

Coordinating the discharge

At the time of discharge, several practical considerations must be met. The introduction provided by the social worker can ease the transition from dependence on the hospital team to the home care health agency. Until recently, most such agencies were unfamiliar with complex procedures and unwilling to take responsibility either for them or for the patients. Now, however, many non-profit organizations, proprietary agencies, and vendors have IV nurses and other specialists to assist them. Shift nursing at home continues to be available only to those with exceptional insurance coverage or substantial financial resources; however, some states are now providing reimbursement for home care for the indigent provided it is less expensive than institutional care.[12] Nevertheless, despite reassurances from the social worker and vendor, the patient fears denial of care on financial grounds which could lead to death.[13] At the time of discharge, the social worker may refer the patient to a local counseling agency. However, a study of discharge planning for general hospital patients corroborates our experience that the psychosocial needs of many patients and families are not adequately met within one month after discharge.[14]

Re-entry

Adjustment to the home environment results in changes in family roles, work rules, social contacts, and community involvement. Changes of the family role are particularly awkward in the period immediately following discharge.[15] Johnston recommends early interaction with the family, discussing each member's tasks, and anticipating how those tasks will change after the patient arrives home.[16] She also characterizes the "Catch 22" that the patient experiences in returning to work. Many physically rehabilitated patients must restrict their schedules due to machine dependency but otherwise feel well enough to work. In one sense, these patients have experienced a catastrophic illness and deserve disability benefits under Social Security and Medicaid. However, if they choose to return to work, they risk not only losing insurance benefits under these programs but also possibly being denied insurance under a new employer due to their pre-existing illness. California is a recent exception to this, allowing previously disabled persons on Medicaid to return to work.[17]

Long-term adjustments

Families resolve some of these re-entry issues within the first six to 12 months of home care. Farkas' discussion of spouse care givers notes that he or she may feel guilty about not having brought the patient in for treatment sooner, as well as anger at assuming the patient's role in the family and being cheated out of a normal life together.[18] One study reports an 87% incidence of "chronic fatique, anger and depression" among care givers in the home.[19] Social workers have demonstrated the effectiveness of group counseling sessions in relieving some of this stress.[20]

Conclusions

In home care planning, the social worker views each patient and family unit in the context of social and technological change, promoting the patient's full participation in the decision to return home, anticipating problems that might arise, and helping the patient work them out and adjust to his or her new role. Coordination of discharge with nursing agencies, vendors, and social service organizations gives the social worker the responsibility of facilitating a smooth transition from hospital to home care. Implicit in these tasks is the need to evaluate the effectiveness and consequences of the home care plan. The appropriateness of home care for certain groups, such as TPN for cancer patients[21] and home care ventilation in progressive neuromuscular disease,[22] needs further evaluation from both a psychosocial and ethical perspective. Both patient and family must comprehend the extent of care required prior to agreeing to leave the hospital. Psychosocial costs to the patient, such as loss of income and changes in both vocational status and quality of life, should be quantified for each type of technology,[23] as has been done for cancer patients.[24] Stress on family care givers

should be monitored and effective forms of interaction developed and tested. These areas of research would assist the medical team in choosing appropriate candidates for home care and also help the patient and his family prepare for possible stress and changes in life style.

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