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ABSTRACT

Frequently any move away from independent living for an elderly person is viewed as a downhill road to the nursing home and ultimate death. Adult foster care has been viewed as one such step closer to institutionalization. Service provision to the elderly needs to be viewed on a continuum where the elderly are seen as being capable of moving in and out of supportive living arrangements when the need arises. Barriers to providing this care are identified with future needs highlighted.

INTRODUCTION

Most elders are quite able to lead independent lives, choosing to live where their financial resources allow. But there are other senior citizens who are in need of supervision whether this be medical and/or physical. Bricker indicates the potential need:

> In the U.S. about 80% of the population in the 65 to 74 age bracket have chronic medical disorders of some kind. This rises to 87% for those over 74; 50% of the people live alone.[1]

The quantity and type of supervision needed, though, is the question that arises for many of these elderly who cannot live alone. Care is viewed on a continuum, ranging from independent living to dependent living (i.e., institutional care). Deciding where a particular individual falls along that continuum is not easy. If an individual has a medical complication that limits mobility thus making it difficult to prepare meals and maintain a residence, is this person a candidate for a nursing home? In the past, few intermediary services were available in the community and this person would have been placed in a nursing home.

The elderly are often placed in an institution even when the placement is inappropriate, but rarely are these elderly persons placed back into the community. With the elderly, professionals typically deal only with the individual's decline and subsequent dependence. Other populations, however, move in both directions along the care continuum due to alternative care options. The mentally retarded or disabled veteran populations, for example, move from institutional living to group home care or even independent living. This two way movement along the continuum is an important dimension of care, for it identifies the fact that not only do physical and emotional needs vary and change over time, but so do service needs.

This article addresses the issue of long term care for the elderly with particular emphasis on adult foster care and the difficulties in promoting such alternatives to institutionalization.

Models of Care

What is adult foster care? Foster care has been defined as a service intended to provide sheltered living arrangements and personal care to individuals who because of limitation in functional capacity and support system are unable to live independently.[2] Ohio law governing the licensing of adult foster care facilities uses this definition:

> A personal residence or family home in which accommodations and personal assistance are provided to not more than five unrelated adults, at least one of whom receives supplemental security income pursuant to Title XVI of the "Social Security Act," 49 Stat. 620 (1935), 42 U.S.C. 1382, as amended or poor relief pursuant to Chapter 5113 of the Revised Code.[3]

Where does foster care fit on the continuum of care? There are two basic models of health care for the population in general: acute care and long term care. Acute care is viewed as short term treatment that may or may not require extensive and intense medical treatment. It is possible that the

individual with minimal time for recuperation can return to normal functions after receiving acute care. There are some persons, though, who are not capable of resuming normal activities and become candidates for long term care. It is important to explore more typical long term care arrangements in order to discuss further alternative forms such as foster care.

Defining Long Term Care

Long term care has been defined numerous ways. The Commission on Chronic Illness defined long term care as any care that extends beyond ninety days.[4] The American Hospital Association, on the other hand, defines long term care as any hospitalization that exceeds thirty days.[5] Although these are accepted definitions in some circles, the concept of long term care should be rooted in the need for assistance with activities of daily living, and not need for hospitalization. Dr. Sylvia Sherwood defines long term care:

> Someone is a long term care person who has reached either suddenly or gradually, a state of collapse or deterioration in human behavioral functioning which requires - for survival, slowing down the rate of deterioration maintenance, or rehabilitation - the services of at least one other human being.[6]

Sherwood's definition is all encompassing, for its considers both the individual who may need just a meal prepared

as well as someone who needs institutionalization. It also acknowledges the potential for rehabilitation that incorporates the idea of returning to independent living. An historical development will help to illustrate the scope of long term care.

Historical Development of Long Term Care

Long term care is a term frequently associated with institutionalization. Although it technically has a more generic definition, long term care is viewed as encompassing any type of care that is a necessity to assure the optimal functioning of the individual. Long term care is a relatively recent development that has become the product of sheer demography: people live longer, therefore, there are more persons who suffer with long term illness. While in 1939 about 1,200 nursing homes (25,000 beds) provided various levels of care,[7] in 1977 there were approximately 18,3000 homes that provided 1,383,6000 beds.[8]

Other factors important in producing the phenomenon of long term care were of a legislative and economic nature: the Social Security Act, 1935, the Hill-Burton Act, 1946, the growth of private hospital insurance in the 1950's, and the passage of Medicare and Medicaid in 1965. The Social Security Act refused payment to residents of public institutions, an effort to prevent the public poor houses from being repositories for the elderly. This Act put the money in the hands of the people. The Hill-Burton Act was designed to encourage the building of nursing homes. This Act insured federal financial aid to those willing to build and operate nursing homes. But still, these

solutions did not solve the problem of the growing numbers of disabled elderly who could not find adequate care. With the growth of private hospital insurance in the 1950's many found their way to hospitals and stayed longer than was necessary due to the lack of alternatives. Nursing home care was typically excluded from this private health insurance coverage. This is one of the reasons that led to the passage in 1965 of the Medicare and Medicaid amendments to the Social Security Act. These amendments provided medical coverage for the elderly (Medicare) and the poor (Medicaid) and made available less expensive lower level care facilities. Medicare provided for extended care facilities while Medicaid provided for the skilled nursing home.

One last feature that has made a great contribution to the development of long term care is the change within the American family. Studies indicate a negative correlation between number of children and institutionalization (i.e., the greater number of children an individual has the less likely they are to reside in a nursing home). It is not that children are less willing to care for their older relatives, but rather that mobility, financial burdens, space limitations and career demands prohibit such care in many more families. The zero population growth has meant that people have fewer children so that the older person has consciously limited living options in later life and increased the likelihood of institutionalization. The future family care of the elderly does not look much brighter with the increased divorce rate, remarriage and disruption of support services which mean greater financial burdens in the form of family and child support.[9]

Quality of Life in Long Term Care

The nursing home, the most typical long term care setting, is viewed as an extension of the acute facility and tends to provide services to the residents within a medical milieu. With this acute care approach, the institutional setting has major limitations in adequately providing for the psycho-social well being of its residents. Furthermore, many individuals in need of supervision do not need the degree of care provided in a nursing home.

Bishop, Bolton and Jones suggest that more appropriate placement of patients could make a tremendous contribution to quality of care and therefore quality of life.` They state:

> Perhaps the single largest factor behind the lack of adequate or appropriate long term care for a large number of the chronically disabled is the general lack of formal alternatives to institutional care. Once it is determined that a person is incapable of living at home without some additional support or health care, the question of whether he or she will remain in the community depends upon existence of social (usually family) support, the adequacy of financial resources, and the availability of non-institutional social services. Unfortunately, many of the elderly are poor and either have no spouse or relative at all or no relative

> living near enough to assist them in basic services. In other cases, the families of the elderly may be unwilling or unable to provide assistance. If there is no social support provided by the family or no formally provided care in the home, the alternatives are a nursing home, in which long term services are heavily subsidized by the government, or no care.[10]

Research by Lawton and Nahemow indicates that variations in living environments have a significant impact upon the functionally impaired person.[11] The environment impacts the potential for adjustment, extent of social integration and degree of independence of the elder. In a restrictive environment, the individual exerts little energy in coping with that type of setting, thus resulting in personal deterioration. On the other hand, when an individual is expected to cope with the excessive demands of an environment, the resulting frustration can cause an equally debilitating situation. The optimal environment is one where there is a balance between the demands that the environment makes on the individual and the resources of the individual. For instance, a person needs to live where he/she will be required to keep in optimal physical health. Therefore, bringing meals to a person's room, as is the case in most acute care facilities, when the person is able to walk to a common dining room, may be debilitating to that person's well being.

It is obvious that the inappropriate placement of an individual in a nursing home can create physical as well as emotional decline. If the person needs little supervision but is unable to live independently, it is obvious that the normal routine of the nursing home would require that an individual minimally participate in daily activities. It is this type of person, one that needs a certain level of supervision but who requires little medical care, that is a candidate for foster family care.

Alternatives to Institutionalization

Although the passage of legislation through the 1930's, 40's, 50's, and 60's has increased accessibility to institutions for those disabled and in need of long term care, the tide is now beginning to shift away from institutionalization. One reason that this shift has occurred for the population of elderly is the increasing cost of institutionalization.

From 1966 to 1975, nursing home expenditures increased more than 500 percent.[12] Data from the 1977 National Nursing Home Survey indicate that the average cost per resident per day was $24.04 ($8,774 per year).[13] As stated earlier, many residents of nursing homes are in need of care but do not require the extensive care provided by nursing homes. This financial as well as physical reality has led to the search for alternative forms of care.

More and more people have looked toward the community to provide these alternatives. Although the family has served as a

transitory step between hospitalization and independent living for many people, this alternative is becoming less viable with the changes in family organization (i.e. frequency of divorce, remarriage and residential mobility). Another alternative has been boarding in private family homes of unrelated persons. This concept of private family care has been in operation since 1885 when patients of mental hospitals were returned to private homes from institutions. Historically, though, there is little evidence for the use of the family care concept in care of the elderly. Many issues are beginning to force the consideration of family care for the elderly.

Cost

The cost of nursing home is high due mostly to the medical care provided. Often times, people placed in nursing homes do not require medical care, but rather are in need of physical supervision. Placement of a person in a nursing home who does not need the skilled care a nursing home provides is a waste of financial resources. An alternative form of care such as family care can be financially advantageous for the individual and represents a far less restrictive living environment.

Guardianship

The degree of needed supervision is difficult to determine. Supervision can be interpreted to mean the need for guardianship. But the consequences of the appointment of a guardian for an individual can be drastic, for guardianship means that a person becomes incapable of performing any legal

act. An elderly person may only need help in certain areas like selling a home and not need the total supervision that the current guardianship regulations require. Presently there is no legal provision for partial guardianship.

Foster care may be the type of care from which the elderly person, having experienced partial deterioration, could benefit. This type of living arrangement would provide supervision when necessary but also allow the freedom of self determination and legal power that is important for a person's sense of well being.

Foster Care as an Alternative to Institutionalization

Numerous studies identify the fact that many nursing home residents can perform activities of daily living without assistance, indicating that institutionalization may be unnecessary if services are available in their communities. Generally speaking, most elderly people prefer to live independently in the residential environment where they resided during their middle years. Although institutionalization provides physical security, it separates the elderly from a familiar world, as well as diminishes their sense of privacy and individuality.

Foster family care is a type of care that approximates the normal living environment with the added dimension of supervision. It allows the older person an element of privacy as well as the freedom not possible in a larger protected environment of the nursing home.

Although foster care offers an alternative living arrangement to elderly in need of care, there are certain inherent problems. One obstacle to the use of foster care on a large scale has been identified by Kahana and Coe.[14] They believe that foster home placement may be unacceptable to families of older persons because this option points to the fact that the older person can be maintained in the community and that the natural family is unwilling or unable to provide the care. Two further problems center on the caregiving relationship per se: the older person's needs and the demands made on the care provider. Unlike foster care for children, where the child moves toward independence and gaining the capacity to contribute to the foster family, the elderly person is viewed as only moving toward greater dependence. Rehabilitation is typically not considered for the older person as it is for other recipients of long term care i.e. the mental patient, disabled veteran, etc. With this view of the older foster care recipient, many potential care providers are reluctant to offer their foster homes to the elderly. They typically view the older persons' dependence as restrictive to their own family life with the caregiving relationship only ending with the older person's death.

The view of an older person as debilitated and dependent is the stereotype that many people have of the elderly in or out of foster care. Changing this view will mean altering attitudes towards the elderly. New legislation will aid in this effort. Policies that help to pay for foster care services will heighten their feasibility among the elderly and provide a level of care that lies somewhere between acute care and institutionalization

on the care continuum. It is also possible that increased financial support and subsequent utilization will begin to change the image of the elderly on the care continuum as only capable moving toward greater dependence.

A word of caution should be noted with the discussion of moving from an institutional setting to an alternative form of care e.g. foster care. Although it has been stated that many nursing home residents could be cared for in other settings,[15] it may not be feasible for the person once institutionalized to return to the community. Kane and Kane state: "The ability to leave an institution and return to the community depends on the quality of the institution and institutionalization as well as the availability of appropriate support system.[16] Once accustomed to the institutional setting, the older person may not be able to tolerate a less restrictive care arrangement such as family foster care. Also once the person has been placed in a nursing home, how does he/she leave the institution unless a person in the community facilitates the move? Very few older persons in this situation could make these arrangements themselves.

Who Will Pay?

The benefits of Medicare and Medicaid have lessened the financial burden of institutional care, but little has been done to help provide home health services. Although Medicare does have home health benefits, utilization of these benefits by the elderly is frequently limited due to eligibility requirements and a limitation of the number of home visits permitted per year

per client. Thus, the very service is restricted that would diminish institutional placement and allow the elderly person to remain at home. Although private payment for these home health services is possible, the cost is often too great for many elderly persons. The result has been the extended use of acute care facilities or the unnecessary utilization of a nursing home.

The issue then arises as to the cost effectiveness of home care. A recent report by the Department of Health and Human Services states that the research evidence on the subject is mixed. A study by the Health Care Financing Administration (to be published) estimates that home care is much less costly than nursing home care; "...a year of home services (based on the 1975 average of $428 per month for those 65 years of age) costs approximately half the monthly bill for nursing home (using a 1975 nursing home cost average of $800 per month).[17] The Congressional Budget Office, on the other hand, states:

> Few studies are available to support the proposition that home care is less costly than nursing home care...the most widely cited home care studies concerning cost saving are of short term acutely ill patients.[18]

Although no payment plans are in place, several alternatives have been proposed. One such plan is to use disability allowance for long term care.[19] Providing cash or in-kind benefits based on disability levels may help the older person

avoid nursing home placement and use foster care which is intended to provide sheltered living arrangements and personal care to individuals who do not need around the clock care but because of limitations cannot live independently. Gruenberg and Pillemer propose that disability allowance payments only be made to those persons not residing in institutions. This would be in keeping with the goal of disability allowance to encourage community living . A similar payment system is in operation in some states that have chosen to supplement SSI payments for individual in foster care.[20]

In discussing expenses for long term care services under a prototype insurance program, Christine Bishop describes how foster care services would be financed. Once an individual is certified as eligible to receive care and after meeting a deductible, they would be able to choose among a wide range of services one of which would be foster care.

With discussion of meeting of current cost requirements of foster care provision there are two comments of caution. Pollak and Hilferty note that "current payment levels are inappropriate in forecasting the future budgetary and social cost of foster care if significant expansion or improvement of foster care is contemplated, since increased payment levels are then likely to be required.[21] In the same vein the impetus to explore such care options frequently rests on two beliefs; that the quality of life for the older person will be better and also cheaper. It has been noted though that, "there has been almost no public discussion of what should be done if alternatives prove to be simultaneously better and more costly.[22]

It appears that the issue of financing alternatives to institutionalization hinges on the idea of gain either for the individual or for the society at large. There is little data to support either contention at this time, thus stalemating the issue of financial payment for alternative forms of long term care.

Evaluating Adult Foster Care Program

Program evaluation in adult foster care has not been actively pursued. The evaluation of these programs should answer the question of what impact do such programs have in relating to identified goals and objectives. In evaluation the basic questions become, who is to be measured?, what is to be measured?, and when should measurement occur? In a comprehensive adult foster care program several groups of individuals are targets for evaluation, e.g. the aged clients, care providers, foster family members, agency representatives or the community at large. Thus far the focus of evaluation has primarily been on the care providers,[23] agency representatives,[24] and the community at large.[25] Unfortunately, no controlled evaluation research related to foster care exists. The question: do older people who are eligible for foster care benefit more from this form of care than that of institutionalization has yet to be answered.

Evaluation of these programs would highlight the battle that community based services (like foster care) need to fight in order to exist. Two national surveys including foster care

conducted by the Gerontology Center, University of Louisville reveal that:

> a variety of state and local agencies were performing many functions within one given program; that agencies involved in surrogate care (foster care) were often unaware of what other agencies were doing; that gaps and overlaps exist in the areas of regulation, placement, training, delivery of services, and payment mechanisms; and the central health and social planning agencies are only minimally involved in this form of community care.[26]

The barriers in delivery of foster care services as well as the impact that these services have on the older person are still only comprehended at a rudimentary level.

Summary and Conclusion

The field of long term care and, specifically, the subject of adult foster care are relatively new considerations in the quality of life for the American elderly. The possibility of choosing the type of care needed is becoming greater although financing is still a serious problem. Foster care has been a dimension of long term care for many segments of the population and now extends to include the elderly. An older person may need a foster care living arrangement to provide a greater sense of well being than was possible when that person lived

independently, but an older person may also find life in a foster care home more rewarding than it was in a nursing home.

Further evaluation of existing programs is needed to answer two crucial questions:

1. What impact does foster care make on the well-being of the older person?

2. What is the realistic cost of foster care in relation to institutionalization?

It is agreed that alternative options like foster care in long term care should exist. How can foster care exist and why should it exist are questions needing further explanation.

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