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Stigmatized and Perpetual Parents: Older Parents Caring for Adult Children with Life-Long Disabilities

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ABSTRACT. Common misconceptions in the popular press focus on the dependency of the aged population, or cast the elderly in the role of the "greedy old geezer." However, large numbers of elders provide care for family members rather than receive care. This paper explores the unique stresses and strains in the caregiving relationships between older parents and their adult children with developmental disabilities or mental illness. Implications for practice and policy are drawn.

Caregiving for older adults has been well researched, and professionals, especially those in the Alzheimer's field, are increasingly aware of the stress and burden involved in caregiving situations (c.f. Pearlin, Mullan, Semple, & Skaff, 1990; Zarit, Todd, & Zarit, 1986; Zarit, Reever, & Bach-Peterson, 1980; Zarit, Orr, & Zarit, 1985). Yet, the needs and experiences of older parents with dependent adult children have only recently begun to receive attention (Jennings, 1987; Lefley, 1987; Schreiber, 1990; Smith & Tobin, 1989). Despite many similarities among the different types of caregiving relationships, elderly parents who care for adult children with life-long disabilities have unique challenges and special needs. Research has documented that older parents experience health-re-

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lated problems and emotional worries that are derived from the cumulative stress of caregiving demands (Fadden, Bebbington & Kuipers, 1987; Gold, Dobrof & Torian, 1987; Caserta et al., 1987; Scheyett, 1990). Other examples of the unique challenges include the history of caregiving. For instance, in many of the other types of caregiving relationships, the caregivers had long periods of time in their lives where they did not have to contend with caring for a person with "deviant" behavior. In addition to the everyday stress and strain, this special type of caregiver must deal with the emotional drain of a child who will not fulfill the dreams and hopes of every parent. Many of these parents were also once stigmatized as parents for having children with special needs.

This article examines the experiences of these forgotten older care providers. Two common caregiving situations will be explored: the "perpetual parents" who are caregivers of adults with developmental disabilities, and the "stigmatized parents" who are caregivers of adult children with chronic mental illness. By using case studies, the unique stresses of each of these caregiving situations will be discussed. Additionally, the service needs of aged care providers will be presented.

PARENTS OF ADULTS WITH DEVELOPMENTAL DISABILITIES: THE PERPETUAL PARENTS

Over the lifespan of the current cohort of parents, life expectancy rates for people with developmental disabilities have increased dramatically. This situation is especially evident in certain forms of genetic retardation, for example in Down Syndrome. Individuals who have this form of mental retardation, the most prevalent genetic cause, had a life expectancy of 9 years in 1929. Today, these individuals commonly live into their 50s and 60s (Eyman, Call & White, 1991; Gold, Dobrof & Torian, 1987). Examples of parents in their 70s and 80s who provide assistance and supervision to a son or daughter with mental retardation are not uncommon (Brunn, 1985; Roberto, 1988).

Estimates suggest that in the coming years, greater numbers of older parents will require assistance with providing care to an adult son or daughter with a developmental disability. With the "greying

of America," the number of adults with developmental disabilities has increased substantially. This population has grown from approximately 350,000 in 1970 (Malone, 1990) to 1,577,340 in 1989 (United States Bureau of Census, 1991). Unfortunately, formalized services have not increased at the same rate. Many older families who are in need of support are unable to access services at the needed time, especially for residential services. In a 45 state study of residential options for people with a developmental disability, it was reported that 63,000 persons were on waiting lists for community-based residential facilities (Davis, 1987). This finding indicates that many families are forced to wait several months or years before a family member can enter a residential program.

For many parents, parenting a son or daughter with mental retardation has meant providing care since the birth of the child. Due to the continuous nature of this role, Jennings (1987) has identified these caregivers as "perpetual parents." Many of the adults with developmental disabilities need assistance with multiple areas of functioning from basic skills (i.e., dressing, bathing, feeding) to more complex tasks (i.e., help with communication, reading, using money). While improvements can be made in some areas of skill development, many people with mental retardation are never able to master skills to live semi- or totally independently. One of the major worries reported by older parents is the uncertainty of future care for a son or daughter (Gold, Dobrof, & Torian, 1987; Roberto, 1988).

Experience of Caregiving

A child who has a developmental disability does not achieve developmental milestones within expected time frames. Parents of younger children report feeling sadness and grief at the times when a child should have mastered skills (i.e., walking, talking, entering school) (Wikler, 1981). These feelings continue for parents into the adult development of their son/daughter (Wikler, 1986). Parents are reminded of the delays of their adult child during certain times such as when a younger child marries before their older disabled sibling, or when a grandchild can read better than a disabled aunt or uncle. The perceptions of loss and sadness are often experienced by these parents across the life cycle of their disabled child.

The cumulative effects of caregiving can negatively affect the parents' own health status. Part of providing care to a person with a developmental disability may include physical assistance such as help with ambulating, dressing, and transferring. Years of this type of assistance can precipitate health problems for the parents. Additionally, evidence indicates that people with developmental disabilities experience an earlier onset of certain health-related problems such as respiratory disease, hearing loss, and Alzheimer's Disease (Cooke, 1988; Hewitt, Carter & Jancar, 1985; Walz, Harper & Wilson, 1986). This situation suggests that a disabled person may need additional assistance with functioning at the same time that parents are beginning to experience their own age-related declines.

Parents make numerous sacrifices within the context of care provision. The actual costs of caregiving are high since the family must assume the costs of necessities of clothes, food, and other basic expenses over the entire life course. Additionally, specialized items may be needed such as adult diapers, wheelchairs, and medications. The opportunity costs of care also diminish families' resources. "Lost opportunities" of caregiving may include the inability to save for retirement, and the loss of wages from a parent who remains out of the labor force. While these costs are similar to caregivers of frail elders, the important difference is that many "perpetual parents" accrue these expenses for the entire life of their dependent son or daughter.

Case Study

The following case is an example of a "perpetual parent." The mother has provided care over the life span of Anita, who is 61 years old and has severe mental retardation. The information demonstrates the tremendous sacrifices by the family, the simultaneous health declines by mother and daughter, and the uncertainty of future residential arrangements.

Anita lives with her 81-year-old mother in a large mid-western city. Her father died several years earlier. She was brought to a developmental disability service agency when the mother needed to be hospitalized for diagnostic tests. At the time of intake, Anita was not receiving any type of services.

Anita has limited skill performance in all aspects of her function-

al abilities. She has a very limited vocabulary and speaks in 1-2 word sentences. Her mother assists with all Activities of Daily Living (ADLs) including bathing and toiletting. Her mother is in frail health, and suffers from arthritis, high blood pressure and cardiac arrhythmia. Anita also has health problems. She is significantly overweight, has high blood pressure, and suffers from frequent respiratory infections. Lately, she has begun to demonstrate a low energy level and is having more difficulty with independent ambulation.

Anita has a sister who lives down the street from the family. The sister, aged 58, is not employed and spends her time assisting the mother with Anita's care. Her husband has recently retired and is also involved in upkeep of his in-law's household such as performing small repairs and lawn maintenance.

The only period when Anita received services was when she was an adolescent. She resided in an institution for about 6 months until a fire erupted and demolished the facility. The mother was haunted by this event and decided that she would care for Anita at home. Since that day, neither Anita nor the mother has spent one night away from their home. The mother believes that Anita will only receive adequate care from her family.

Anita's sister and brother-in-law brought her to the agency for an intake. They are concerned that Anita will need to move in with them if the mother is too ill to continue caregiving. Although they have continued to provide instrumental and emotional support, they are committed to spending their retirement years without the daily responsibility for Anita's care. They are interested in pursuing day activity and residential services for her.

PARENTS OF ADULTS WITH CHRONIC MENTAL ILLNESS: THE STIGMATIZED PARENTS

A second group of older parents provide care to adult children with chronic mental illness. Although some similarity exists with parents of developmentally disabled adults, this second group faces some unique issues due to the nature of a psychiatric disorder. These families are plagued by the stigma of mental illness; unfortunately, they may even be blamed for the condition of their son or

daughter. Additionally, the episodic nature of the illness makes this type of caregiving erratic and unpredictable.

The deinstitutionalization movement placed many families with a chronically ill member in a situation of being long-term care providers. While deinstitutionalization was a societal movement that intended to reintegrate hospitalized patients into the mainstream of society, this goal is a difficult one to achieve for all but the highest functioning patients (Iodice & Wodarski, 1987). Many individuals need much more support than is available in their communities, and have to rely on families as long-term caregivers. Estimates suggest that about between 50-65% of patients are discharged from psychiatric hospitals into the family home (Lamb & Oliphant, 1978; Minkoff, 1979). Within this group of patients, about 25% are estimated to be chronically mentally ill (Goldman, 1982).

These statistics have important implications in an aging society. The United States will experience a dramatic increase in the percentage of its population 65 and over between the present time and the year 2025 (Myers, 1990). Many families who provide care for chronically mentally ill persons are currently older adults, and an increase can only be expected as society in general ages. For example, a New York Community Support Program (CSP) found that 12.5% of their clients lived with older parents (Perlman et al., 1988). Most family caregivers are parents who are in their late fifties or sixties (Lefley, 1987). The concomitant changes of growing older, such as declining health status and widowhood, make older parents especially susceptible to stresses of caring for an adult with chronic mental illness (Belcher, 1988).

Unfortunately, families and the individual with a psychiatric disorder suffer from the stigma of mental illness. Social barriers are often constructed around the entire family of a person with a mental illness, creating isolation and alienation for the family unit. This stigma may even stem from mental health professionals who often see families as contributors to a mentally ill person's pathology (Fadden, Bebbington, & Kuipers, 1987; Lefley, 1989). This situation has precipitated an antagonistic relationship between families and the mental health system. In the past, most treatment programs did not allow families to have access to the mental health system

unless they themselves were viewed as clients (Ferris & Marshall, 1987).

The client-identified system of care has negative consequences for family caregiving of people with mental illness. Community care is strictly patient focused and no support is given to the family (Fadden, Bebbington, & Kuipers, 1987). This common sentiment is most unfortunate as family caregiving is humanitarian and psychosocially stabilizing, and it prevents the outlay of large public money (Perlman et al., 1988). For example, Franks (1987) estimated that a sample of older parents of mentally ill adults (n = 409) spent an aggregate of over $4,000,000 in time and money on caregiving expenses. The difficulties faced by a family caring for a mentally ill member do not improve over time; conversely, the situation often becomes worse (Fadden, Bebbington, & Kuipers, 1987; Lefley, 1987).

Experience of Caregiving

In an effort to maintain a functional family, families often relinquish more "expendable" activities that promote positive health and provide rejuvenation. One of the most devastating consequences of living with a mentally ill relative is the damage that occurs to families' social and leisure activities. The family expends energy on managing problematic behaviors which include aggression, delusions, hallucinations, confusion, incapacity for self-care, reclusiveness, and medication non-compliance. Older parents may have little energy for any other activities than dealing with these difficult behaviors. Families may also voluntarily isolate from others in an effort to prevent socially embarrassing behaviors being performed in public such as mood swings, unpredictable sexual behaviors, poor hygiene, unprovoked physical attacks, and verbal abuse.

In addition to the objective stress of caregiving, parents also experience subjective burden (Lefley, 1987). These perceptions are related to the quality of the relationship with their son/daughter having chronic mental illness such as grief and loss for his or her pre-morbid personality, worries about the future caregiving arrangements, and balancing the demands of this and other relationships such as other adult children and grandchildren. Parents also

face concerns about their own health status such as worrying about their own physical and emotional well-being, feeling isolated from others, and grief over the inability to make or fulfill personal plans.

Another major concern is the incidence of aggression demonstrated by people with chronic mental illness. The patient may direct anger and abuse towards family members without any identifiable reason. Family members who provide care to a person with violent tendencies describe this situation as "'walking on eggshells' to avoid a fight" (Swan & Lavitt, 1988, p. 48). This type of abuse may be an especially frightening prospect for an older parent who has less resources, energy, and stamina to handle physical aggression.

Case Example

The following case provides an example of parents who care for an adult son with chronic mental illness. The case demonstrates the episodic nature of psychiatric disorders, and the attempts of the parents to reconcile the changed behaviors of their son after his first psychotic episode. The case also highlights how the stigma of mental illness is attached to the whole family, not just the identified client.

Philip is a 40-year-old, single, white male with a diagnosis of schizophrenia. He lives at home with his 75-year-old parents, and has a 22 year history of mental illness. Philip experienced numerous psychiatric hospitalizations but has remained out of the hospital for the past two years. Currently he has a flat affect, depressed mood, and mild paranoid ideation concerning his parents. He reports bizarre hallucinations involving religious themes and sexual thoughts. He and his parents live in a small southern town where his father is a retired pastor from the local Baptist church. Although there are two other brothers in the family, neither assists the parents with caregiving responsibilities.

Despite the overprotective and strict nature of his parents, Philip was by most standards a "normal" child. In school, he usually received A and B grades and had plans for attending seminary. He was somewhat shy and withdrawn in his school years, but it was during his senior year that he began to exhibit strange behaviors. For example, he made bizarre sexual statements during his father's Sunday sermons. He also became reclusive and refused to bathe.

Since the family was prominent in the town, the community overlooked and ignored Philip's increasingly bizarre behavior. His parents were at a loss to understand the behavioral change, and assumed it was part of an adolescent phase. Eventually he became violent, culminating in an incident where he shot out windows in the town square and held the police at bay for several hours. His explanation was that he attempted to kill the evil spirits that were "eating at his brain." Philip was sent away to the state hospital which was located more than 100 miles from the community. This was the first of many hospitalizations for him.

At the time of his first psychotic break, Philip' parents were in their mid-fifties. They were looking forward to retirement, spending time with their grandchildren, and reaping the benefits of life in a small coastal area. His parents blamed themselves for Philip's illness, and prayed fervently for him to be "cured and return to being normal."

The mental health system was not very helpful to the family. Instead of offering support and education about mental illness, mental health professionals blamed the family and their strict religious values for many of Philip's problems. Eventually when residential placements were initiated in the community, Philip's behavior proved too disruptive for the group living programs. The only service he currently uses is a day treatment program for three days a week.

Instead of regaining his emotional health, Philip's condition has worsened over time. After each hospitalization he would return home over-medicated but manageable. Eventually, he would resume bizarre and aggressive behaviors. His father retired prematurely, believing that if he devoted all his time to caring for his son, Philip would improve. However, the retirement caused the father to become isolated from his support system and eventually family and friends totally stopped visiting.

The cumulative stress of caregiving have taken a toll on all areas of family functioning. They are older now and have less energy to deal with his periods of decompensation. They continue to be isolated, fatigued, withdrawn and depressed. They are financially ruined, and their glamorous old house is in a state of disrepair. The medical and legal expenses have mounted over the years despite

government assistance. Five years ago, Philip became psychotic and pushed his mother down, breaking her arm. She is developing osteoporosis, and lives in fear of another violent attack.

Despite the numerous problems that accompany the caregiving for Philip, both parents have a strong desire to continue caring for him. Their determination, loyalty, and love are remarkable. A major worry which plagues the parents is the future of Philip's care when they die. Despite the long history of his illness, both parents continue to lament the "old Philip."

SERVICES FOR AGED CAREGIVERS

Clinical interventions can assist parents of dependent adults with late life caregiving responsibilities. As exemplified in the case examples, parents have to make many difficult choices and sacrifices to provide for their son or daughter which causes sadness about the inability to fulfill personal goals. These decisions affect current functioning since relationships, activities, and opportunities often must be relinquished to accommodate caregiving responsibilities.

Life review, a common therapeutic technique used with the aged, can facilitate current life transitions and help integrate past life experiences and choices for older parents (Kropf & Greene, 1993). Through the life review process, older parents have the opportunity to re-examine personal accomplishments, frustrations, and disappointments over their lifetime. This can help parents decrease feelings of depression and unfulfillment to enhance their present outlook and perception of their future.

Another clinical intervention that can benefit these caregivers is psychoeducational family models of treatment. Although many aged caregivers have been caring for a person with a disability for many years, they may not have received appropriate or helpful information from the service delivery system. Therefore, clinicians can assist the family by describing in non-technical language information about their adult child's disability, the medical etiology, the prognosis, problem-solving techniques, behavioral management techniques and other useful information. A group approach can be especially beneficially as older caregivers would discover that they are "not the only ones" who are in this type of caregiving situation in addi-

tion to providing much needed social support. However, long-term services are also needed by older families to assist with dynamic situations in late life caregiving. On-going support services such as comprehensive case management, information and referral, and follow-up care would help families problem solve and make decisions when behavior management or other problems arise.

Relationships are particularly important when working with older parents due to the historical treatment by professional service personnel. In working with older parents, practitioners need to be especially sensitive to the past relationships between parents and professionals. Current services to people with disabilities are constructed within community based settings, and emphasize collaboration between the family and formalized service system. However, the current cohort of older parents have experience with the previous and more adversarial system. Older parents may be distrustful of professionals and be reluctant to participate in formalized services. The establishment of rapport and trust, an important phase in any clinical relationship, is especially critical with these parents.

Concrete services also benefit these older care providers. Respite care, for example, can provide a much needed break for the caregiver. Like any caregiver, these parents need a break from caregiving responsibilities. Mandatory education provides younger parents relief during the day when children with disabilities are in school programs. However, no counterpart services exist for adults. Programs such as homemaker services can help older parents manage household and caregiving responsibilities. For frail elderly parents, a double need for home health services exists to assist with both their own care needs and those of their dependent son or daughter.

Outreach efforts need to target older families before a caregiving crisis occurs, as in the case of Anita's family. Involvement with developmental disabilities or mental health services provides a respite for the parents and promotes a sense of familiarity in services for the person with a disability. When services are initiated at the point of an emergency, the disabled adult is forced to face both the crisis situation and adapt to the service system. These adjustments may be overwhelming for individuals who have a developmental or psychiatric disability. Outreach services to older families can be facilitated by cooperation between aging and developmental dis-

ability service networks. Increased efforts to bridge these two service networks can provide additional outreach to and access for older families in need of services (Kropf, 1994). Individuals in other support roles (i.e., clergy or rabbi, physicians, pharmacists) can be helpful in connecting older families to needed services. Developmental disability and mental health networks can maintain outreach to other community programs to promote referrals for older families prior to the onset of a crisis situation.

An area of concern of older parents is preparing for the future care of their son or daughter. Unfortunately, many parents have no plans about the care of their adult child when they become incapacitated or die (Kaufman, Adams & Campbell, 1991). Even with good intentions, parents can make mistakes or leave gaps in future care plans, such as a situation where parents hope that a sibling will assume care. Legal services, estate planning, and guardianship information can assist older parents with plans for their son's or daughter's future care.

Although the older adults are a very heterogenous segment of our population, the caregiving role undertaken by older parents has been little understood and under-appreciated. This article has explored the experiences and needs of older parents who have an adult child with a developmental disability or chronic mental illness. Social and demographic changes have increased the number of older caregivers and the diversity of their service needs. As gerontologists, our responsibility is to help in developing policies and programs that assist these groups of forgotten care providers.

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