Caregiver Burden: the Impact on Aging Parents who Care for Adult Children

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Abstract
Contemporary research on caregiving has focused mainly on caregiver burden experienced by children caring for elderly parents. Most gerontological research (e.g., Greenberg, 1991; Greenberg & Becker, 1988) has stressed the movement of caregiver burden and related stress down through the intergenerational family system from parents to children. This research has ignored the impact of caregiver burden and stress on aging parents whose adult children have experienced major life stressors. In this situation, the movement of the caregiver burden moves up through the intergenerational family system as parents assume the caregiving role for adult children.
CAREGIVER BURDEN: THE IMPACT ON AGING PARENTS WHO CARE FOR ADULT CHILDREN

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Contemporary research on caregiving has focused mainly on caregiver burden experienced by children caring for elderly parents. Most gerontological research (e.g., Greenberg, 1991; Greenberg & Becker, 1988) has stressed the movement of caregiver burden and related stress down through the intergenerational family system from parents to children. This research has ignored the impact of caregiver burden and stress on aging parents whose adult children have experienced major life stressors. In this situation, the movement of the caregiver burden moves up through the intergenerational family system as parents assume the caregiving role for adult children.

The purpose of this paper is to explore the issues of parents who have become the caregivers for adult children and/or their families. These issues are important to counselors and other helping professionals as this caregiving situation is becoming increasingly more common due to trends in family and economic stressors in the intergenerational family system. The caregiving situation may be due to major life disruptions of adult children such as divorce, mental illness, substance abuse, long term unemployment, or parenting problems. These major life problems often disrupt the lives of aging parents and contribute to emotional, physical health, and economic problems for them. Many caregiver characteristics such as age, ethnicity, and gender affect how the parent perceives the burden of care. Caregiver burden is not always negative and is often viewed as positive by parents or family members (Freedman, Wolf, Soldo, & Stephen, 1991). Adult children who are the recipients of parental and
family caregiving often experience feelings of guilt and shame when they must depend on others for support.

Caregiving can be a life long or a temporary relationship between a child and parent. More current research (Blieszner & Mancini, 1987; Greenberg & Becker, 1988) is being focused on the aspects of caregiving across the life span with the increasing possibility of family members becoming caregivers many times during their lifetime. Aging parents are increasingly being viewed as a resource for their families, especially adult children with major life problems (Greenberg & Becker, 1988).

Caregiver burden can be defined in many ways and the definition is often based on the perception of the caregiver. "Burden" can be defined in terms of the parents' or families' caregiving tasks and their feelings about those tasks. The perceived burden can include financial, physical, and emotional distress (Reinhard & Horwitz, 1995). This paper will distinguish between the consequences of subjective burden or the emotional aspects of care and objective burden or the instrumental aspects of caregiving by parents for adult children.

Research on caregiving by aging parents for adult children has focused on parents age 50 and over (Horwitz, Reinhard, & Howell-White, 1996). This age designation can be misleading as many parents who are younger have cared for children as they have moved into adulthood and have not assumed the burden after the child became an adult. This would apply specifically to those families who care for mentally ill adult children who may have been chronically ill most of their life (Horwitz, et. al., 1996).
Ethnic groups may attach a different age distinction to aging. In some ethnic groups, parenting begins at a much younger age, so parents caring for adult children may be much younger than age 50 (Burton, 1996).

Family caregivers bring a wide variety of concerns to counseling. These concerns may be a reflection of the most common caregiving tasks which are: care for the care receiver; interpersonal concerns, tasks and difficulties for the caregiver including caregiver burden; and interactions with other family members and healthcare, treatment and societal networks. These caregiving problems fit into four categories: (a) behavioral problems, such as poor coping skills; (b) psychological problems, such as depression, guilt, anger, and frustration; (c) lack of formal and informal support; and (d) situational problems, such as providing housing, financial support and decline in functioning of the care receiver (Smith, Smith & Toseland, 1991).

To intervene effectively with parents and families caring for adult children, counselors need to be aware of the changing trends in society that affect intergenerational families: (a) the precipitating factors for parental caregiving; (b) the consequences of caregiving; the gratifications of caregiving; (c) the caregiver characteristics that impact the caregiving role, and (d) the implications for counselors. Knowledge of these factors will increase counselors' understanding of the burdens of parental caregiving and how the factors may impact each caregiving situation differently.
divorced families include younger children. Therefore, divorced parents often seek support from aging parents for housing and child care (Freedman, et al., 1991). Adult children who are divorced are also less likely to provide support or care for their aging parents. In recent research by Marks (1996) on aging for ages 50-74, 1 in 10 adults were providing in household care for younger care recipients who were not elderly.

**Emotional and Financial Support**

The return of adult children to the home of their parents for emotional and financial support has increased since 1985 (Mancini & Blieszner, 1989). Sharing a household, receiving social and emotional support, assistance with child care and other support needs from parents are the result of high unemployment rates, economic problems, personal problems and high divorce rates experienced by adult children (Mancini & Blieszner, 1989). Downsizing and other employment changes continue to affect unemployment. Many aging parents contribute financial support to unemployed children (Greenberg, 1991).

**Substance and Alcohol Abuse**

Substance abuse and alcohol dependence problems have increased steadily since 1967 with approximately 20% of adult males reporting problems with abusing substances and alcohol (Greenberg, 1988). In a 1988 study by Greenberg, cited in Greenberg 1991, 82% of the fathers in the study stated that their adult child had or was experiencing drug or alcohol abuse problems and required some parental support (Greenberg, 1991).
Mental Illness

Deinstitutionalization and the growth of community mental health centers in the 1970s has contributed to the shift in the care of adults who have mental illnesses (Cook, 1988). Currently, treatment which was based in mental health institutions in the past, is now being provided in the community. The burden of care for the chronically mentally ill has shifted from institutional care to the families of these patients.

Approximately two thirds of mental health patients return to their parent's home for aftercare following brief inpatient hospitalizations. The family, usually the parents, are the major source of support for mentally ill family members (Cook, 1988). Frequent shifts between brief hospital stays, community living and family support represent the revolving door pattern of many mentally ill persons in the public mental health care system. This pattern causes many stressors for parents and families (Reinhard & Horwitz, 1995).

The total number of adults who experience mental illness has risen dramatically as the baby boom generation has reached adulthood. As parents live longer, the primary burden of care for the mentally ill has been assumed by parents who are responsible for long periods of caregiving (Greenberg, Greenley, McKee, Brown, & Griffin-Francell, 1993).

Grandchildren

The number of grandparents rearing their grandchildren has increased with as high as 3.4 million grandchildren living with
grandparents. This trend is a result of divorce, unemployment, substance abuse, AIDS, and incarceration experienced by the children's parents (Giarrusso, Silverstein, & Bengtson, 1996). The United States Bureau of Census (1991) estimated that 5% of children under age 18 live with grandparents with neither parent present in at least one-third of these households. In some inner city areas, the number of children living with grandparents is believed to be as high as 30-50%. This is mainly due to socio-economic problems of the children's parents (Minkler & Roe, 1996). Other factors that influence the increase of surrogate parenting by grandparents include teenage pregnancy, neglect, child abuse and parental illness (Pryor, 1995).

Precipitating Factors for Parental Caregiving

A number of factors such as mental illness, chemical dependency, divorce and marital problems, parenting problems, and unemployment may contribute to parental caregiving for adult children and their families. Mental Illness

Families are often faced with a lifelong burden of care when a family member is mentally ill. The effects of mental illness are often difficult for a family to cope with and societal support is often lacking. Families are co-victims of mental illness as they are responsible for caring for the family member and are often blamed for causing the illness (Reinhard & Horwitz, 1995). Families, especially parents, become advocates for the mentally ill family member during readjustment to the
community after treatment or hospitalization (Cook, Lefley, Pickett, & Cohler, 1994).

The level of perceived burden of care is usually highest during the first five to ten years of care. In the beginning, parents must accept and adjust to the diagnosis of mental illness. Parents often have unrealistic expectations for the child and face frustration when hopes for recovery are not realized. The changes in their lives, lack of support and information about the mental illness results in confusion and fear for the parents (Cook et al., 1994). Parents must also deal with the frustrations of working with mental health service systems and community resources. There is an acceptance that the adult child may never be able to function independently or live a normal life. The realization for parents is that there are limited alternatives for care other than the family. Even when the adult child does not live with the family, the parents may remain responsible for the delivery of care (Pruchno, Patrick, & Burant, 1996).

After the first five to ten years of care, the parents often experience a diminished level of burden of care as they accept and recognize the chronicity of the mental illness. The parents adopt more realistic expectations for the adult child, adapt to the care and problem management, and experience an increase in coping skills and resources (Cook et al., 1994).

**Chemical Dependency**

Adult children who experience problems with chemical dependency, including alcohol and drug abuse, are often dependent on
their parents for emotional and financial support. The parents experience frustration with repeated attempts of rehabilitation for the adult child whom for the parents often take on the financial responsibility. The parents' hope is for the adult child to become more independent and have a more productive life. The parents find themselves in a continuing dilemma of whether helping the child contributes to the ongoing chemical dependency problems or if withdrawing the support will motivate the child to change the chemical dependency behaviors (Greenberg, 1991).

Substance abusers rely on parents in times of stress and crisis. They are more likely than other adult children with major life problems to experience problems with leaving the family home (Greenberg & Becker, 1988). This dependency on family occurs more often for sons than for daughters. A national survey on alcohol consumption in 1987 found that alcohol consumption increases significantly for males in adulthood, but not for females (Greenberg & Becker, 1988). Adult children who abuse substances often face employment problems, so parents often assume financial and housing responsibilities for the adult child which may also include the child's family (Bass, 1990).

For parents whose adult child has problems with both mental illness and substance abuse, concerns center around impaired judgment. The adult child often exhibits self-defeating and self-destructive behaviors. Drug overdose intentionally or accidentally is a major concern for parents in this situation. This concern increases the stresses of caregiver burden (Bernheim, Lewine, & Beale, 1982).
The number of grandparents who are raising grandchildren due to the adult child's substance abuse problems has been increasing, especially as a result of crack cocaine. Parents care for the grandchildren, while parents go through treatment or until the childrens' parent can assume the care (Minkler & Roe, 1996). Grandparents fear having alcohol dependent adult children raise their children as, they view the parents as unstable and lacking in parenting skills. Many are afraid that if they do not offer assistance the grandchild may end up being taken away from the parent and put in foster care. Grandparents may also have concerns about the ability to care for and be responsible for babies who are born with Fetal Alcohol Syndrome or drug addiction (Pryor, 1995).

Divorce and Marital Problems

A 1986 study by Glick and Lin, cited in Greenberg and Becker (1988), of separated and divorced adult children ages 30-34 found that 17% lived with relatives and most often parents. Parents ages 52-91 had more contact with divorced adult children after their divorces than before. This was usually to provide emotional, financial, child care, and housing support. Most divorced daughters had custody of children which, added to intergenerational care burden stress (Greenberg & Becker, 1988).

Many parents perceive changes in the parenting role as a result of the increasing divorce rates. Single parent families, which are the result of divorce, have made parenting more difficult for the adult child's parents. Many responsibilities for helping the single parent family are assumed by the parents. Most parents reported being positive about being needed,
loved, exchanging advice and assistance and giving financial support despite the added stresses of caretaking (Blieszner & Mancini, 1987).

When all major life stressors are taken into consideration, a study by Aldous (1987) found that parents gave the greatest support to their adult children who were divorced with children or single without children (Greenberg, 1991). These changes, increased divorce rates and caring for grandchildren, in the intergenerational family structure yielded both costs and rewards for parents involved in caregiving. Parents believe the support given to adult children and their families has increased the emotional closeness of family relationships and added to the quality time spent with grandchildren. Most parents believe these positive aspects outweigh the financial burdens assumed by them in these caregiving situations (Giarrusso, Silverstein, & Bengtson, 1996).

Divorce can weaken or strengthen family structure and bonds. Relations between parents, grandparents and grandchildren are often weakened on the non-custodial side of the family, but are usually strengthened on the custodial side. Grandparents on the custodial side usually assume a greater burden of care for the adult child and the grandchildren. Grandparents often become surrogate parents and assume full-time caregiving if the divorced parent is employed or is unable to parent due to other problems (Giarrusso et al., 1996). The daily life for these parents changed as they experienced a return to full-time childcare, changed relationships with family and friends, and lost the
freedom they had before their parenting role was changed by their adult child's divorce (Pinson-Millburn, Fabian, Schlossberg, & Pyle, 1996).

Parenting Problems

The number of parents who cannot care for their children or lack parenting skills has been increasing in recent years. This increase is due to the inability to learn or use appropriate parenting skills, incarceration, unemployment, abandonment, abuse, or neglect (Pryor, 1995, Pinson-Millburn et al., 1996).

The new caretaking role of parenting for grandparents is often sudden, due to circumstances under which the child's parent can not continue in the parenting role or assume the stressors of parenting. The circumstances may also include increase in drug use by the parent, infants with serious developmental problems due to substance abuse by the mother, children born to single mothers or to young parents who are unable to assume the care and HIV/AIDS (Pinson-Millburn et al., 1996). Many parents assume this role willingly with the best interest of the child in mind, but are unprepared for the stressors of caregiving and raising children again (Pryor, 1995).

Unemployment

Unemployment, especially long term, presents caregiving problems for many parents. Parents offer advice, support for coping, housing, and financial support. Most parents give this support voluntarily, as they are concerned about their child's welfare. Lower morale and higher frustration levels for parents are associated with longer term
unemployment and continued dependence and support (Greenberg, 1991).

For the adult child, unemployment is related to a recent trend of residential transition referred to by Field and Minkler, (cited in Giarrusso et al. 1996), as the "boomerang generation". The number of adult children moving back into parental homes has increased significantly in recent years. This is often in time of crisis, and is usually to take advantage of a lower shared cost of living with parents (Giarrusso et al., 1996). These intergenerational households can be stressful for all family members involved. Parents give up their empty nest to accommodate adult children and often their families (Greenberg, 1991).

In recent years more adult children are unable to deal with the stressors of increased economic pressures. Many couples must both be employed outside the home to keep up with inflation and the high cost of housing. Nationwide 4% of intergenerational families are a result of unemployment as reported by Woodward, 1994 (Pinson-Millburn, et al., 1996). One survey by Downey, 1995 and one survey by the National Council on Aging, 1995, (Pinson-Millburn, et al., 1996) found that poverty is an issue of concern for these families and that many adults over 65 are in a low socioeconomic status. So by financially supporting and providing caregiving to unemployed family members, there is a likelihood of being poor or becoming poorer (Pinson-Millburn et al., 1996).
Consequences of Caregiving

Caregiver burden is a multidimensional concept and the interpretation of the burden by each parent or family is as different as each family is in its interaction with the care receiver. Counselors working with parents in caregiving situations should be aware of how the consequences impact the caregiving role and the interactions in the family. Some families are able to cope with caregiving and others are not (Reinhard & Horwitz, 1995). The concept of caregiver burden is defined as the consequences of providing instrumental or objective and emotional or subjective assistance to adult children or other family members. Research is limited on factors that may explain or assist helping professionals in understanding why some families experience less caregiver burden than others (Bulger, Wandersman, & Goldman, 1993; Reinhard & Horwitz, 1995). The consequences of caregiving are more clearly defined in terms of objective and subjective burden and how these aspects are viewed by caregivers.

Objective Burden

Objective burden is defined in the terms of behavioral aspects of the care receiver, in this case, the adult child. These aspects may include behaviors such as the disruption of the parents' life, hostility toward the caregiver or over-dependency on the caregiver (Bulger et al., 1993). Essential predictors of objective burden are lack of social support systems for the caregiver and disruptive behaviors by the care receiver. There are other factors which effect the perceived caregiver burden by the parents.
These factors include living arrangements, the relationship between the caregiver and the care receiver, ethnic differences, financial burden, age, and gender (Reinhard & Horwitz, 1995).

Adult children with a mental illness often exhibit impaired social functioning and disruptive behaviors (Reinhard & Horwitz, 1995). These factors can also be experienced by adult children who experience problems with substance abuse or antisocial behavior (Greenberg, 1991). Burden studies by Cook and Pickett and Noh and Turner, (cited in Reinhard & Horwitz, 1995), indicate that living with an adult child who is experiencing major life problems can be related to higher levels of burden as the parents provide more assistance on a daily basis. However, caregiving from a distance can also be stressful as the parent or family is not involved in the direction of care. Parents who provide caregiving from a distance do not provide as much assistance with activities of daily living or immediate support. These aspects of care are often provided by services in the adult child's community and the parents may have little or no control or input into the situation which can be stressful for all involved (Reinhard & Horwitz, 1995).

Relationship issues are also a factor in caregiver burden. Caring for a child may create ambivalent feelings. Higher levels of conflict are associated with a close relationship (Bulger et al., 1993). Family members find caregiving more stressful than parents because they are called upon more often in times of crisis. It can be difficult for family members to intervene in a crisis as they may not have an understanding
of the care receivers needs or current situation (Reinhard & Horwitz, 1995).

The financial burden for parents is less for those with higher income and more resources. The more demands for financial support or the longer the support is given to the adult child, the greater the perceived burden is for the parents. Financial support is viewed by some parents as enabling the dependency of the adult child on them for continued support (Greenberg, 1991; Reinhard & Horwitz, 1995). Other economic stressors for parents may include costs of medical care, therapy, hospitalizations for treatment, support for the adult child's family, loss of income and opportunity and use of savings or pension (Bass, 1990). Parents provide more financial assistance for adult children than they receive from them. The most common pattern of intergenerational financial transfer is from parents to children, with children not reciprocating or paying parents back. For those who help children financially, 89% did so for satisfaction or pleasure. For 8.6%, financial support was a source of anxiety, worry and increased burden (Bass & Caro, 1996). Parents who give financial support to a nonresidential adult child was estimated at one-fourth of the total older population (Freedman et al., 1991; Greenberg et al., 1993).

In a study by Bulger et al. (1993), an objective-burden measure in the form of questions was used to explore the relationship between the burden of caregiving tasks and the emotional burdens of caregiving. The measure assessed the forms of help caregivers may give the care receiver daily such as taking medications, social and leisure activities,
household tasks, childcare, and tasks that require supervision and transportation (Bulger et al., 1993). Many caregivers rate their level of burden using the amount of time they spend daily on the caregiving tasks. If much of the daily routine is taken up by caregiving, they perceive themselves as burdened by the caregiving. Some caregivers may expect caregiving to be a burden even though it does not interfere with other aspects of their lives (Stull, Kosloski, & Kercher, 1994).

Objective burden can take many forms and the emotional strain on the parents, care receiver, and family members can be experienced in varying degrees. Most families experience objective burden from frictions between family members, change in household routines, and distractions from routine activities (Bulger et al., 1993).

Counselors can help families view behaviors, assistance, and burden as separate constructs and to see how these aspects interact and affect the relationships in their family. The goal of counseling is to reduce caregiver burden by reducing or reevaluating caregiving responsibilities (Reinhard & Horwitz, 1995).

**Subjective Burden**

Objective burden explains some of the behavioral aspects of caregiving, while subjective burden focuses on the emotional aspects. Subjective burden has been defined as the emotional reactions to caregiving. It is the parents' feelings concerning the care they provide for the adult child and the emotional strains that are the result of the caregiving (Bulger et al., 1993; Greenberg et al., 1993). Some research
defines subjective burden as the stressful consequences of caregiving activities (Reinhard & Horwitz, 1995). The emotional or psychological reactions that appear to be most common to caregivers in most caregiving situations are tension, stress, worry, sadness, resentment, depression, and difficulty sleeping (Bulger et al., 1993).

In families who care for adult children with mental illness, the emotional consequences include feelings of stigma, loss of the companionship or support, fear for the future of the adult child, and worry. These reactions are viewed as sources of chronic stress on the parents and family (Greenberg et al., 1993).

The most pervasive emotional burden for these families is stigma. Stigma is a source of shame which is experienced by the parents and the family of the mentally ill person. Parents tend to protect the adult child by limiting social and public interactions to avoid embarrassing situations for themselves and the adult child. The result may be the increased lack of social and coping support for the parents and the adult child as they withdraw from activities. This lack of support is also related negatively to parents' health and well-being (Greenberg et al., 1993).

The second major emotional stressor for these parents is the fear that the child will harm herself or himself or others. Anxiety and worry are the third major stressors for parents of the mentally ill. This stressor ranges from worry about daily concerns to what will happen to the adult child when the parents can not longer provide care or die (Cook, 1988; Greenberg et al., 1993; Pruchno et al., 1996).
Grief and loss are results of the cyclical nature of mental illness. The parents may have hope every time the adult child is stable and functioning well, but grieve again when the adult child becomes symptomatic. The grief and loss can be compared to the death of a loved one in that the person they once knew is no longer psychologically present (Bernheim et al., 1982; Greenberg et al., 1993). The mourning process reflects the loss of the hopes and expectations that parents once had for the child. The mourning process also allows parents to lower their expectations, set new realistic goals, and gain recognition and acceptance of the loss and live with less stress and grief (Berheim et al., 1982).

The subjective burdens of stigma and worry which are associated with mental illness are significant predictors that influence the physical and mental health of the parent caregivers. According to Greenberg et al. (1993) the factors associated with worry and stigma and the resulting health status for the parent are age, marital status and education, and the adult child's gender, residence, and psychiatric symptoms. Parents who reported higher levels of worry and stigma reported poorer physical health. Parents who coresided with adult children reported better physical health than those who did not (Greenberg et al., 1993). Subjective burden was less for those parents whose adult child lived with them as the child participated in family activities, expressed affection, contributed financially, and provided emotional support for the parents (Horwitz et al., 1996).
The parents who care for adult children with schizophrenia experience greater subjective burden associated with the severity of the adult child's symptoms. The more severe the symptoms, the greater the burden experienced by the parent (Bulger et al., 1993).

Guilt and anger are also experienced by parents of adult children with major life problems. Parents may blame themselves for the adult child's problems, feel guilty, and try to find reasons for blame such as inappropriate discipline, lack of communication, social environment, and parental conflicts. Parents search for reasons and need to come to accept that the adult child has made decisions that have contributed to the major life problems being experienced (Bernheim et al., 1982; Greenberg, 1991). Parents may experience emotional distress due to concerns about the adult child's welfare and future. Dependence on aging parents by adult children is associated with greater subjective burden. This may affect the parents' freedom in pursuing personal goals and plans for the future. The dominant emotions focused on the unhappiness experienced by the child, and feeling powerless and helpless in being able to lessen the pain for themselves and the adult child concerning the current situation and the future (Greenberg, 1991).

Subjective burden can also take many forms and affect each caregiving situation differently. The emotional strains of stress, worry, concern about the future, sadness, resentment, stigma, grief, and stigma can all be viewed as chronic and ongoing sources of stress for the parents and family. Counselors need to be aware of the emotional
stressors, the impact on the parents and family, and assist in helping the family to learn appropriate coping strategies.

**Gratifications of Caregiving**

Research on caregiver burden has focused mainly on the negative aspects of caregiving. The benefits of caregiving are not as obvious, but many families have experienced gratification from caregiving for family members. Gratifications for caregiving include support for the adult child, intergenerational sharing, and increased understanding and personal growth.

**Support for the Adult Child**

The parents or family who provide caregiving benefit from knowing that their family member has been given loving care, in ways they believed was most beneficial for the care receiver. Many parents prefer to care for the person who is experiencing mental illness or other disabilities at home, rather than in an institution or other residential care. Most families take pride in caring for the family member. For parents, there is often a strong sense of family and responsibility to the welfare of the child (Bass, 1990).

Gratification for parents was often reflected by the fact that the support they gave adult children increased the emotional closeness in family relationships. They expressed being happy that they could care for and assist the adult child and/or their family. Parents often realized after a crisis that they were stronger and more supportive than they had expected they could be (Bulger et al., 1993).
Intergenerational Sharing

When multiple generations live together and share experiences, they learn and benefit from one another. This is one of the most important aspects of intergenerational caregiving (Bass, 1990).

In helping adult children, parents often view the experience as a relationship of exchange, assistance, and support. The intergenerational exchange is based on concern, respect, and caring for one another and enhancing the quality of life for all involved. These parents do not view the everyday tasks, giving advice, and counseling about life problems as burdensome. Intergenerational households can increase mutual assistance and understanding (Lee et al., 1995; Mancini & Blieszner, 1989).

Increased Understanding and Personal Growth

Parents and families often come through a crisis they face with major life problems stronger and having learned from the experience. Caregivers have positive feelings of accomplishment, higher self esteem, and self satisfaction from having been able to support an adult child in the time of need. Caregivers also gain gratification from learning new caretaking skills, having a sense of purpose and self efficacy, developing a sense of emotional closeness with the adult child, increased tolerance for the adult child's major life problem and experience personal growth (Bass, 1990; Singer et al., 1996).

Counselors should be aware that there are positive aspects to intergenerational caregiving. The multigenerational family should be
viewed as a caring system despite the consequences of burden. Crisis and sharing often brings families closer as they struggle together to gain stability and the caregivers often perceive the experience as positive.

**Caregiver Characteristics**

Caregiver characteristics such as ethnicity, age, and gender affect how the parent perceives the burden of care. These characteristics are important aspects to consider when working with caregiving families.

**Ethnicity**

Cultural differences impact how parents and families view caregiving roles and burden. Aspects of these differences are affected by living arrangements, interaction patterns, values, support systems and affectional ties (Taylor, Chatters, & Jackson, 1993).

In a study by Bulger et al. (1993), a strong correlation between race, caregiver burden, and gratification was found. For White caregivers, there was a significant positive correlation between race and burden. For African American caregivers, there was a significant correlation between race and gratification. White caregivers with higher income and education whose adult child did not live with them experienced greater burden and less gratification than African American families (Bulger et al., 1993).

There are discrepancies in research investigating the level of burden experienced by minority and White families. Minority parents feel more responsibility for the adult child and experience more cognitive preoccupation concerning responsibility. White parents experience more
distress concerning the adult child’s disruptive behavior, actions, and decisions.

Intergenerational living arrangements for families reflect cultural differences. African American adult children are 1.5 times more likely to live with parents than adult children from White families (Freedman et al., 1991). African American caregivers experience less burden in co-residence than White caregivers due to cultural factors concerning the families’ interpretation of the importance or level of burden associated with disruptive behavior, functioning of and responsibility for the adult child. Parents who provide more support and deal with more disruptive behaviors report more burden regardless of the living situation or cultural background (Reinhard & Horwitz, 1995). More African American families live in three generation households or other extended living arrangements than do White families. African American parents are more likely to take adult children and grandchildren into their homes, while more White parents provide economic assistance with living arrangements. Whites and Mexican Americans experience a high degree of intergenerational support, interaction and kinship exchange and low levels of burden of care due to cultural expectations of caring for family members (Taylor et al., 1993).

Caregiving by African American parents, especially mothers, included activities such as providing babysitting, socializing, parenting of grandchildren, housing, financial assistance, emotional support, meals, and daily needs of their children’s families (Burton, 1996). The African
American extended family serves as an important resource for survival, exchange of mutual support, and kinship ties. These kinship ties are much stronger for African American families than for White families (Mui, 1992). White families rely more on formal care resources, while African American families rely more on family resources. African American and White caregivers perceive caregiving responsibilities in different ways. African American families experience lower levels of burden than White families due to differences in interpretation of emotional strain or coping mechanisms (Mui, 1992). Whites were more likely to be caregivers than Hispanic Americans. This may be due to the fact that, while Hispanics are known to have close kinship ties, more Hispanics than any other ethnic group are recent immigrants and may not have family in the United States to care for them (Marks, 1996).

African American families exchange informal and social support more often than White families (Horwitz & Reinhard, 1995). African American families have higher cultural expectations of receiving and providing support such as affection, exchange of gifts, and participation in rituals and family events (Horwitz et al., 1996). Non White parents with lower education, less income, and in poorer health have higher expectations of family support and interdependence and experience less burden than White and non White parents with higher levels of these factors (Lee et al., 1995).
Gender and Age

Characteristics such as gender and age may impact the perceived caregiver burden and may affect relationships in the intergenerational family.

Women in all age and ethnic groups tend to provide more caregiving support, both physical and emotional, than men. This is especially true for parents of the mentally ill (Horwitz et al., 1996). Women caregivers experience more burden and worry and less satisfaction when caring for an adult child with a chronic disability (Pruchno et al., 1996). Parents who care for adult children with a mental illness experience stress and anxiety. Mothers who are usually the primary caregivers, experience greater burden and stress than fathers. Mothers were more depressed, while fathers expressed more anger and frustration (Cook, 1988; Cook et al., 1994).

In most cultures and ethnic groups, women spend more years caring for others than men do. It is culturally and socially acceptable in most cultures for women to become the caregivers for other family members. Men can care about, but not necessarily be expected to care for other family members (Campling, 1988). Women are more likely to be caregivers than men, but a substantial number of men do provide care. Women are more likely to be burdened by caring for multiple generations than men (Marks, 1996).

Older parents experienced less caregiver burden in caring for family members than younger parents. Older parents have had more life
experience and have adjusted to major life changes therefore were less distressed by major life changes and chronic conditions in the lives of adult children. Younger parents had not adapted to the responsibility and demands of caregiving (Cook et al., 1994; Reinhard & Horwitz, 1995). Older parents well being was more positively related to providing support for adult children than receiving help from them (Mancini et al., 1989). Older parents experience more burden concerning emotional involvement with adult children's life issues and worry about what will happen when they are gone (Cook et al., 1994).

There is a relationship between the number of problems in the lives of adult children and the parents' stress level (Lee et al., 1995). The mothers experience higher levels of stress when adult children experience more problems while fathers were less affected. Mothers were more open to discussing the frustrations while fathers expressed helplessness and powerlessness in helping adult children deal with major life problems. Fathers tend to minimize the stress while mothers experience greater stress (Lee et al., 1995). Fathers serve as a source of financial support more often than mothers and may limit the effects of stress by offering financial support (Greenberg, 1991; Greenberg et al., 1988).

It is more stressful for fathers who have a son who has continued to depend on the parents for emotional and financial support than it is for the mother. The parents were not as distressed when they experienced continued dependency by an adult daughter. This difference in level of
stress may reflect differing attitudes concerning gender differences in parental expectations of independence (Greenberg et al., 1988).

Implications For Counseling

The literature on caregiving addresses several implications for counseling that may influence how the counselor or human service professional interacts with parent caregivers and the interventions that may be used. Smith et al., (1991) suggest that counselors should assess the caregiver's concerns and family relationships to become aware of the relationship between problems identified by caregivers in counseling and personal or situational characteristics such as the caregiver's age, gender, ethnicity, family structure, socioeconomic status, and duration and type of caregiving. Awareness of these factors can assist the counselor in determining which interventions are most appropriate for each individual and family (Smith et al., 1991). An example of this aspect may be a father who has been caring for his son's family and comes to counseling experiencing stress, increased use of alcohol, lack of concentration and self confidence, and financial problems. A counselor may assume all of the concerns are due to the burden of caregiving. Further assessment may indicate a long history of substance abuse or other issues which may explain the lack of concentration, low self esteem, and financial problems.

Effective Therapeutic Interventions

Bass (1990) suggests that individual counseling for the caregiver is beneficial to enhance problem solving and coping. By learning problem
solving and coping skills in a counseling situation, the caregiver can improve the ability to manage personal problems in the caregiving role and diminish caregiver burden. Brief individual counseling can help the caregiver accept the diagnosis or crisis faced in giving support to an adult child (Bass, 1990).

Individual counseling should be considered by helping professionals before referring the individual, parents, or family to support or psychoeducational groups. Individuals with high levels of burden and distress should be assessed for the type and level of subjective distress being experienced before targeting the intervention. Parents with high levels of subjective burden may benefit more from individual counseling followed by psychoeducational group counseling (Greenberg et al., 1993). A detailed assessment of the parent/child relationship is important in counseling older parents involved in caregiving roles. An adult child's divorce, mental illness, unemployment, or substance abuse may cause distress for caregiving parents that could be addressed in counseling (Greenberg, 1991).

Individual and family counseling may be more appropriate than group counseling initially for parents who need to resolve issues of depression, anxiety, and coping with mental illness and chemical dependency of family members. Family, ethnic, and cultural differences pertaining to these issues should be explored in sessions with individuals and families before being referred to groups because groups may not address these issues. Individual and family counseling can be beneficial
in assisting intergenerational family systems to recognize individual and family strengths and weaknesses in the caregiving network (Taylor et al., 1993).

Groups work is effective as group members share experiences, support one another, and the interaction leads to a normalization of the caregiving experience for each member. Assessment of networks systems and strategies can enhance the parents and families support resources. Counselors should also assess family structure, multigenerational aspects and family characteristics when deciding what interventions would be appropriate for the client (Taylor, et al., 1993).

Family counseling is very important in helping parents recognize and deal with the adult child’s problems, but also to help them gain understanding of how these problems affect the entire family. Counselors work with the entire family rather than just the caregiver or the client, to help family members solve the problems in the caregiving relationship together as a group rather than individually. The level of caregiver burden experienced by caregivers depends on the amount of help and support they receive from other family members and other support systems. During family counseling many issues can be discussed and resolved including support by others for the caregiver (Bass, 1990).

Cook (1988) encourages the use of an interactive model of family therapy which assesses all aspects of family interaction and can be used effectively for families coping with mental illness. The therapy should avoid focusing only on the adult child with the mental illness, but should
be an interactive process that includes the caregiver or parents and other family members. The counselor should gain an understanding of what caregiving means within that particular family system as each family is in a unique situation with different definitions of burden and expectations of care. The social and emotional situations of each family should be taken into consideration (Cook, 1988).

Family interventions should vary according to the parents' age as well as stage the stage of the child's mental illness. Interventions for a long term chronic mental illness may include long term care, while a newly diagnosed illness may call for individual counseling and assessment of medications (Cook et al., 1994). Counseling for older parents could focus on cognitive aspects and worry by assisting them with estate planning to provide for future care of the adult child. A life review process can be useful in helping parents deal with feelings about their own death. Aspects of burden should be addressed in counseling for parents and families (Cook et al., 1994). Parents who have had long term care of a mentally ill or ill adult child are at increased risk for burden. Conflict management and family problem solving can be taught in counseling to help families resolve issues of who will care for the ill family member when the parents no longer can (Cook et al., 1994).

Interventions in counseling for caregivers have focused on the burden of caregiving, but a broader approach that addresses burden, satisfaction, and the parent-child relationship may be a better approach in working with families. Counselors should help parents recognize the
positive aspects of caregiving which is their personal growth, affection for the adult children, and closer parent-child relationships (Bulger et al., 1993).

For African American families and other ethnic families in therapy, a multisystems approach is effective as it assesses all aspects of the caregiving system. The multisystems approach recognizes that non-White families rely more on intergenerational family and community systems for support than White families (Boyd-Franklin, 1989). The multisystems approach focuses on the use of all the families resources used for coping and support which may include extended family, church, and neighborhood resources. This approach provides a model that is useful for resolving the problem presented by the family. The therapist must be flexible and use various systems theories in the overall treatment plan. Interventions include the use of a variety of system levels such as individual, family, extended family community, church and social services (Boyd-Franklin, 1989).

Needs for More Supportive Services

Counselors, practitioners, and health care providers who work with parents who are caregivers for adult children should be aware of changes in life span development and intergenerational support systems. Aging parents who have often been viewed as a burden for families are now being recognized as major resources for adult children who experience major life problems. There are increasing needs for supportive services and development of programs for parents who are distressed by their
adult children's struggles with major life problems. Intergenerational
counseling which includes the adult child, parents, and often other family
members is beneficial in helping families cope with the major life
problems (Greenberg & Becker, 1988).

Helping professionals need to be aware of the diversity of ethnic
influences and family structure. Knowledge about each family's
differences are crucial for effective interventions, counseling and program
development. Helping professionals should be aware of stereotyping
families in relation to ethnic background or family situation, as this can
affect the interventions and perspective used by the helping professional
(Taylor et al., 1993). Culturally appropriate interventions for caregivers in
individual and group counseling should be considered when working with
multicultural groups. Interventions which may be appropriate for one
cultural group may not be appropriate for another cultural group due to
differing interpretations of intergenerational caregiving and cultural beliefs
(Mui, 1992).

Individual, family, and ethnic norms may influence parents against
using formal or professional systems to resolve caregiving issues. In
these circumstances, interventions can include existing networks of peer
or lay helpers. These interventions can be existing family, social or
spiritual networks, community support systems, or intergenerational family
support systems (Taylor et al, 1993). Most Asian Americans deal with
psychological problems without seeking professional help. They use self
reliance or choose to seek help from family, friends, clergy, and
physicians (Uba, 1994). Hispanics have a tendency to underutilize professional counseling and mental health services more than most other ethnic groups (Rogler, Malgady, & Rodriguez, 1989). The family is seen as a supportive, help-giving system. Families serve protective and supportive functions in time of need, especially in taking care of family members in intergenerational family systems (Rogler et al., 1989).

**Support Groups**

Support groups are very effective for families after individual and family counseling. These groups provide continued support and affirmation of techniques and strategies learned in counseling (Taylor et al., 1993).

Psychoeducational groups and programs have been very effective in meeting the needs of caregivers and assisting them in the recognition of the stressors of caregiver burden. Research by Abramowitz and Coursey cited in Bulger et al. (1993), provided evidence that the psychoeducational approach did reduce levels of caregiver burden, increased parent's understanding of mental illness and were effective in teaching problem solving skills. However, this approach was not successful in diminishing parents' negative feelings toward their adult children in relation to the burden of caregiving (Abramowitz & Coursey, cited in Bulger et al., 1993).

Participation in psychoeducational groups broadens the family's available support systems as the parent's and family members interact with others who are experiencing the stressors of caregiving roles and
responsibilities (Greenberg et al., 1993). As a therapeutic modality, group work is very effective. Self help, therapy and psychoeducational groups are all important interventions for parents in caregiving roles. These groups have many positive aspects including; providing interaction with others with similar problems; giving guidance, advice and suggestions about caregiving; creating new social support networks; developing and learning new coping skills; dealing with emotional issues such as anger, depression, and guilt, and enhancing self esteem (Taylor et al., 1993).

Conclusion

Caregiving responsibilities transcend gender, family structure, ethnic/race, and socioeconomic boundaries as the responsibility and burden is assumed by adults of all ages. In the future, research should take a life span perspective as this focuses on the similarities as well as differences in the dependency and care taking needs of all ages. This perspective recognizes the crisis events in peoples lives, such as major life problems in the lives of adult children, but also views dependencies and obligations of families as part of the normal life span. Life span perspective recognizes the need to understand family structure and relationships and how these factors affect the experiences of past, present and future caregiving and the perception of caregiver burden (Marks, 1996).

As the aging population continues to grow in numbers, it is important for researchers to keep in mind that the majority of middle age and older parents are healthy, active and are involved in the lives of their
adult children and grandchildren. Research is needed to explore further the caregiving burdens parents face as adult children experience major life problems (Blieszner & Mancini, 1987; Greenberg, 1991). Research should also continue to explore the effects of age, gender, ethnicity, and culture on the patterns of utilization of formal and informal support services, such as counseling and community support systems (Mui, 1992).

Programs need to be designed to train counselors and helping professionals to understand the importance of lifespan and intergenerational perspectives. Helping professionals need to understand how these perspectives influence caregiving roles in families and to identify and appreciate the unique needs of each family and caregiver situation. More emphasis needs to be focused on the development of support systems for caregiving parents as the burden of caring for adult children and grandchildren has increased in recent years (Blieszner & Mancini, 1987; Mui, 1992).

Research on parenthood in later years should include recognition of the positive aspects of parent-child relationships which are characterized by mutual assistance, affection, frequent and open communication and emotional support. Recognition of the relationship between the need and desire for parents to continue to be active in the parenting role and the resulting emotional and psychological well being is important. The relationship between perceived skill, burden and caregiving roles in the lives of adult children and the positive feelings of
accomplishment, mastery and competence for parents in later years should be explored further (Blieszner & Mancini, 1987).
References


