INTRODUCTION

In their daily routines, families have more influence on the personal health of each member than any other individual or any health service provider. This is particularly true in the development of and adjustment to a chronic disease or disability such that any palliative effects of interactions with a health care service provider can be augmented or undermined by family members who assume pivotal roles in the ongoing health behaviors of their kin. Although these family members are typically viewed as ancillary to the delivery of health services, this chapter asserts that families are an integral and vital component of health, and that health care professionals must attend to the unique features of families in order to enhance the health of the patient. Because families living with those with disease and disability probably have more influence on their health than any single professional health care provider, it is prudent that these persons receive as equitable a degree of training and skill development as observed in the training of other health professionals (Lengnick-Hall, 1995). This approach will necessitate a collaborative—rather than an authoritarian or paternalistic—partnership with families that includes their opinions about needs and solutions in research projects and service delivery programs (Israel et al., 1998), and may also require more community-based, in-home intervention programs than typically offered by most professional psychologists.

It must be noted that families, in which individuals assume both care recipient and carer roles, vary in the degree to which they include non-blood kin ("fictive kin"); families also differ in ways in which members from older and extended generations are involved in the immediate family circle. In this chapter, we discuss the experience of individuals faced with the care of a family member with a chronic illness or disability as they attempt to navigate
health care systems. We will begin with a discussion of the historical background of caregiving in the United States as an example, outline the dilemma faced by carers in the USA, then present models of caregiver stress and, finally, review current treatment approaches.

Demographic trends and changes in the health care system in the USA, as elsewhere, have focused attention on the welfare and quality of life of an increasing elderly and disabled population. In the USA there are more than four million adults aged 65 years and older living in their communities, and another 33 million persons with disabilities (US Census Bureau, 1997), who require some form of assistance with such basic needs as bathing, dressing and toileting. It is generally up to their family members to provide this care as well as emotional, physical and financial support (Alzheimer’s Association & National Alliance for Caregiving, 1999; National Alliance for Caregiving & American Association of Retired Persons, 1997).

It is acknowledged that the responsibility and commitment associated with the carer role can take a toll on the individual’s emotional well-being and resources thus compromising the carer’s productivity, mental health, and physical well-being, and increasing the possibility of abuse directed at the dependent individual (Quayhagen et al., 1997).

Factors such as the physical and psychological demands made by the care recipient, the limitations on freedom and social interactions that accompany the care recipient’s need for supervision, the financial burden, and the additional roles assumed by most carers including those of wife, parent, spouse and employee, all contribute to carer distress (Alzheimer’s Association & National Alliance for Caregiving, 1999; National Alliance for Caregiving & American Association of Retired Persons, 1997; National Institute on Aging & National Institute on Mental Health, 1999).

**HISTORICAL BACKGROUND OF CAREGIVING**

Demographic, social and economic trends including reduced health care services have all contributed to an increase in personal responsibility for the care of family members. While in the USA, for example, the Social Security Act of 1930 made provision for some services that allowed individuals to increase dependence on public and private resources for the personal care of their disabled or elderly kin (Schorr, 1980), the services and programs were neither comprehensive nor a solution to the problem of caregiving. Furthermore, decreased birth rates, increased life expectancy, increased divorce rates, and more women in the workforce have reduced the pool of available caregivers in the USA and most Western countries. Thus, for example, the millions of Americans who rely on informal care from family members have found themselves in a situation where there are many more seniors and disabled adults than there are carers (Subcommittee on Human Services of the Select Committee on Aging, 1987).

Fifty-nine per cent of American women between the ages of 45 and 54 work full time (US Department of Labor, Bureau of Labor Statistics 1995). This segment of the population is the group in the USA most likely to assume the role of family carer to an aging parent or disabled spouse or child. While the result of this trend is a reduced pool of potential female carers in the home, today’s increased acceptance of men in non-traditional roles coupled with the prohibitive costs of institutionalization and professional in-home care may actually encourage men to take a more active approach in caregiving.

The high rates of divorce have also had important ramifications. For those individuals who have not remarried, spousal support—the primary source of carer support—is not available,
and their caregiving responsibilities often fall on the children (Cicirelli, 1983). In addition to overcoming resentments and family conflict issues, these carers must also struggle with providing care and supervision to individuals who may not live together. For those divorcees who do remarry, filial responsibility may actually decrease, thereby reducing the pool of available carers (Cicirelli, 1983).

Finally, the number of chronic health problems have escalated in most Western societies and health care programs often limit services to persons with these conditions, thus compelling many family members to assume carer roles during periods that are not traditionally associated with provision of care (Hoffman, Rice & Sung, 1996). The role of the family carer has intensified with dramatic cutbacks in health care services, and the emergence of managed care as the predominant health care paradigm in Western countries has had many adverse effects on families with a member who has a chronic disease or disability (Council on Scientific Affairs, American Medical Association 1993). With these changes in health care allocation—and with increases in the incidence of chronic disease and disability—more individuals will be compelled to assume the role of primary carer for a family member who incurs chronic disease or disability. Chronic health conditions and the management of symptoms associated with them account for approximately 68% of all health care expenditures in American health care systems, for example, and this may represent the greatest single challenge facing modern health care (Frank, 1997). As the number of chronic health problems continues to increase in contemporary society, and as the number of elderly individuals increases with advances in medical care, increased pressure will be placed on families to assume responsibility for the ongoing health care and adjustment of members with these conditions.

REACTIONS TO CHANGING ROLES AND EXPECTATIONS

When an individual incurs a chronic health condition, the degree of onset can vary in impact on the family. Some problems that are commonly considered to be age-related may be perceived as developmentally on-time (cf. Neugarten, 1979) albeit stressful and undesirable. In contrast, conditions that occur in accidents or trauma can be more stressful to a family in that these are construed as off-time events, in terms of developmental expectations for the individual and the family. Many young adults who incur severe physical disability in these circumstances may have considerable difficulty living independently, and a parent or spouse may have to assume carer duties at the expense of other career goals and activities. Individuals who incur severe physical disability often have considerable life expectancy, and thus the need for assistance from a family member may exist throughout a lifetime.

The roles and responsibilities associated with caregiving for a family member with a disability are many, and may vary from simple errands to such physically and emotionally challenging tasks as feeding, transferring, bathing or toileting. Depending on the type of care required, carers may also provide assistance ranging from a few hours a day to round-the-clock care. Although the type of assistance given depends on an individual’s level of disability, one basic responsibility is for the carer to provide emotional support through regular contact, company and conversation.

The emotional life of a family, however, is influenced tremendously by factors that are typically operational prior to the onset of any health condition. There is no universal response or sequence of emotional reactions that characterize a family’s experience. Clinicians are
often vigilant for manifestations of denial, assuming family members are unconsciously unable to accept the fact that a loved one may be permanently affected by a diagnosis. But clinicians often fail to appreciate that many people are generally unaware or uninformed about specific health problems and their concomitants, and thus may have legitimate difficulty in understanding the meaning and ramifications of a specific condition. Denial is not a single, simplistic entity: families may not deny the factual existence of a particular condition, but they may not accept the implications of the condition as promulgated by clinical staff (Lazarus, 1983). Families that maintain goals and expectations, and who express optimism in the wake of acquired disability, are often labeled by staff and treated with disregard and condescension (Elliott & Kurylo, 2000), when in fact the family is expressing little more than a difference of opinion with staff (Novack & Richards, 1991).

At times, clinicians may embrace erroneous assumptions about the healing properties of time for family members. For example, it is often assumed that family members who are compelled to accept caregiving duties following the onset of disability will become more comfortable over time with routine and familiarity. However, empirical research indicates that carers who are depressed, anxious and in ill health during the initial inpatient stay of a loved one who has incurred disability are more likely to display increases in depression, anxiety and ill health over the course of the first year of caregiving. In contrast, carers who do not report adjustment problems during the inpatient stay are more likely to adapt well over the year (Shewchuk, Richards & Elliott, 1998).

Elaborate research designs and methodologies reveal that carers are at risk for disruptions in cardiovascular and immune functioning (Vitaliano, 1997). Their psychological and physical problems can be exacerbated as carers neglect their own health and care (Burton et al., 1997). Carers often face competing demands of multiple roles such as employment, and lack time for recreational and leisure pursuits, thus compromising their personal health and opportunities for positive mood experiences (Quittner et al., 1998; Quittner et al., 1992). The factors identified as having the greatest negative impact on carer burden and stress are time limitations on personal activities, caregiving demands, patient deterioration, and patient uncooperativeness (Alzheimer’s Association & National Alliance for Caregiving, 1999; National Alliance for Caregiving & American Association of Retired Persons, 1997).

Many more adults with disabilities are admitted to long-term nursing facilities because of carer burnout than from a worsening of their physical condition (National Family Caregivers Association, 1999). Evidence indicates that older carers are at risk of mortality, compared to peers who are not carers, presumably due to the combined factors of prolonged stress, physical demands of providing care, and biological vulnerabilities (Schulz & Beach, 1999).

The financial burden resulting from missed work, termination of long-term public assistance such as social security benefits, or the cost of in-home services is another source of stress faced by carers (Pavalko & Artis, 1997). For example, the typical cost for Adult Day Care in California is $40 per day, or over $4100 a year if used twice a week. The use of an in-home attendant for eight hours weekly can add another $4500 a year, bringing the cost of care to almost $9000 annually. And although many state or private agencies exist to offer respite assistance to those in need, qualification criteria frequently exclude families in greatest need such as those on assistance programs.

While researchers and clinicians usually focus on the adjustment problems experienced by families following disability and disease, some families may actually experience positive changes (Perlesz, Kinsella & Crowe, 1999). Olkin (1999) observes that acquired disability
FAMILY CARERS

FAMILY CARERS can force family members to directly confront issues of trust, mortality and values, which in turn compel members to develop deeper commitments and restructure the meaning of marriage or kinship. Some family members report a greater sense of closeness, a greater emphasis on family and personal relationships, and positive changes in shared family values (Crewe, 1993). Support from family members is associated with greater acceptance of disability and personal meaning among persons with physical disability (Li & Moore, 1993). Many studies appear to over-report or misrepresent distress experienced by siblings of children with disability, and these issues seem to be adversely slanted by methodological and theoretical approaches that perpetrate negative views and ignore positive aspects of this experience (Perlesz et al., 1999; Summers, White & Summers, 1994).

Family carers may experience positive shifts in their values and reconsider goals that were altered in the face of disability, and these shifts are indicative of stress-related growth and subjective well-being (King & Patterson, 2000; King et al., 2000). There is evidence to suggest that older family members in particular may be likely to experience some health and emotional benefits in providing care for a loved one (Beach et al., 2000; Kramer, 1997).

CULTURAL ISSUES

It is critical to remember that all factors affecting a carer’s experience must be considered within the context of the individual’s cultural and interpersonal life experiences (Aranda & Knight, 1997; Ingersoll-Dayton, Morgan & Antonucci, 1997; Martire, Stephens & Atienza, 1997). Ethnicity and culture contribute to a variation in the stress and coping process because of (a) differential risks to specific diseases and disorders, (b) differences in appraisal of stressors, and (c) the differential effects of stress-mediating factors such as family and social support. For example, the impact of role change and anticipatory grief is likely to be experienced quite differently by a traditionally home-based wife who must learn to run a household effectively while simultaneously trying to maintain the dignity of her disabled husband, than by the independent working woman who finds herself challenged by the domestic tasks of caring for her aging parents (Rivera & Marlo, 1999). Additionally, other factors such as socio-economic status, familial interdependence, level of acculturation, immigration status, and fear of stigma regarding a disease or physical disability (Aranda & Knight, 1997; Sotomayor & Randolph, 1988) may influence minority group members’ experiences of caregiving, and place them at a disadvantage for social and professional services, resulting in levels of distress that are much greater than those documented in samples of non-minority carers.

In order to best address the needs of minority consumers of health care services it is important to understand some of the common misconceptions which surround their utilization of psychologically based services. Errors in judgment about cultural groups are frequently based on stereotypes. Because families of color are often stereotyped as being close-knit and supportive of their kin, for example, social service agencies may not take the time to assess the actual needs of this population. This assumption may lead to less allocation of resources, manpower, and finances for outreach to those communities (Valle, 1981), which in turn, may help to perpetuate the misconception that they underutilize social services because they are taken care of by their own families (Henderson & Gutierrez-Mayka, 1992).

Valle (1981) proposed that a collaborative, community-based approach is needed to meet the challenges of working with carers of minority elderly and disabled persons. Valle
recommends that education occur through culturally pre-existing social networks such as churches, community link-persons or religious leaders, and family networks. Aranda (1990) has further argued that interventions that are culturally relevant and utilize bilingual/bicultural staff are likely to increase minority utilization of services, as are interventions such as classes or support groups which do not carry stigmas of mental health problems, and which facilitate empowerment and encourage personal responsibility for change. Considerably more information about the experience of caregiving for individuals of differing cultural backgrounds must be obtained, in order to adequately address service needs, delivery and utilization.

There are also cross-cultural issues that should be considered when studying the experience of families and health. Research has documented compelling differences between carers in American families and those in other nations. Among carers for disabled, older adults, for example, carers in American families appear to have spent less time with a care recipient before assuming the carer role than family carers in Switzerland (Karlin, O’Reilly & Williams, 1997). Another study found family carers of Alzheimer’s disease (AD) patients in the USA reported more depression and anxiety than carers of AD patients in China, although coping styles and behaviors were similar between the two groups (Shaw et al., 1997). The reasons for these and other differences are unclear and they are open to further study. It is important to note, however, that study of within-group differences between members of a specific culture reveals that psychological characteristics often predict adjustment among family members in a theoretically consistent and interpretable manner (Chan, Lee & Lieh-Mak, 2000).

EXPERTS ON THEIR DAILY LIVES

Qualitative research designs provide valuable insights into the family experience. But many theorists and researchers make assumptions about families and their reactions, needs and problems following the onset of disease and disability, and take a “top-down” approach to the development of services and programs that does not take into account the opinions and perspectives of individuals who live daily with chronic health conditions (Shewchuk & Elliott, 2000). It is preferable to regard families who have a member with health problem as experts on the “realities of their daily lives” (Mechanic, 1998, p. 284).

Severe physical disabilities that necessitate both changes and assistance in basic self-care and activities of daily living compel families to deal with a range of unique problems. Typically, professionals assume these problems constitute the sources of burden on families, however, in a focus group of carers for persons with spinal cord injury (SCI), carers ranked problems concerning interpersonal and familial stress higher than instrumental activities associated with self-care regimens (Elliott & Shewchuk, in press). Specifically, carers ranked the following as problematic: “hateful attitudes of the care recipients”, “carer feelings of guilt”, “lack of appreciation”, “care recipient is demanding and bossy”, “finding challenging activities for the care recipient”, “not enough time in the day”, and “sense of obligation to keep care recipient busy”. Out of 18 problems ranked by these carers, only one specifically concerned self-care activities. In contrast, a self-report study in Hong Kong found that spouses of persons with SCI reported a health- or disability-related problem as the primary source of stress in their lives; family interactions and relationship issues were the second most frequently nominated problem (Chan, 2000).
Neurological disabilities that primarily affect brain-related functions can have substantial cognitive sequelae in addition to occasional physical impairments. This can result in substantive changes in behavioral expression, memory, and self-regulation. In another focus group study, husbands of women with traumatic brain injury (TBI) identified specific problems with their wives’ loss of autonomy, mood swings, insecurities, overprotectiveness, reluctance to leave home, and change in lifestyle as particularly stressful (Willer et al., 1991). Wives of men with TBI reported specific problems with husbands’ personality changes, memory loss, lack of insight, lack of acceptance, reduction in financial resources, loss of emotional support, and feeling unable to meet children’s needs. Other qualitative studies have found that family carers have many concerns about interpersonal relationships, quality of life, and emotional commitments (Chwalisz & Stark-Wroblewski, 1996; Long, Glueckauf & Rasmussen, 1998).

There is some evidence that family members may have more ongoing concerns about management and adherence issues when a member has a chronic disease like diabetes. These carers report great concern about their loved one “driving alone”, the disease progression, and the adherence to insulin dosing schedules and dietary habits (Miller et al., 2000). It appears that chronic disease imposes fewer interpersonal and familial disruptions than mobility-related impairments (e.g., SCI) or neurological disabilities (e.g., TBI). Once a family manages the instrumental tasks associated with disability, the quality of interpersonal relationships may then be of chief concern to those in committed, ongoing relationships. The ambiguity of disease management and progression, however, may be salient to family carers who assist a member with a chronic disease.

SOCIAL AND FAMILY SUPPORT

Families are often considered an extension—if not an embodiment—of social support. Indeed, individuals who have incurred spinal cord injury report that partners and family members are more useful than friends and professional staff in helping them to cope during the first year of disability (Rogers & Kennedy, 2000). Dakof and Taylor (1990) found that patients with chronic health problems identified practical assistance from spouses and other family members to be especially supportive, and lower levels of family support have been associated with a greater mortality rate among hemodialysis patients (Christensen et al., 1994). Effective family support has also been associated with improved social adjustment and less psychological distress among bone marrow transplant survivors in Europe (Molassiotis, Van Den Akker & Boughton, 1997).

Specific characteristics of these supportive networks that have been identified as crucial include the amount of support available, the adequacy of the support, and overall satisfaction with the support received (Mittleman et al., 1994). Alternatively, unmet needs and negative interactions with others are two additional characteristics of social support that have been reported to contribute to psychological distress in carers (MaloneBeach & Zarit, 1995; Redinbaugh, MacCallum & Kiecolt-Glaser, 1995; Rivera et al., 1991). People who are married reported greater life satisfaction in the first year of disability than persons who are single or divorced (Putzke, Elliott & Richards, 2001), but spousal partners can be a source of considerable stress (Coyne & DeLongis, 1986). In some cases, family members offer less support in reaction to the emotional distress of the care recipient, which can burden and alienate family members (Bolger et al., 1996), and induce expressions of anger.
Family interaction patterns have stronger associations with self-reported health behavior among cardiac patients than other social support variables (Franks, Campbell & Shields, 1992). Marital quality and satisfaction may be directly related to patient adjustment following the onset of disease and disability (Coyne & Smith, 1991). The care recipient may at times encounter expressions of hostility, which exacerbates their distress (Fiske, Coyne & Smith, 1991). Spousal criticism, in particular, has been predictive of greater patient distress and maladaptive coping behaviors (Manne & Zautra, 1989), with patient health-compromising behaviors (Franks, Campbell & Shields, 1992), and with increased primary care utilization of cardiac patients (Fiscella, Franks & Shields, 1997). In other situations, family members may overprotect the care recipient from potentially stressful situations that might inadvertently compromise the emotional adjustment of both carer and care recipient (Coyne & Smith, 1991; Suls et al., 1997). Care recipients who place a high premium on functional independence prior to their debilitating condition may have the greatest difficulty accepting support from a spouse (Martire et al., 2002).

### PARENTING AND GENDER ROLES

Women are more likely to assume the role of carer for an ill family member. Much of the extant literature has understandably focused on mothers, wives and daughters in these roles (Moen, Robison & Dempster-McClain, 1995). Although women report more distress than men in caregiving roles, these differences might be due to the willingness of women to report distress (Gallagher-Thompson et al., 1998). Gender differences in adjustment may cloud our understanding of how spousal and parental carers react differently to the health of a family member. Wives of patients with heart failure report more distress than husbands of women with this condition, and the distress reported by the women in the carer role is directly associated with their perceptions of marital quality (Rohrbaugh et al., 2002). Rose et al. (1996) found that while husbands increased household activity after a wife experienced a myocardial infarction, the recovering wives still took on as many household duties as the husbands. One explanation for this finding might be that the resumption of the homemaker role of these women was critical to their well-being and recovery.

Children’s adjustment is often associated with the mother’s adjustment, but maternal carer adjustment is influenced more by stress, family support, and personal resources than the severity of the condition or functional abilities of the child (Wallander et al., 1988; Wallander, Pitt & Mellins, 1990; Wallander & Varni, 1989; Wallander et al., 1989a; Wallander et al., 1989b). Mothers often encounter social isolation as they care for a child with a chronic disease or disability, while fathers encounter strains associated with financial obligations and work-related activities that may affect the care and well-being of the child (Frank et al., 2001; Holmbeck et al., 1997). Although the impact of fathers on child adjustment has been largely overlooked in past research, accumulating evidence now demonstrates that fathers have a considerable impact on the adjustment of a child with a chronic health condition, even when the father does operate as the family carer per se. For example, father’s drinking problems and parental strain were predictive of child adjustment over a four-year period (Timko et al., 1993). Chaney et al. (1997) found child adjustment over a year was directly related to increases in fathers’ distress, and not the mothers’ distress. A decline in fathers’ adjustment was inversely related to mothers’ adjustment.
Parents can model effective coping skills for their ill children, who in turn may utilize similar strategies with beneficial results (Kliewer & Lewis, 1995) in their self-care regimens (Chaney & Peterson, 1989). Behavioral problems and health complaints of adolescents with chronic disease are more likely in families lower in family competence (Kell et al., 1998) and in those marriages characterized by poor adjustment and interactional strain between husbands and wives (Clay et al., 1995; Frank et al., 1998).

THEORETICAL EXPLANATIONS OF FAMILY EXPERIENCE FOLLOWING DISABILITY

Several important models have tried to explain family dynamics in the wake of a chronic health condition in a member. Notable among these is Minuchin’s conceptualization of rigid, over-protective, and enmeshed family interaction patterns that contribute to the development and exacerbation of psychosomatic illnesses in children (Minuchin et al., 1975). Subsequent research has not supported the basic tenets of this model (Coyne & Anderson, 1989). Recent evidence indicates that some of these interactive patterns in which a child’s input is recruited into dyadic discussions may be related to marital quality, and be useful in long-term coping, monitoring, and management of a chronic condition (Northey, Griffin & Krainz, 1998). Increased family cohesion and the high quality of mother–child interactions are predictive of positive growth in socialization, daily living skills, and communication among young children with Down’s syndrome (Hauser-Cram et al., 1999).

In contrast, research has supported models of family behavior that posit that well-intentioned efforts by a spouse to allay the pain and suffering expressed by a partner may inadvertently reinforce “disabled” behavior and reward the patient for emitting these behaviors (Foryce, 1976). Spouses of chronic pain patients tend to be more solicitous than spouses of persons without pain (Flor, Kerns & Turk, 1987; Romano et al., 1992). Furthermore, parents who have more effective written and verbal problem-solving skills have been found to be more adherent with complex self-care regimens for their children than parents of children noted for poor compliance (Fehrenbach & Peterson, 1989), and may exhibit less distress with long-lasting benefits that can be observed up to three years later (Rivara et al., 1996). These skills may be a major determinant of patient behavioral outcomes in the first year of injury (Kinsella et al., 1999).

Effective social problem-solving abilities are associated with optimal adjustment among people in general (D’Zurilla & Nezu, 1999) and are predictive of carer depression, anxiety, and ill health in the first year of caring for a family member with a disability (Elliott, Shewchuk & Richards, 2001). Other data indicate that problem-solving abilities are predictably associated with carer adjustment across the life span, including mothers of disabled children (Noojin & Wallander, 1997) and spouses of persons who have experienced a stroke (Grant et al., 2001a).

The ability of the carer to solve problems associated with life in general, and those associated with caregiving may be directly related to the adjustment and health of the care recipient. Carer tendencies to carelessly and impulsively solve problems have been associated with lower acceptance of disability among persons with SCI at discharge from a rehabilitation hospital. Moreover, carer impulsive and careless problem-solving styles—assessed at discharge—correctly classified the majority of care recipients who developed pressure sores a year later (Elliott, Shewchuk & Richards, 1999). A problem-solving model
is attractive because it features a logical framework with testable hypotheses, a supportive literature base, a psychometrically sound measure, and clear directions for interventions (D’Zurilla & Nezu, 1999). Cognitive-behavioral perspectives appear to have considerable potential in understanding and conceptualizing family dynamics following disability.

**PSYCHOLOGICAL INTERVENTIONS**

There is an urgent need for programs that help family carers to address the routines and tasks “. . . essential to maintaining family functioning” (Altman, Cooper & Cunningham, 1999, p. 67). Psychologists can have an immense impact in developing, evaluating, and delivering interventions that address the everyday needs of carers and their care recipients. Intervention research in family health psychology indicates that psychoeducational strategies are consistently more effective than other modalities, presumably because these approaches address the specific needs of family members and often actively involve family members (Burman & Margolin, 1992; Campbell & Patterson, 1995). Psychoeducational interventions can be conducted in inpatient, outpatient, community and home settings; they can be effectively adapted to serve culturally diverse populations (e.g., in Spanish; Gallagher-Thompson et al., 2001). Programs that address the specific needs of families may be more likely to succeed (Burman & Margolin, 1992).

Interventions that include spouses as part of patient treatment, without any clear goals specific for the spouse, do not seem to be particularly effective (Moore & Chaney, 1985). However, programs that educate the spouse about a health condition and skills in self-care and coping, and that instill a greater understanding of the patient experience, are more promising (Moore, 1989). Others maintain that family therapies are still better for families that have a member presenting symptoms sensitive to family distress and interaction patterns (e.g., asthma, diabetes; Campbell & Patterson, 1995).

It is vital to consider the multiple systems that directly impinge not only on the delivery of needed services to families, but the availability and access to health care in contemporary society. Theory-based interventions can be delivered in community settings by low-cost personnel (e.g., problem-solving training for family carers: Elliott & Shewchuk, in press; Houts et al., 1996). Problem-solving principles can be incorporated seamlessly into family education programs (Bucher et al., 1999). Program evaluation research and predictive models that take into account unique patient/family subgroups will help us to identify individuals who require more intensive therapeutic interventions from skilled staff and who are most likely to benefit from these high-cost services (Shewchuk & Elliott, 2000).

Effective interventions will address the problems as experienced by families (Elliott & Shewchuk, 2000). These interventions should help families to become more active and expert in their self-management and to operate competently as extensions of the formal health care system (Wagner, Austin & Von Korff, 1996). Recent programs that emphasize “partnerships” with family carers recognize their needs for education, support, and counseling in the home environment (Grant et al., 2001b). These programs circumvent problems with mobility and transportation restrictions, and work within the time constraints that many carers experience. Evidence indicates that family carers and care recipients benefit from problem-solving-based interventions provided in telephone interactions (Grant et al., in press; Roberts et al., 1995). Distance education for family carers using telephone sessions
may be as effective as support groups in alleviating burden and promoting family interactions (Brown et al., 1999). Other programs have relied on home visits to provide on-site assessment and training for family carers in the first year of acquired disability (Kurylo, Elliott & Shewchuk, 2001). Computer-based technologies can be used to conduct family counseling sessions, and these modalities have been used successfully with families that have a teenage child with seizure disorders (Hufford, Glueckauf & Webb, 1999). Home-based video counseling and speaker phone counseling, and face-to-face office-based counseling appear to be equally effective in reducing problems severity experienced by families and pre-adolescents with epilepsy; moreover, these respondents preferred the two home-based modalities over the traditional office visit (Glueckauf et al., 2002).

FUTURE DIRECTIONS FOR PROGRAM AND POLICY DEVELOPMENT

The numerous creative approaches to managing carer distress and their variability in results have led to the need to identify mechanisms of action, or reasons for the efficacy of particular treatments. Identifying the “how” and “why” a treatment does what it is intended to do is a basic tenet in clinical trials and can be used in a similar fashion in examining the effectiveness of carer interventions (Gitlin et al., 2000).

Carer interventions generally cluster within four categories: family, individual, behavior management, or home-modification. While the underpinning theoretical frameworks of each imply a mechanism of action, they do not necessarily explain how burden or distress is reduced or eliminated. Theory refinement is an unquestionable and ongoing process in science that attempts to answer the question of how. Lichstein, Riedel and Grieve (1994) have proposed treatment fidelity as an approach to explaining why a particular procedure works. Through the careful measurement and documentation of (a) treatment delivery, (b) treatment dosage, and (c) treatment implementation by participants, critical characteristics of the intervention process can be identified. Furthermore, such systematic assessment will allow comparisons between differing treatment modalities, with the goal of identifying the mechanisms of action and the conditions necessary for optimal efficacy.

Empirical research that is embedded within a sound conceptual framework and incorporates cultural and individual differences can efficiently contribute to policy reform. Under conditions that include sufficient data, proof of cost-effectiveness, and endorsement from a consensus group, interventions can become a “standard of care” (Mahoney, Burns & Harrow, 2000), benefiting not only the consumers, but also service providers. As persons living with a chronic disease or disability have more influence on outcome than any single health provider, scientists and practitioners must form partnerships with these consumers in serving their needs and finding solutions in a manner that effects positive change at individual, systemic and programmatic levels.

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