

# International Encyclopedia of Rehabilitation

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Center for International Rehabilitation Research Information and Exchange (CIRRIE)  
515 Kimball Tower  
University at Buffalo, The State University of New York  
Buffalo, NY 14214  
E-mail: [ub-cirrie@buffalo.edu](mailto:ub-cirrie@buffalo.edu)  
Web: <http://cirrie.buffalo.edu>

*This publication of the Center for International Rehabilitation Research Information and Exchange is supported by funds received from the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education under grant number H133A050008. The opinions contained in this publication are those of the authors and do not necessarily reflect those of CIRRIE or the Department of Education.*

# Caregivers: Their Role in Rehabilitation

**Nancy Guberman**  
**Professor of Social Work**  
**University of Quebec in Montreal**

Note: The term “caregiver” is widely used in North America, while in other English-speaking countries (U.K., Australia, New Zealand), the preferred term is “carer”, and there have been debates about these terms. It has been difficult to find a corresponding term in other languages such as French, Spanish and Portuguese and different countries have developed different vocabularies to designate the people whom we discuss in this chapter.

This chapter is based on work that I have done in collaboration with Pierre Maheu and Jean-Pierre Lavoie, who, to a certain extent, should be recognized as co-authors.

Carol and Philip are anxious and frustrated as they negotiate the ins and outs of the world of rehabilitation since their teenage son’s motorcycle accident. Angela has “put her life on the back burner” since she started caring for her aging parents suffering from multiple chronic conditions. Mary sometimes wishes her husband, totally paralyzed from a work accident, would die and set her free, and suffers from enormous guilt for having such thoughts. Carol, Philip, Angela, and Mary are but four of millions of people caring for an ill or disabled relative or friend. They are caregivers. Not all caregivers make the same sacrifices as Angela, or experience the level of distress and pain that colour Carol’s, Philip’s and Mary’s lives. But the experience of becoming a caregiver is the reality of a growing number of individuals around the world.

Indeed, the number of people with disabilities and illnesses requiring help to manage their daily lives is increasing every year. Those who are over 80 are the fastest growing group, being most likely to have chronic disabilities and illnesses that prevent them from being able to accomplish their daily activities. But older people are not the only group with disabilities that is growing, as modern medical technology and pharmaceuticals are saving and prolonging more and more lives of people who would not have survived their conditions thirty or forty years ago. Current policies favor maintaining people with chronic disabilities in their communities, in their homes if possible. To achieve this goal, in most countries, they count on family and friend caregivers to assume much of the support required (Keefe et al. 2005; Keefe and Rabinovitch 2007; Lavoie et al. 2005). However, even when people with disabilities are institutionalized, caregivers often play an essential role in ensuring care (Ducharme et al. 2005). This is all the more so in developing countries. (Guberman and Maheu 1997). Indeed, in many of these countries, strong family values that parallel the absence of community home and long-term care mean that families assure almost all care.

From the early 1980s, studies have documented the disproportional investment of caregivers (Guberman et al. 1988; Shanas 1978) who assume 70-80% of all care and support offered to people with disabilities (Bontout et al. 2002; Lavoie et al. 2005; Thompson 2004; Wimo et al. 2002). According to Statistics Canada (1996), this means that at any point in time, 14% of all Canadian women over 15 years old are active caregivers. In the U.S. unpaid family caregivers will likely continue to be the largest source of long-term care services and are estimated to reach

37 million caregivers by 2050, an increase of 85% from 2000 (Health and Human Services and Assistant Secretary for Planning and Evaluation 2003). And, one in five US caregivers provides more than 40 hours of care per week (NAC and AARP 2004). In dollar terms, it is estimated that American caregivers to the elderly furnished unpaid labor that would have cost the health system 257 billion dollars in 2000 (Cowan et al. 2002). And yet, despite this reality, it is only recently, in a certain number of Western countries such as the US, France and the U.K., that caregivers are recognized as having specific needs. Another well-known fact that is often taken for granted and rarely addressed in social policy is that up to three quarters of caregivers are women (Atchley and Barusch 2004; Green 1988; Statistics Canada 1996; MSSS 1988; Schofield et al. 1998; Stone et al. 1987). And the 20-30 % of care that is not provided by families is also the work of women, often women from minority groups, especially in the case of personal care. (Neysmith and Aronson 1997).

In this chapter, we will first describe the people that we call caregivers and the work that they accomplish. Secondly, we will examine the consequences that caring can have on the lives of those who assume this work, and thirdly, we will examine what is known about caregiver-practitioner relations.

## **A Portrait of Caregivers**

Definitions of what a caregiver is vary greatly, but in the opinion of many, they must include two aspects: a measure of the work that is being accomplished, and an indicator that the person receiving this help has a functional, cognitive or mental limitation that prevents them from accomplishing those activities alone (Kane and Penrod 1995; Stone 1991).

Studies have revealed that it is rarely “the family” that cares for members with disabilities, especially when we are talking about hands-on care. Rather, generally, one or two family members take on primary responsibility for care, and these members are most likely to be women (Bocquet et al. 1996; Brody 1995; Hareven and Adams 1994; Lesemann and Martin 1993). Historically, the ideology of separate spheres that apportioned caring to women within the household, and profit-making to men within the market, became a source of this unbalanced distribution of caring work between men and women (Williams 2001 ; Lamoureux 1996). Although there is often one main caregiver, this fact does not put into question the reality that several family members may participate in different aspects of the care or in supporting the primary caregiver, but it points to the specific responsibility of certain members.

Although there is a tendency to speak about caregivers globally, we shouldn't forget that caregivers are, in fact, a very heterogeneous group including older spouses, working men and women, neighbors and more distant relatives (daughters-in-law, nephews, sisters, step-children, etc.) living in very diverse circumstances. They can offer a variety of forms of support and care to people of all ages with physical, mental, cognitive or intellectual disabilities. The care may have begun a few months ago or more than forty years ago. The quality of the affective relation with the person they care for can vary greatly. Caregivers are to be found in all circumstances, in all socio-economic groups, in all ethno-cultural groups. Here are a few portraits of caregivers:

- Sam is caring for his 27 year-old wife, Shari, who is paraplegic following a car accident. The couple has a 3 year-old child and Sam is the only income earner, although Shari has

- Christine, 42 years old, has four minor children including two teenagers, lives on social security and cares for her mother who co-resides with the family. Her 72-year-old mother is quadriplegic, incontinent, diabetic, and can no longer communicate verbally.
- Josiane and Maryse are 17 and 19 year old sisters, who take care of their 75 year-old grandmother suffering from mental health problems, as well as their 43 year-old mother who suffers from MS. They try to juggle their caring work with their studies but are fearful of leaving the two women alone. The family lives on social security.
- Antonio, 62 and Marietta, 64, care for Antonio's 91 year-old father who is very frail and suffers from memory loss, incontinence, chronic pulmonary disease, deafness and osteoporosis. The couple assumes all his care despite the fact that Antonio has heart problems himself and Marietta is recovering from a major knee injury.

While researchers and practitioners define caregivers using criteria such as hours of help provided, many people offering substantial care do not self-identify with the term "caregiver". They see themselves as fulfilling their normal role as family member, in particular wives and husbands, but also children. This situation appears to be changing, at least in North America, as caregivers, particularly those of the baby-boom generation, have adopted this term to indicate that the care they are providing often goes beyond what they consider to be the normal help that family members offer one another (Guberman et al. 2009).

## **What Do We Mean When We Talk About Caregiving?**

The variety of activities accomplished by caregivers covers all the work required to respond to the physical, psychological, and social needs of the person requiring support. Generally, there is a tendency to describe this work by referring to the category of activities of daily living (ADLs) – personal grooming, bathing, dressing, feeding, transfers, etc, and to that of instrumental activities of daily living (IADLs) – preparing meals, housework, managing budgets, etc. These measures of care are seductive in their simplicity and the easiness with which they can be measured. But, according to many (Bowers 1987; Lavoie 2000; Levine and Hart 2004), they offer a traditional image of caregiving as something normal and natural, comparable to the domestic work that women have always accomplished in the home. As well, emphasis on "tasks" tends to obscure the essential nature of these activities - the fact that they take place within intimate personal relationships (Able 1991; Bowers 1987) – as well as making invisible much of what else is going on at the same time such as emotional support and identity work, behaviour management, supervision of rehab exercises, meds and other treatments, mobilisation and advocacy for services and other resources, mediation with various professionals, control of the quality of the care, decision - making for the person and the development of strategies enabling caregivers to juggle the caregiving work with their other responsibilities (Guberman et al. 1993; Lavoie 2000; Levine and Hart 2004). In many situations, caregiving to a person with severe limitations is a full time monopolizing responsibility – 24 hours a day (Armstrong et al. 1994; Guberman et al. 1991;

Guberman and Maheu 1997). This is particularly true in the case of caring for someone with cognitive impairment.

When trying to appreciate the work of caregivers, it is also extremely important to consider the context within which it is accomplished. Contrary to institutional settings, homes are rarely adapted for specialized care. They do not have the appropriate spaces or equipment and have not been designed for people with special needs. Caregivers do not have access to the same information, training, or supervision as professionals (Guberman et al. 2005). In institutions, three teams cover 24-hour days, each working 8 hours a day, with coffee breaks, meal breaks and two days off a week, while caregivers are generally alone with little respite. Staff who go to the hospital or the rehab centre generally have only their paid work to accomplish during their time there, while in the home, caregivers must integrate the caring work into on-going family life.

Taking care of a friend or relative can be a positive and fulfilling activity. It can lead to closer ties with the person requiring support, the development of new competencies and even give meaning to one's life (Farran 1997; Kramer 1997; Nolan Grant and Keady 1996). However, it can also be difficult, complicated and disturbing.

## **Consequences of Caregiving**

Caregiving inevitably transforms the lives of caregivers, although its impacts vary greatly from one person to another. Most caregivers are faced with work overload and role conflicts given the multiplicity of responsibilities they assume, most often in the absence of adequate family and formal support, and without recognition on the part of other family members and professionals.

There is a substantial body of research that indicates that caregiving is associated with negative mental health consequences. It has been shown that emotional strain within the family unit may include: mental illness symptoms such as severe depression, anxiety, isolation, boredom, or sleep disturbances; low morale; sadness; feelings of helplessness, and conflict and frustration over competing demands (Brody and Brody 1989; Coe and Van Houtven 2009; Given et al. 2004; Kim et al. 2006 ; Zarit 1991).

There is growing evidence that caregivers experience an increase in personal health problems (Biegel et al. 1991; Cranswick 1997; Guberman et al. 1991; Sommers and Shields 1987). Various studies estimate that between 15% and 33% of caregivers experience detrimental effects on their physical health including back problems from lifting and turning care-recipients, physical exhaustion and stress-related ailments such as ulcers (Horowitz and Dubrof 1982; in Brody, 1995; NAC and AARP 2004; Schulz et al. 1999). There is also evidence of over-consumption of medication, particularly psychotropic drugs (Schulz et al. 1995).

According to Strawbridge and Wallhagen (1991), family conflict is an often-overlooked aspect of caregiving to older people. As their study and others (George 1986; Guberman et al. 1991; Guberman and Maheu 1997) reveal, these conflicts often occur among family members over the sharing of the caregiving responsibilities. Other studies, in particular concerning families caring for a mentally handicapped or ill child (Guberman et al. 1993; Thompson and Doll 1982) have found that respondents indicate they often neglect their other children and their spouses and this can lead to conflict within the family.

People caring for someone with a cognitive disability face particular challenges. Not only do Alzheimer's and related diseases bring cognitive, behavioural and personality changes, along with increasing dependency, they also disrupts normal patterns of relating. Caregiving for persons with Alzheimer's disease and other dementias is associated with higher levels of loneliness, stress and depression than caring for people with non-dementia conditions, and also results in high levels of unmet need (Philp et al. 1995). Research indicates a link between conjugal caregiving and psychological distress, especially for those who are caring for a person with Alzheimer's disease or related dementias (Clipp and George, 1993; Hooker et al., 1998). The stress of conjugal caregivers of persons with Alzheimer's disease is intensified by the concomitant loss of their spouse's companionship, emotional support, shared responsibilities and decision-making and intimate/sexual relations (Murray, J., Schneider, J., Banerjee, S., and Mann, A., 1999).

In addition, constricted social and leisure time is one of the most frequently cited consequences of caregiving for all caregivers, ranging from 33% to 75% of caregivers across empirical studies (Hooyman and Gonyea 1995). Studies have shown how interrupted sleep and limitations on social life can lead to chronic fatigue, social isolation, self-neglect and depression (Brody and Brody 1989; Pfeiffer 1987; Zarit 1991).

Caregiving can also lead to three levels of economic costs: employment-related (income, benefits, employee productivity, forfeiting career opportunities), out-of-pocket (expenditures on the person, expenditures on help, money transfers, costs of relocation, transportation, etc) and unpaid care labour, all resulting in a loss in buying power, as well as important long term losses of direct income and pension levels (Fast et al. 1999). Caregiving responsibilities can also have impacts in the workplace, both indirectly, by creating conflict between family and work (Gignac et al. 1996; Guberman et al. 1993; Marks 1998; NAC and AARP 2004), and directly, by increasing absenteeism (Scharlach et al. 1990; Neal et al. 1993; NAC and AARPP 2004), reducing concentration, affecting job performance (Singleton, 1997) and increasing caregiver strain and distress (Brody 1990; Gerstel and Gallagher 1993) leading to part or full-time withdrawal from the workforce (Paraponaris et al. 2006).

Despite all these documented consequences, it should be noted that, at any one time, it appears that most caregivers do not feel overly burdened (Vitaliano Young and Zhang 2004) and that feelings of burden do not necessarily preclude concomitant feelings of well-being (Chappell and Reid 2002).

## **Caregiver – Professional Relationships**

Caregivers' relationships with professionals, while often positive, can sometimes be another factor contributing to caregiver distress. Few studies have explored the relationship between practitioners and family/friend caregivers, and this despite caregivers' strategic role in care. This relative lack of interest can probably be attributed to the ambiguous status given to caregivers within home, rehab and long-term care policies and services. Home, rehab and long-term care services are essentially aimed at compensating for and improving the functional disabilities of the person requiring care and not as a support to caregivers (Béland and Arweiler 1996; Wiener 2005). It is only recently that policy in some countries has addressed the issue of family/friend

caregiving but even then, caregivers' status remains ambiguous. Caregivers are generally not official clients of the health and social service systems; files are opened in the name of the person requiring care. Although they are sometimes named as partners in care (MSSS 2003), policy generally identifies them as resources that must be mobilized and educated to meet the needs of the person requiring care (Lavoie et al. 2003; Martin 1995; Twigg 1988).

In the 1980's and 90's, for the majority of practitioners, caregivers were often invisible, either because practitioners' attention was focused on the person requiring care (Twigg 1988), or because caregiving, especially by women, was taken for granted as something normal and natural (Clément 1996). However, as of the mid-nineties, the growing visibility of caregivers and the difficulties they were experiencing led to the development of a vision of them as potential clients. But, although practitioners may now offer some psycho-social, educational or respite support to caregivers, the main thrust of interventions is aimed at mobilizing them to become more involved in and to offer better care (Béland and Arweiler 1996) or what Guberman and Maheu (2002) have called the "caregiver as resource" approach. This approach encourages the re-appropriation of caregiving responsibilities by the caregiver, often couched in a discourse of empowerment. The stated goal of this approach is to maximize the potential of the caregivers and give them the skills required to care for the person with limitations. But, in fact, this approach, implicitly, if not explicitly, takes for granted that caregiving is a family responsibility and tends to ignore issues related to the burden imposed by the level of incapacity of people being maintained at home, given the nature, and complexity of care involved and the demands on and investment required of caregivers.

Practitioners generally accept the caregiver as resource approach because they appear to have stronger family values than the general public (Lavoie et al. 2003) and thus hold strong expectations that families will provide care. They believe that caregivers should participate actively in the care and treatments of their clients. However, often, practitioners will determine and define this participation. Practitioners expect that caregivers will follow the care plan developed by professionals, recognize professionals' expertise and play a subordinate role (Guberman and Maheu 2002; Lavoie et al. 2003; Twigg, 1988; Ward-Griffin and McKeever 2000). Public services are perceived as a back-up support system to the family, required when expert professional care is needed or when families become overburdened and can then be offered support as clients.

Practitioners' expectations and values directly confront families' and caregivers' own understanding of family responsibilities for care. Increasingly, family members, especially those of the baby-boom generation, have high expectations of service support (Lavoie et al. 2009; Attias-Donfut et al. 2002). In opposition to previous generations, at least in Canada, for these caregivers, caregiving is not their only or even dominant identity (Guberman et al. 2009). They are actively trying to maintain multiple identities: worker, wife, mother, friend, social activist, etc., alongside that of caregiver. As well, in contemporary society, caregiving is less and less a normative obligation and has a more discretionary nature (see Aboderin 2007 for sub-Saharan Africa; Clément Grand and Grand-Filaire, 1996; Clément Gagnon and Rolland 2005 for France; Lavoie 2000 for Quebec). Services play an essential role in enabling caregivers to both maintain multiple identities and to make choices about the care they will provide. To that extent, caregivers are increasingly open to services and have expectations that practitioners will assume a large part of the care responsibility (Guberman et al. 2005; Lavoie and Guberman 2007). They

also expect practitioners to recognize their contribution, their expertise and their specific needs and to consider them as equal partners in all decisions regarding the care (Lavoie et al. 2009). The scene is thus set for tension and misunderstanding between practitioners and caregivers given these contradictory expectations and understandings of each others' roles.

These tensions are magnified, by the confusion and ambiguity that reigns with regard to caregivers' status, leading to a situation where caregivers' needs are rarely considered in practitioners' evaluations and interventions. To address these problems, researchers and practitioners in several countries are working to develop models of intervention and appropriate tools for assessing carers' situations and needs, aimed at promoting practitioner partnership with carers and encouraging greater recognition of the complexities of caregiving and its impact on all aspects of life (Family Caregiver Alliance 2006; Guberman et al. 2001, 2007; Keefe et al. 2008; Kröger 2003; Nicholas 2001; Nolan Grant and Keady 1998). The lack of recognition of caregivers as essential partners or "co-experts" has been shown to limit the appropriateness and acceptability of services aimed at supporting them (Daatland and Herlofson 2003; Nolan and Mestheneos 2006).

## **Conclusion**

Despite the similarities in the experience of caregiving and the major issues that confront caregivers: lack of recognition, isolation, financial insecurity, juggling care with other responsibilities, insufficient resources and a lack of power to influence care decisions, the broad heterogeneity of caregivers should not be forgotten. In order to respond to the unique circumstances of each caregiver and to those of the person they are caring for, services and resources must be as flexible and person-centred as possible, and to the extent possible, caregivers should be involved in their conception.

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