

ON BEING A FAMILY CAREGIVER. DISRUPTION IN ALL ASPECTS OF LIFE

Maryse GAIMARD

Professor, Ph.D., University of Burgundy, Dijon (France)

E-mail: maryse.gaimard@u-bourgogne.fr

Abstract: *Given the aging of the French population, more and more elderly people find themselves in a situation of incapacity requiring the intervention of family carers. A multidisciplinary research project on the longitudinal monitoring of a cohort of family caregivers whose elderly relative has been diagnosed with a chronic pathology (cancer, Alzheimer's disease, Parkinson's disease, cardiac pathologies, AMD), the ICE cohort (Informal Carers of the Elderly), was initiated in Burgundy Franche-Comté (France). The objective is to analyze the life trajectory of caregivers, highlighting the repercussions on family life, social life, professional life, etc. Primary results show that the new responsibilities of carers take a toll and that the family relationship may give way to a feeling dominated by obligation, constraint, renuncements (leisure, work, social relationships, etc.) which can vary depending on the pathology of the person cared for. There are, however, positive effects. The activity of caregiving strengthens the bond with the person being helped.*

Key words: *aging; family caregivers; ICE cohort; life course; chronic pathology.*

Introduction

The aging of the population and gains in life expectancy are increasing the number of elderly people who are dependent or losing their independence. Although the majority of older people age without disability, the risk of loss of physical and mental autonomy increases with advancing age. In France, the average age at which dependency occurs and the elderly person feels the need to be helped is around 83 years old. Daily support then generally becomes indispensable (Ennuyer, 2001 and 2004). The care of these dependent persons has seen the development of new social roles and a "new category" is becoming increasingly important in society, namely family carers. The involvement of relatives and family members in caring for sick, frail, elderly or disabled people is far from being a new phenomenon, but its identification by the public authorities and its designation under the generic term *carer* (*aidant*) dates mainly from the 2000s (Laporthe, 2005). This family assistance is characterized by its non-professional aspect, its regularity and its origin in a relative's situation of dependence or disability. Caregivers therefore have a dual social role: they are both motivated by an emotional position induced by family ties or proximity with the person being cared for and have a caregiving position (with its technical implications) that is governed by the state of dependence of the person being cared for.

The number of people aged 16 or over providing regular, voluntary help to one or more of their relatives is estimated at more than 11 million in France, i.e., one person in five (Fondation April and BVA, 2018). According to the April Foundation's Caregiver Barometer 2015, 11 million people even declare that they provide "regular help". Among them, 57% help a relative in a situation of dependency due to old age. The number of people taking on the role of caregiver continues to grow due to the increase in the number of elderly people. In more than 80% of cases, assistance is provided in the home of the person being helped (67%) or in that of the caregiver (14%). Assistance is a family affair, with 86% of caregivers supporting a family member, either alone (50%) or with professional help (33%) and relying on a single person, either the

spouse or a child (40%). The caregiver is most often a woman (58%), the spouse or daughter of the person being helped (Fondation April and BVA, 2018; Soullier, 2011; Fontaine, 2009) with an average age of 50 for the daughter caregiver and 70 for the wife caregiver (Soullier, 2012).

There is a great diversity of situations of assistance and therefore of family caregivers, which vary according to various factors: the age of the person being helped, the degree of dependence of the person being helped, the pathology of the elderly person, the nature of the assistance provided, the activity of the caregiver, the material resources available to the caregiver to cope with the situation. Beyond the objective elements distinguishing each situation, several factors influence the subjective experience of this situation by the caregiver him/herself (age, the nature of the relationship with the person cared for, gender, etc.). Finally, diversity is found in the motivations put forward, which themselves vary according to cultural traditions, lifestyles and the particular history of the family. Despite this diversity, it appears that caregivers are more vulnerable than the rest of the population in terms of their health, but also in terms of their social and professional lives (Novella, 2001; Davin, 2011).

The difficulties they encounter in their caregiving role, both in terms of quality of life and of economics, have already been the subject of studies, but these studies focus on Alzheimer's disease (HAS, 2010; Jolly, 2010; Carpentier, 2010; Ducharme et al., 2011a, 2011b), at the expense of chronic age-related, non-neurodegenerative diseases, which are nonetheless frequent and whose specificities modulate the impact on caregivers.

In order to further knowledge in this field, a longitudinal study, the ICE (Informal Carers of the Elderly) cohort, was initiated in Burgundy Franche-Comté, France, to follow a cohort of family caregivers whose elderly relative, aged at least 60, has been diagnosed with a chronic disease (Alzheimer's disease, Parkinson's disease, stroke, age-related macular degeneration, breast, prostate and colon-rectum cancers). The objectives of this research are, among others, to analyze and characterize the caregiver-care receiver relationship over time, to evaluate the repercussions induced by the relationship on the daily life of family caregivers, and to study the needs and expectations of family caregivers. These aspects of the caregiver-care receiver relationship are also analyzed in terms of a comparative dimension between pathologies.

In the rest of this article, we will situate the ICE cohort in the more general context of the work on informal caregivers and then we will present the experience of the caregiving relationship and its evolution in cases of cancer or cardiovascular accident of the person being cared for. The analysis of the interview data focuses on the entry into the role of caregiver, the representations of this role and the experience of the helping relationship; certain specificities are apparent according to the pathology of the person being helped.

1. The ICE cohort

1.1 Context of the cohort

Reflection on informal caregiving as an essential condition for keeping elderly people experiencing loss of autonomy at home places the concept of quality of life at the centre of work on the health of such elderly. In a health system that favors maintenance in the home, the family members designated as caregivers are then responsible for providing most of the assistance required by the elderly patient and the obligations attached to it. This work is invisible insofar as it is not subject to a financial assessment that quantifies the time and cost of the energy spent by the carer to provide support for

the person being cared for. For several years now, public authorities have been dealing with the issue of carers: first of all, with the law of 4 March 2002, relating to the designation of the trusted person; then with the creation of the Informal Caregiver Charter in 2004 and finally with the introduction of family support leave in 2006.

Various reasons lead to taking on the role of caregiver, including long illness (51%), advanced age (44%), physical disability (30%) and mental disability (13%) but illness appears to be the most common reason (MACIF, 2008). The involvement of carers in the management of chronic pathologies opens up new fields of intervention for which, medically and socially speaking, there are not yet established rules or know-how. This pitfall is reinforced by an imperfect understanding of the life course of carers. The real constraints of the helping relationship and the difficulty of self-identification on the part of the carer him/herself in the role of caregiver may lead to under use of existing aid. Similarly, the notion of need evolves according to the context of the disease, its management and the environment of the sick person and the caregiver. It is essential to provide support for the family and friends of the sick person, whose quality of life must be preserved to the greatest extent possible.

The role of caregiver may be accompanied by a state of vulnerability that creates a risk of reinforcing social inequalities in relation to “non-caregivers” in society (Novella, 2001). Lasting over an average of seven years, the caregiving relationship has negative effects on the general state of the caregiver. Certain psychological factors in the caregiving relationship, particularly chronic stress, are associated with an increased risk of cardio-neurovascular mortality and morbidity. The caregiving relationship also has an impact on the caregiver's health: 22% of caregivers forego medical appointments or hospitalization and a third use tranquilizers or sleeping pills (HAS, 2010). The results of the HAS report show that, in nearly half of all informal caregivers, physical and psychological health is impacted by the support they provide. The deterioration of their health finds expression in a certain number of well-defined disorders (anxiety disorders, sleep disorders, nutritional disorders, cardiovascular problems, memory disorders, decompensation of chronic pathologies) which may lead to increased consumption of care and medical products (anti-hypertensives, psychotropic drugs, antidepressants, anxiolytics, sleeping pills and tranquilizers, etc.). The consequences of informal help go beyond the sphere of health as they also concern the social, professional or financial aspects of the lives of caregivers:

- social consequences due to the limited amount of time the caregiver has left to devote to family and leisure activities (Novartis Foundation, 2010);
- professional consequences due to the adjustments, reductions or cessation of professional activities that the support mission may induce. The caregiver's burden can also be a major factor in professional decisions, sometimes leading the caregiver to refuse a transfer or promotion, or inducing him/her to change jobs or even to retrain (Le Bihan Youinou and Martin, 2006);
- finally, there are financial consequences, as changes in professional activity may lead to a reduction in income (and ultimately in retirement pensions) and monetary disbursements (e.g. adjustments to the living space).

The burden of aid is defined according to two dimensions: an objective dimension (nature of the aid provided, volume in hours) and a subjective dimension (consequences of the aid, as perceived by the caregiver, on his or her quality of life, health and relationship with the person being helped). 20% of caregivers report feeling a heavy burden; of these, 80% experience physical fatigue and 90% experience mental fatigue (Soullier, 2012). The relationship frequently causes a disruption in the lifestyle habits of the caregiver, who must adapt to the pace of the person being cared for, his or

her needs and the activities of outside caregivers. The feeling of being overwhelmed is sometimes so strong that it pushes caregivers to abuse or to an unprepared and hasty institutionalization of the assisted patient, which in turn reinforces their guilt (Imbert et al., 2010).

The majority of studies deal with caregivers of people afflicted with neurodegenerative diseases, whereas other diseases are also likely to require a caregiver. Thus, the present research project, the "ICE" cohort, concerns a cohort of informal caregivers who have been followed since the announcement of the patient's diagnosis for various chronic diseases: neurovascular pathology (stroke), heart failure, neurodegenerative pathologies (Alzheimer's disease, Parkinson's disease), cancerous pathologies (breast, prostate and colon-rectum cancer). The choice of the different pathologies was influenced by their incidence, prevalence and the effects induced in terms of help and support. The role of caregiver significantly influences the burden as well as the quality of life in terms of physical and emotional health, depressive symptoms, social support and anxiety (Novartis, 2001; Pressler et al., 2013). Furthermore, the inclusion of multiple conditions as inclusion criteria was intended to result in a sufficiently large recruitment potential to achieve diversity in caregiver profiles by including conditions with a priori different disease courses and day-to-day impacts. The longitudinal approach makes it possible to follow the caregiver from the moment he or she enters into the helping relationship at the moment of diagnosis of a chronic or acute pathology in the person being cared for.

In a holistic approach integrating the social, behavioral, psychosocial and economic dimensions of the caregiving role, monitoring this cohort will make it possible to assess the positive or negative impacts of becoming a caregiver on the caregiver's own health. It will evaluate efficiency in the form of a randomized trial of an intervention carried out by a social worker with the caregiver. Beyond a sort of typical profile of a caregiver identified by the nature of the pathology of the person he or she is caring for, the longitudinal perspective will also make it possible to identify a caregiver's "journey" as may be done with the "patient's journey", highlighting specific phases with different impacts on quality of life, resources mobilized to deal with stress, social support, emotional state (anxiety-depression) and the perceived burden. The caregiver's life course can also be analyzed in terms of "career", a concept used in sociology. Hughes uses this concept to study the concrete social relationships of the actors over time and defines it as "the path or progression of a person over the course of his or her life" (Hughes, 1996: 175). The notion of career thus refers to the way in which individuals' lives unfold, the different stages they go through and the psychological changes that accompany them, depending on the social system.

1.2 Socio-demographic profile of the caregivers in the cohort

Since the beginning of the study, 135 primary caregivers have been included in the cohort, the primary caregiver being the person providing most of the assistance. In accordance with the literature, almost two-thirds of the caregivers are women. When it comes to caregiving support, the task is more frequently delegated to a woman (Segalen, 2010; Bennelli and Modak, 2010). (We will return to this gendered distribution of caregiving tasks below in section 2.) Parsons showed that men were more likely to be public entities, involved in work and social activities, while women were more likely to be active in the private sphere (Parsons, 1955).

These women are on average 10 years younger than male caregivers. The average age of female caregivers is 62, while the average age of male caregivers is 73. This difference in age according to the sex of the caregivers needs to be understood in

relation to the age of the person being cared for, which is on average older for women: 75.9 years compared to 72.1 years for men. The difference in the age of caregivers is mainly attributable to the relationship between the caregiver and the person being cared for. While 85% of the men who are caregivers are spouses, women are spouses in 56% of cases and daughters in 21% of cases. This tends to lower the average age of female caregivers. Daughters especially provide assistance to parents aged over 75, due to widowhood or the health of the spouse. In cases where assistance is provided by daughters or daughters-in-law, the latter are often engaged in a professional activity that they have to reconcile with their role as caregiver. In this way, 31% of female caregivers in the cohort are employed.

The most frequently identified diseases are cancerous pathologies (56%), of which more than half are breast cancers, the other half being prostate and colon cancers. Next come neurodegenerative pathologies (29%), two-thirds of which are related to Alzheimer's disease. In what follows, we have focused on the cancerous or cardiovascular pathologies of the elderly person being cared for, as the case of neurodegenerative pathologies has already been studied closely and is better understood.

The first elements of this study examine the caregiver-care receiver relationship via different perspectives: the circumstances in which the support was set up, the family caregiver's entourage, the description of the help provided, the consequences induced by this relationship, the possible improvements and/or desires of the caregiver as well as his or her representations of the role¹. This analysis of the aid relationship was carried out by means of a qualitative survey. The data was collected during semi-directive interviews with the carer in the absence of the person being cared for. The interview needed to provide a framework facilitating exchange, a moment when the respondent could confide in the interviewer and go back over the central moments of the support relationship. The presence of the person being helped could have hindered the caregiver's willingness to speak out. 37 semi-directive interviews, lasting from one hour to one and a half hours, were conducted and 11 carers were interviewed during a second round a few months later. The availability of family carers varies according to the overall state of health of their loved one but also to the possibility of freeing up time for a formal interview. The caregivers surveyed expressed their satisfaction that such a study is being carried out, allowing them to share their experiences of managing a pathology, particularly when the care receivers are diagnosed with cancer. The interviews were marked by a large variety of distinct feelings and emotions, referring, depending on the situation, to the hospitalization of the loved one, the establishment of a medical diagnosis, the return home phase, a potential remission--but above all to changes in their lifestyles. The analysis of the interview data, by theme, concerns the entry into the role of carer, the representations of this role and the experience of the helping relationship and reveals certain specificities according to the pathology of the person being helped.

¹ The concept of social representation can be briefly defined, following D. Jodelet, as "*a form of socially elaborated and shared knowledge, having a practical aim and encouraging the construction of a reality common to a set of social (...)*". Social representations thus correspond to the operation of a mental transformation that turns social objects into symbolic categories used as systems of interpretation. They "*govern our relationship to the world and to others, and guide and organize social behavior and communication*" (Jodelet, 1989: 36).

2. Entry into the role of carer

In the ICE cohort, the choice was made to focus on the person providing the largest share of assistance. It is the care receiver who, at the time of diagnosis, identifies the person they consider to be their primary caregiver from among their loved ones. In the event of incapacity, it is the caregiver who designates himself or herself. In fact, 73% of caregivers were self-identified and 27% were designated by the care receiver. Women (77%) more frequently self-identify as caregivers than men (67%), whether it be the wife, partner or daughter, while male caregivers are more often designated by the person being cared for, especially in cases of breast cancer. The role of caregiver appears more natural, in the scheme of things, for women than for men, who are less likely to self-identify. Emotions and the moral duty of marriage seem to go without saying: *"It seemed normal to help my husband"*¹ (woman, 83 years old, family carer for her husband). The delegation of the role of caregiver to the children follows the logic of filial solidarity: *"The logic of children is to help their parents... In most families we don't ask ourselves any questions. If there is a problem with the older generation, we will help"* (woman, 64 years old, her father's caregiver).

Women more often consider themselves to be primary caregivers than men: 76% of women and 64% of men. When the caregiver is a child, in almost all cases it is a daughter. There is therefore a strong propensity to delegate the role of caregiver to women belonging to the inner family network, who have a close and emotional relationship with the person being cared for that is inscribed into the family history. The caregiver is often designated by family positions that give rise to the responsibility for taking on this role (Membrado and Lavoie, 2015).

Several studies have revealed the mechanisms at work in the designation of the caregiver within the family sphere. The caregiver spouse's motivations are often ones of affection and the desire for continuity in the relationship with the loved one, the desire to avoid institutionalization, and a sense of accomplishment in assuming these responsibilities (Cohen, 2002). The child's involvement as a caregiver responds to specific issues. Marcel Mauss' theory of the gift sheds light on this notion of solidarity with one's forefathers (Mauss, 2013), the quest for a recognition that the child has never had, or a desire to make amends for a past relationship that was unsatisfactory. Depending on the profile of the family, the role of caregiver may be freely chosen or constrained.

Beyond family status and emotional bonds, a set of efficiency criteria are also taken into account for a better intervention of the family caregiver. The health of the caregiver, the sense of responsibility and the experience of care must be weighed in the balance. These last two criteria are considered more feminine than masculine and guide choices within families by encouraging the designation of women as guarantors of good care practices. It is commonly accepted that women are endowed with innate qualities (more "sensitive", "skillful", "good listeners", etc.) which make them more competent in the role of helper (Pennec, 2010). Within the couple, they are more likely than men to take on this role of caregiver. When the spouse's dependency becomes severe, a man will have more difficulty coping with his wife's loss of autonomy than vice versa and will more often resort to professional help or institutionalization (Fontaine, 2009). The caregiver becomes the guarantor of the "well-being" of the person being cared for. Thus, in addition to the position within the family, whether marital or filial (Dechaux,

¹ Sentences in italics are taken from the caregiver interviews.

2009), the influence of gender weighs on women because *“they naturally have the qualities”* to cope with the situation.

Geographic proximity and availability are also criteria for designating the primary caregiver. *“Living close to the person being cared for”* allows for daily visits and rapid intervention in case of emergency. This proximity makes it easier to accompany the loved ones being cared for, particularly in the event of hospitalization, and caregivers act as links between the medical profession and other family members. Availability should be taken into account when designating the caregiver, but in reality the caregiver makes himself/herself available once he/she has entered into the helping relationship.

In sum, the designation of the caregiver by ill seniors is based on pre-established choices. The caregiver's position in the family, both marital and filial, part of the inner concentric circles, is the first criterion for designation. Gender also plays a role in the choice of caregiver, as support, especially care support, is more easily delegated to a woman. While the designation of the *“chosen child”* seems to be based on a hierarchy of criteria (emotional bonds, proximity, availability, experience of care), that of the spouse is based on the continuity of the marriage contract, sealed by the expression *“for better or for worse.”*

The socio-demographic changes that will affect the population in the coming years (lower fertility, geographical remoteness of children, more frequent ruptures within couples) will lead to a decrease in the average number of family caregivers, which in turn may increase the difficulty of designation. Families will then have to turn to professional caregivers or care and support services that make it possible to mobilize an *“auxiliary of the self”* (Ruffiot, 2010).

3. The caregiver's role

Commitment to the care of an elderly relative brings new identities into play. The spouse, daughter, daughter-in-law or son must take on a new role and move from being a simple family member to being a caregiver. This caregiving position is an addition to the caregiver's other social roles. Although the caregiver is sometimes assisted by a professional, the bulk of the help rests with the family caregiver. This new role encompasses a plurality of relationships, situations, forms of assistance and difficulties and can have repercussions, both positive and negative, in various areas of daily life (professional, familial, social, physical and moral well-being, etc.). Position instability creates tensions among these roles that can cause intrapsychic disorders.

3.1 Representations of the role of caregiver

During the interviews, our caregivers were asked two questions, the first concerning the definition of their own role and the second the representations they have of it. The answers obtained differ according to the gender of the caregiver. Generally speaking, women caregivers define their role not on the basis of the precise performance of tasks or activities, but on the basis of skills. *“Already, I think that a caregiver is someone who has empathy, it's a question of teamwork. Yes, for me it's teamwork because I tell him we're fighting this together, you're not the only one fighting the disease”* (woman, 62 years old, her husband's caregiver). They define their position based on the investment necessary for the well-being of their loved one. The description of soft skills prevails, but is completed by a description of the know-how and the dedication of time essential for the proper accomplishment of the role. *“In the term caregiver there are two things, the moral and the physical. To start, there is moral support for the sick person and then there is the actual help, for someone who is no longer*

able to wash, who can no longer cook for himself, to do all the daily things of life, to get him out if he is in a wheelchair, or things like that. Helping is that, it's 24-hour assistance. The caregiver is the one who helps the person in need for everything" (woman, 62 years old, her husband's caregiver).

When the caregivers are men, the description of the role is more ambiguous. The need to provide psychological support is described, but it is mainly the narrow margin of presence that is highlighted. For male caregivers, the appreciation of the psychological needs of the person cared for is more complex to grasp and is found in a "close but distant" positioning. *"[The caregiver] is someone who must live in your circle but on tiptoe and be your buddy, your relation and your friend. Your confessor or whatever. But it is not always easy and it's really important not to impose yourself by saying you must do this or you must do that; no, that must not exist. There is the emotionality and the feeling that come into play. [...] We must leave it up to the person we are assisting to make decisions as if nothing has changed. Let them have the opportunity to participate in their life, not have their life dictated to them. You have to accompany the person"* (man, 74, wife's caregiver).

The anticipation of the caregiver role is perceived differently depending on the situation. In the case of "first-time carers", the anticipation of this future function does not take place because these individuals do not have any concrete elements to enable projection and thus imagine that it "only happens to other people", especially in the larger circle of acquaintances. On the other hand, the role of caregiver can be anticipated according to past experiences (caregiver for another family member) and recurrent pathologies within the family (especially in the case of cancers).

The representation of the caregiver role, as well as its anticipation, varies according to the family position of the caregiver in relation to the person being cared for. The same principles do not apply to a caregiver who is the spouse as to one who is a child of the assisted person. The helping relationship between spouses constitutes a continuity of the life of the couple that seems inevitable. Interviewing caregivers when the helping relationship takes place within the couple is inappropriate to the extent that this new role does not constitute an object of reflection. Sooner or later the caregiver may become, in turn, the person being cared for, and in the form of a "gift for a gift" inherent in the private sphere, the roles are reversed. However, when the caregiver occupies another family position (daughter/son, sister/brother, daughter-in-law/son-in-law), the support relationship oscillates between satisfaction and constraint because the caregiver has to manage a double family life, the two often similarly demanding.

3.2 The experience of being a caregiver

The role of caregiver that seems "natural" to a family member motivated by affection or by the family relationship may give way to a feeling dominated by obligation, constraint. There is a dimension of being "on-call" to family solidarity. Faced with support that is characterized by its unpredictability, since it occurs following a health accident that will constitute an inevitable biographical break (or "turning point", Hughes, 1996), caregivers may feel oppressed, trapped in this situation where their margin of freedom is small and negatively perceived. Caregivers' lives will be changed by taking up this responsibility, by carrying out support activities, by this concern for the other person that is seen as invisible work. Several studies have reported on the type of assistance provided by caregivers (Pennec, 2010; Soullier, 2012).

The first impact of this role on the lives of designated caregivers, the first change, is the responsibility that this role implies and that they must bear. A spouse caring for

his wife explains that the status of caregiver imposes decision making, not only with regard to the person being cared for, but also with regard to the family as a whole: *"It's hard to go through this. It's very hard because I suddenly felt a huge responsibility... In those moments, you don't think about yourself but about the family"* (man, 74, wife's caregiver). In this case, the caregiver was appointed because it seemed natural to him to help his wife. He was the one who took the first steps in the care of his wife after her stroke. The caregiver is suddenly given a responsibility for which he/she was not necessarily prepared and which he/she will have to assume for the good of the person being helped.

Being a caregiver is most often about experiencing time-related stresses and strains. The availability required by the caregiving relationship is another of the consequences and changes that occur in the life of the caregiver. It is mentioned in connection with the balancing act between the caregiver's personal and professional activities and the tasks related to the assistance provided. The various tasks performed by these caregivers take time, a lot of time. While 62% of caregivers spend less than 10 hours a week on care, 21% spend 20 hours or more with their loved one. On average, women spend two hours more each day when they are working alone. Moreover, men and women do not provide the same support. Women caregivers who are spouses or daughters of the person being cared for are more likely to provide regular, daily help in the form of domestic or household tasks, whereas men are more likely to provide one-time and financial assistance. These constraints lead caregivers to make choices, give up things and rearrange their lives: reduction in sleeping time, then "non-priority" activities such as leisure, outings, social relations and, eventually, frequent reductions in working time.

If half of these carers do not have an outside job, the other half works outside the home, in addition to helping the family member. They must therefore free up time to fulfill their role as caregiver for the benefit of the person being cared for. The constraints of assistance therefore lead to renunciations, choices, a reorganization of their time and lifestyle, with a reduction in non-priority activities such as outings, leisure activities and social relations. One wife caregiver said of her husband: *"He doesn't want to go out anymore. He doesn't want to go to the movies, he doesn't go shopping, we haven't gone on vacation, we don't go to restaurants, we don't go to friends' homes because he's not comfortable. And that is perhaps the hardest thing to live with. It's not fun for him, but it's not fun for me either ... It cuts down on activities, that's for sure"* (wife, 64, her husband's caregiver). Another caregiver recounts the difficulty of reconciling her personal and caregiving activities; she confesses that she was forced to reduce her personal time for the benefit of the close relative, a situation that does not satisfy her: *"On my own time, and at one point, I told myself that I was retired all the same and yet I don't take care of myself, I take care of others and not myself"* (woman, 64, her father's caregiver).

Ultimately, the final step in the reorganization of time (since work can also be a bulwark against the total monopolization of the caregiver), is the reduction in professional activity (Fontaine, 2009; Le Bihan-Youinon and Martin, 2006). This reduction in working time when aid intensity is high can have a significant financial impact, both immediately and in the future, on retirement pensions. Finally, a withdrawal of the carer from the labor market has social consequences, leading to a risk of de-insertion. Overall, in French society, work provides access to dignity and self-esteem, helps to build one's individual identity and to feel integrated into society. Thus,

giving up work means losing one's dignity and social ties. We can also talk about social disaffiliation¹, as defined by Robert Castel (1999) in the sense that, for these caregivers, withdrawal from the labor market is not only a break from employment but also from the societal bond: a loss of belonging for these individuals.

The helping relationship and the availability of the caregiver for the care receiver can lead to a confusion of feelings in which the more active the caregiver is in relation to the care receiver, the more the latter will ask for. Faced with his/her pathology, the person being helped becomes more demanding in terms of affection and presence. This increases the possessive feelings and the interdependence of those involved in the relationship. In addition to these constraints, there are also tensions that may arise within siblings or the family. Concern for the person being cared for takes on an almost exclusive importance.

Most of these caregivers belong to the so-called "pivot" generations, which are at the heart of ascending and descending family lines, as they are at the same time children, parents and grandparents. This position confers upon them a dual responsibility, towards both grandchildren and elderly parents. When the latter need them for occasional assistance only, the presence of grandchildren results in a slight reduction in the assistance they are able to supply. On the other hand, if elderly parents require regular support, then the "competition" between commitments ceases and the accumulation of assistance to both becomes necessary.

The implications of the helping relationship are multiple for the caregiver. During the first few weeks of the helping relationship, the caregiver, who may have difficulty organizing in his or her new life, experiences this new role as a burden. Anxiety, exhaustion, overwork, feeling deprived of freedom, social isolation, etc.: caregivers have little room for respite. It is this feeling that dominates, accentuated by the "negative" aspects of the caregiving role, and the caregiver feels physical and psychological exhaustion. One caregiver explains: *"It's the whole adaptation of life that changes, the caregiver has to adapt and increase his physical capacity to do things and his mental capacity to support the partner. That's why the caregiver wears himself out. We ask more of him, we ask him to be active on all fronts. There are all these things that are put on a single person when before they were shared within the couple"* (man, 74, his wife's caregiver).

All of the physical, psychological, emotional, social and financial consequences borne by the caregiver, and which may be reinforced by a situation of isolation, are known in the literature, particularly in the literature of psychology, by the term "burden". Researchers (Antoine et al., 2010) distinguish two components of this burden: the objective burden corresponding to "objectively observable negative consequences" and the subjective burden that refers to "feelings of unease or overload experienced by the caregiver during the period of assistance" such as fatigue or social isolation. This burden can lead to caregiver burnout that is detrimental to the caregiver's health, but also to the quality of the relationship with the cared-for person, including the possible risk of abuse.

This state of exhaustion may place the caregiver in a situation where he/she can no longer assume the role of carer and in turn becomes the person being helped. For example, one caregiver explains that after his wife's hospitalization and once he had understood that the risks were minimal, he suffered a "backlash": *"Afterwards, I had a backlash but it was really pretty hard because the emotional shock was tough. I tend to*

¹ Disaffiliation is the historical process of the weakening of social cohesion through job insecurity and the weakening of other social ties (family, friends, etc.).

have joint pain and I developed sciatica [...] Then I started to get depressed [...] I was extremely tired and during this period of distress I lost a lot of weight, about 5 or 6 kilos. I didn't recognize myself anymore and I had no energy left, I was drained. [...] I had an antidepressant treatment [...] There was also physical and mental fatigue. She [his wife] felt like she was the one who was now taking care of me" (man, 83, wife's caregiver).

All is not negative in the helping relationship; there are attractive aspects for the caregiver as well. Supporting relationships are vectors of intense satisfaction as they reinforce the feeling of usefulness in the face of a pathology or treatment. The pathology becomes an adversary that must be fought together (as the frequent use of "we" in our interviews attests). Caregivers, in addition to their almost daily presence, participate in improving the quality of life of the person being cared for by providing comfort or securing well-being. The struggle may become unbalanced when the symptoms of the disease become too severe, but the survival of the person being cared for becomes the goal of a normalization in which caregivers invest themselves without respite. The support activity strengthens complicity with the person being cared for, fostering moments of sharing and dialogue that bring them closer together. Some caregivers consider the support activity to be rewarding, allowing them to acquire knowledge, feel useful or exercise values such as generosity, dedication or respect. The role of caregiver then appears to be rewarding and provides satisfaction.

Although the caregiver's burden is heavy, there is no (or very little) delegation of certain activities to care professionals. Recourse to external help is essentially based on the need to carry out the same tasks as before in order to maintain stability between the period before (understood as being before the onset of the loved one's pathology), during and after. Calling on outside help means acknowledging one's inability to meet the needs of the loved one, but also recognizing the loved one's difficulties. This failure to call on outside help has an irreparable impact on the daily lives of carers, since it excludes any form of respite, particularly psychological respite. Professional services are accepted when caregivers have no other choice, particularly when the family network is limited or non-existent (geographical distance, lack of time, etc.). When families have sufficient financial resources, recourse is more oriented towards hiring a private person who is either known to the family or referred by a trusted person. Families who use outside helpers do not see them as professionals (dependent on a contractual service) but rather want a perfect translation of the family model into a professional service. Families often criticize professional carers for changing schedules, an excessive turnover of professional helpers, lack of commitment and failure to anticipate the needs of the person being helped. The positioning of the professional caregiver within the relationship is delicate and expectations are divergent. Mario Paquet (2014) discusses a problem of positioning within the relationship that has opposite repercussions. Family caregivers participate in a relationship of "proximity at a distance" while professional caregivers are part of a relationship of "distance in close proximity". The stakes are not the same depending on the relationship which is privileged, since in the latter, there is no reciprocity.

Not all professional interventions are a source of additional anxiety for family caregivers and many recognize that a special relationship can develop if the conditions established at the outset are met. Moreover, the need for professional services may be adapted not only to the needs of the person cared for but also to those of the family caregiver.

The failure to make use of gerontological home support services may also be due to a lack of information among family caregivers. Some of them find themselves face to face with a complex medico-social system which they do not understand when they are

rushed into the role of caregiver (Joël, 2014). *“When it happens to you, you should have a little piece of paper so you know where to go, where to go for this help, where to go for that help, or where to go for something else. And then have a quick, simple phone number.”* The situation of this caregiver became more complex when a member of the medical team presented the available services directly to the person in need of care without informing the primary caregiver: *“At the hospital, they immediately asked him: do you want a lady to do the housework? Do you want this or that...? But, no, he wants no one, no one, no one. Doesn’t want his things moved around”* (woman, 62 years old, her father's carer).

Caregiver support does not only include home help, which may seem intrusive to those who are entitled to it. There are also reception structures (day care centers, temporary accommodation, etc.) whose aim is to relieve the family, avoid social isolation of the carer and delay institutionalization. This comprehensive assistance is set up to provide respite or rest for caregivers, to relieve them emotionally and physically and to allow them to have some personal time. *“To do something else, to take the time to read, to take the time to go into town. All the things we don’t have time to do, we take the time then. It’s only a week, but that’s all it takes”* (woman, 64, her father's caregiver). However, the benefits of these rest periods need to be qualified. The guilt of “abandoning” the relative, the preoccupation with the care received during their absence or the feeling of being “judged” by other family members can all be sources of stress.

4. The specificities of the care according to the pathology of the person being cared for

In the ICE cohort, the role of caregiver was not anticipated but rather materialized following the diagnosis of a chronic condition in the loved one. In addition to the tasks involved in a classic helping relationship, medical consultations, medical treatments, and changes in the state of the relative's health with its “ups and downs” become part of the equation. Depending on the pathology of the person being cared for, there are differences in the day-to-day assistance and the overall commitment of the carer. In the situations encountered, consideration of the caregiver's investment in the person being cared for may depend on the “seriousness” of the pathology and the progress of recovery. Becoming the caregiver of a loved one who is suffering from cancer or one with a neurological disease, such as Parkinson's disease, will modify the appreciation and weight of this caregiving role on a daily basis because the conditions under which the aid is implemented will be based on different elements (duration of support, intensity, medical protocol, etc.).

Thus, in cases of cancer, the announcement of the diagnosis inevitably leads to distress, anxiety. Indeed, these pathologies are overwhelmingly considered incurable and/or the treatments painful. Even without knowing the seriousness of the specific case, the representations of cancer in the common imagination establish a form of impotence in which the caregiver understands he/she will be limited to a field of action that is purely psychological. A form of resignation imposes itself on the caregiver in the form of an ordeal, a fight. The fight against the disease becomes a leitmotiv, a supplement that reinforces the bonds that unite the caregiver and the person being helped. The person being cared for then enters a “long” course of care that is highly unpredictable (biopsy, invasive surgery, radiotherapy and/or chemotherapy). The caregiver ensures the psychological support of the pair (caregiver and cared-for) through a permanent presence at all phases of the treatment, characterized by swings of the pendulum. The vast majority of the caregivers we met anticipated and managed

the daily constraints that could alter the rest phases of the person being cared for. In fact, radiotherapy and/or chemotherapy sessions impose an unequal rhythm on the pair in which the person being helped can be said to be in a “passive” position (post-treatment fatigue) and the caregiver in a “hyper-active” position (management of movement, stress management, anticipation of possible pain, etc.) in order to preserve the loved one. *“Yes, she was operated on. She had breast cancer. I don't tell her, but I'm worried because she is losing weight quickly and she was already thin [...] For a day or two she sinks really low. I think it's the effects of the drugs that make her go under”* (man, 75, caregiver for his wife with breast cancer).

Following a stroke, the helping relationship is mainly established between spouses and it is the family caregivers who discover changes in behavior that are initially scarcely noticeable to outsiders. They confide their distress: *“But now the after-effects are becoming obvious. He has memory loss, he takes a lot longer to understand and there are things he forgets or can no longer do. He used to tinker around a bit, now there are many things he can't do anymore.”* These caregivers carry the burden of responsibility for prompt medical management in the event of another stroke. *“Let's say that for me it was a change because I didn't dare leave him alone anymore. At first, I didn't even dare sleep at night because I was afraid it would happen again. Knowing that he has had a stroke, you tell yourself that automatically he can have another one”* (woman, 82 years old, caregiver to her husband who had a stroke).

Strokes push family caregivers into a new pace of life never before anticipated. Caregivers are disillusioned and claim to be physically and emotionally tired themselves. *“Yes, and emotionally ... it's true that sometimes I can get a bit angry because I'd like to relax in the evening too ... I've worked all my life and I'd like to sit on a couch at night and be served. That's what I thought when I got married, so be careful. We don't think about it ... I mean, I've been taking care of everybody my whole life, so there you go. It's true that having help wouldn't be a bad thing”* (wife, 82-year-old caregiver to her husband who had a stroke).

Caregivers ensure a constant “back and forth” communication between the small circle of loved ones (family, friends), the caregiver and the person being cared for. Confidentiality is not the same with each interlocutor and very often the caregiver tries to remain positive about the evolution of the pathology of the person being cared for so as not to “worry” the loved ones. This experience of a double posture, both personal (with the carer's fears, anxiety, etc.) and in representation (providing an upbeat version of the truth, positivity, etc.), generates acute psychological suffering.

Many caregivers expressed the impossibility of anticipating the future and specifically the general impact on the person being cared for as a result of his/her medical condition. The desire to overcome an illness, or to minimize its symptoms, is a source of satisfaction and daily anguish whereby any physical or psychological after-effects on the person being cared for are considered as failures.

When the people being helped have recovered or are released from the intense phase of the treatment (radiotherapy, chemotherapy, return home, etc.) during which the caregiver is omnipresent, there is no real break because the caregiver continues his or her benevolent supervision of the care receiver. If, after several weeks, months or years, the person being cared for contracts a new pathology/symptom (with or without an apparent link to the first one), the basis of the new relationship is not the same and acceptance is more difficult. There are many examples during our interviews in which caregivers recognize that the new symptoms are more complex on a daily basis. The succession of the curative and rest phases leads to a questioning of the caregiver's choices, particularly in terms of the means to be implemented (or to be avoided) in

order to be more efficient on a daily basis for the cared-for person. The question of institutionalization, for example, remains the ultimate solution considered between the caregiver and the person being cared for and is based on a still complex criterion which is "loss of mind".

In the event of the death of the person being helped, the situation is no respite for the caregiver because the helping relationship based on commitment or alteration has placed the caregiver at the heart of a new organization where he/she is an essential member. The disappearance of the loved one inevitably leads to a loss of reference points, a non-existence that makes little sense in daily life and at which time psychological and physical problems may appear. The spouse of a deceased loved one puts it this way: *"Tough ... This has been very tough for me. I've been stuck on this thing, I have to move on, but I can't seem to do it. [...] No, I can't because physically... I feel worse physically than I did for a while. No, no, I haven't picked up the pace at all"* (woman, 76 years old, widow of the person being helped). Some caregivers in this case, few in number, try to adopt a positive approach by displacing the help to other family members (grandchildren, children, brothers, sisters, etc.) from time to time.

Conclusion

With the aging of the population, the number of dependent elderly people is increasing. Taking care of these people at home requires the provision of help to assist them in the acts of daily life. The present ongoing survey on the longitudinal follow-up of a cohort of family carers of elderly patients is seeking to deepen the understanding of the carer-care receiver relationship and to follow the life course of the carers. The entry into the role of caregiver is rather abrupt, linked to the diagnosis of a pathology. Caregivers designated by the ill person are not prepared for this new role and feel the full weight of the responsibility that it implies. There are many upheavals in the lives of caregivers: workload, reduced available time, reduced leisure time. Sometimes, even their professional life is disrupted: they are forced to adjust their working time or take time off to take care of the person in need of help. This workload can lead to psychological, moral and physical exhaustion, a form of "burnout". It can be said that these people working for a sick relative, engaged in the same social process, are building careers as carers.

This family solidarity will evolve in the future as a result of a changing demographic context. The arrival of the baby-boom generations at more advanced ages and the increase in life expectancy will lead to a significant increase in the number of very old and dependent persons. Tomorrow's men will be more often confronted with the dependency of their spouses and thus the need to care for them. The number of double dependent couples will certainly increase in number. At the same time, the average number of potential carers per dependent elderly person will tend to decrease as a result of more frequent breakups of couples, the decline in the number of children per family and their geographical distance. Today, caring is seen as a women's issue, but tomorrow, men will more frequently find themselves in a position as potential carers, especially conjugal carers. Thus the profile of family carers will change in the future. Their role is likely to diminish in favor of professional help (Bonnet et al., 2011).

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