Cuadernos de **Relaciones Laborales**
ISSN: 1131-8635

https://dx.doi.org/10.5209/crla.70882

EDICIONES
COMPLUTENSE

Caregivers with diverse actions and orientations: putting the expression of caregivers in France and Japan in perspective

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Received: december 11, 2019/Accepted: may 14, 2020

Abstract. This article analyzes caregivers' narratives in France and Japan from a comparative perspective. After reproducing institutional elements of the perspective of the two situations, the article focuses on showing the heuristic value of a qualitative comparison, presenting the difficulties as well. Caregivers' language is analyzed through the implementation of a two-axis orientation concept: the mobilization of their resources and the evaluation of care organization. This positioning of caregivers reveals four distinct poles that allow us to draw proximity between caregivers beyond national contexts and the difference in the situations of cared persons.
Keywords: care; language; comparative perspective; methodology.

[es] Personas cuidadoras con acciones y posiciones variadas: perspectiva comparada de la expresión "personas cuidadoras" en Francia y Japón.

Resumen. Este artículo tiene como objetivo analizar los relatos de los cuidadores en una perspectiva comparativa entre Francia y Japón. Tras delinear los elementos institucionales para poner las dos situaciones en perspectiva, el artículo intenta mostrar el valor heurístico de una comparación cualitativa, al tiempo que presenta las dificultades que se dan en dicho abordaje. El lenguaje de las personas cuidadoras se analiza gracias a la implementación de un esquema de significado construido a partir de dos ejes, el de la movilización de sus recursos y el de la evaluación de la organización del cuidado. Este posicionamiento de las personas cuidadoras revela cuatro polos distintos que permiten establecer proximidades entre los cuidadores más allá de los contextos nacionales y la diferencia en las situaciones de las personas cuidadas.
Palabras clave: cuidado; lenguaje; perspectiva comparativa; metodología.

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Cómo citar: Damamme, A.; Sugita, K. (2020). Caregivers with diverse actions and orientations: putting the expression of caregivers in France and Japan in perspective, *Cuadernos de Relaciones Laborales*, 38(2), 251-268.

What are common expressions of concern for loved ones in countries as different as France and Japan? Is providing care to an elderly or disabled relative always and primarily a fundamentally unique activity, implementing provisions that language alone has difficulty in understanding (Laugier, 2009; Paperman, 2013)? Furthermore, care activities are primarily shaped by socio-political contexts that organize their distribution methods (Jenson, 2001). Why then seek to put into perspective situations that we know are likely to be immeasurable?

Even if we are part of a fundamentally qualitative approach, attentive to the expression of singularities, we have nevertheless opted for the view that such a perspective is of interest. For despite the difficulties of comparison, it seemed heuristic to us to try to explore the common forms of this language of care. While elsewhere, we have endeavored to analyze the interdependence between the professional and carer trajectories (Damamme, Sugita, Wierink, et al., 2015[3]), in this article we will focus on the narrative dimension of these caring activities. Our understanding of care has been enriched by different studies, from those on the ethics of care by Joan Tronto (2009) and Evelyn Nakano Glenn (2016) to those in the field of kinship care (Weber et al., 2003). From these different roots, we have considered care in its material and moral dimensions (Laugier et Paperman, 2005). It also seems central to us to take into account the possibility of a spectrum of expressions around the activities of care – love as well as hate or anger (Molinier, 2013).

In order to understand this multiplicity of actions and expressions of caregivers, we used a survey based on interviews and multi-site questionnaires (in Osaka, Japan in 2011–2012 and the Île-de-France and Rhône-Alpes regions of France in 2012–2013) with caregivers of elderly relatives, relatives with disabilities, and “young” Alzheimer patients. Unlike the survey in Osaka, caregivers in France were interviewed twice, one year apart.Access to the respondents was made possible thanks to the support of several organizations and groups that provide support or mutual aid to caregivers.

In this article, we will focus on analyzing how the caregivers we met shared this experience of care, focusing on their description of the situation on a practical, emotional, and moral level. To this end, we have drawn on 50 caregiver situations from Japan and 32 from France.

Before getting to the heart of the narratives, we will briefly present the institutional aspects of the accompaniment of different types of loss of autonomy in both countries.

1. Institutional differences and representations of vulnerability in support of the elderly and disabled in France and Japan

Although this article is not intended to explore all the organizational differences between the two countries, we felt it was essential to recall the main legislative provisions that shape the organization of care in both countries.

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[3] This report was produced as part of a project entitled “Les aidants informels: la vie professionnelle et le réseau du *care:* comparaison France/Japon” [Informal carers: working life and the care network: a France/Japan comparison] funded by MIRE-DREES.

1.1. Support systems for disability and age-related loss of autonomy

On 1 January 2002, French public authorities introduced the personal autonomy allowance (APA) for situations of age-related loss of autonomy, reflecting a policy of granting assistance for the performance of daily tasks. This was contingent on the person's situation in terms of health and autonomy and not just on income, as had previously been the case with the special dependency benefit.[4] Even if the practical organization of care is very different according to class (Weber, 2010), home help policies have developed to such an extent over the last fifteen years that the legitimacy of receiving help for an elderly relative seems to have become established in the current representations of French families (Trabut, 2014).

The Japanese public care system for dependency has moved from the logic of social assistance to that of the contract. The introduction of this insurance system, which we will refer to by the acronym LTCI,[5] has encouraged the use of assistance and has resulted in a definite increase in the use of personal services (Masuda, 2003; Sugisawa et al., 2005). Indeed, some respondents speak of a new facility of access in seeking public assistance, since being the object of social assistance was and still is stigmatizing. The principle of the contract has removed this barrier and made the use of services more psychologically affordable. In this way, society's views and the social values underlying them play an essential role in the use of support services. In the Japanese case, the dense territorial network of "care managers"[6] and associations of carers for the elderly also encourages the use of these services and information in the practical organization of care. In Osaka Prefecture, for example, these associations organize a variety of training courses, ranging from lectures with academic guests to practical workshops on practical support tasks. These regular activities are organizationally, administratively, and materially supported by the Council for Social Work.[7] These favorable conditions, combined with the relatively long history of these aid associations,[8] promote the stability of these locally rooted associations.

On the other hand, there is no organization at the national level equivalent to the French Caregivers' Association. There is a severe lack of political action on the part of the Japanese caregivers' associations, which do not make formal demands for the recognition of caregivers by public authorities but rather focus on the practical organization of care for elderly or disabled people (Sugita, 2011). In France, recognition of the role of carers has increased considerably in recent years (Gand et al., 2014), and the introduction of a new care leave for caregivers is evidence of this. However, resources are still minimal compared to the support needs expressed by existing caregiver associations, which often center their work according to the type of autonomy loss – mental or psychological disability, and Alzheimer's disease, among others.

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[4] Even if the person's resources are taken into account in the amount of in-kind assistance allocated.

[5] Long-Term Care Insurance.

[6] In Japan, the *Kaigo shien senmon in*, or "care manager" as it is commonly known, was created within the framework of long-term insurance, to help informal caregivers to set up files that are, in fact, much less cumbersome and complex than in France.

[7] *Shakai Fukushi Kyôgikai*. A special body which is a private association whose status is defined in the Social Welfare Act, and whose funding comes mainly from the public administration budget. It is organised according to administrative units (county, commune, district) with the aim of disseminating information on social services and promoting social and voluntary activities.

[8] In Osaka Prefecture, the oldest association of family carers for the elderly was established in 1983 in the city of Hirakata.

Work comparing the assistance provided to the elderly in France and Japan highlights organizational differences which have two main effects: on the one hand, they lead to a lower use of specific services by Japanese carers, due to a lack of sufficient means to support the share that goes to the beneficiaries and their carers, penalizing low– and middle-income carers. The French organizational system has resulted in greater reduction of social inequalities in access to the services offered (Ishii, 2013).

On the other hand, one should also note the differences in the offer of services between the two countries. These have affected the practical organization of assistance. Thus, French respondents make greater use of residential facilities for elderly dependents (Ephad) than their Japanese counterparts. Conversely, the relatives of the people surveyed in Japan oriented more towards daycare centers and temporary accommodation establishments for their relatives, who are more numerous in Japan than in France.

The law of 11 February 2005 introduced a new architecture and new concepts of care. It introduced a single reception facility, the *Maison départementale des personnes handicapées* [Departmental Center for the Disabled] (MDPH). The Commission on the Rights and Autonomy of Disabled People (CDAPH) plays a pivotal role, as it is responsible for assessing the rate of personal disability, from which a set of benefits is derived. This includes allowances such as the *Allocation d'éducation de l'enfant handicapé* [Education Allowance for Disabled Children] (AEEH) and *Allocation adulte handicapée* [Allowance for Disabled Adults] (AAH) as well as a set of administrative aids, including the recognition of the disabled person's card. The CDAPH also decides on the allocation of the Disability Compensation Benefit (PCH), a benefit created by the 2005 law and which makes physical adaptations and the presence of human aid possible through the implementation of a personalized compensation plan. This new law "for equal rights and opportunities, participation and citizenship of persons with disabilities" reflects an increased concern for inclusion in the community, even if this new paradigm does not accompany sufficient political will and resources (Ville et al. 2014).

In Japan, the Law of Assistance for the Autonomy of Persons with Disabilities was introduced in 2006 for children and adults and concerns all types of disability – motor, cognitive, psychic, and sensory. Municipalities are responsible for implementing the law. In Japan, as in France, a child's disability is a political cause, unlike the loss of autonomy linked to advancing age, which is still mainly considered to be the responsibility of families. Thus, disability is the subject of a significant mobilization of associations of disabled persons, as well as of associations of relatives, which have made possible a more vigorous defense of the legitimacy of the state's commitment to providing support for persons with disa bilities. However, in both Japan and France, the integration of persons with disabilities is still very much undermined by a history of their insertion oriented towards the creation of separate establishments, both for work and housing (Heyer, 2013). As for the question of support for elderly persons with loss of autonomy, this remains a subject that has few relays in terms of social and political movements in France (Gucher, 2008; Ennuyer, 2016), a fact that the current global pandemic situation highlights in the most tragic way (Laugier, Molinier, Paperman, 2020).

1.2. Social representations of vulnerability and family carers

In terms of language and representation, it seems interesting to note the greater visibility of the vulnerability theme in Japan, as evidenced both by a more significant presence of the theme in popular culture (through manga and books for the general public) but also through the dissemination of technologies to facilitate the sharing of vulnerability issues in the public space.[9]

While there is a higher social valuation of the caregiver role in Japan, the pressure on women is also more substantial and is even becoming a concern for the public authorities. For example, the Japanese government has been concerned about the consequences of women's massive involvement with people who are losing their autonomy. This has brought down women's activity rate, which is much lower than the average for OECD countries.

The responsibility of caregivers has also led to changes. More men are involved in caring for women. Distribution of assistance within the couple or among siblings has increased. There is also greater recourse to outside help (Sugita, 2011). This situation has also been documented for France (Banens, Thomas, and Boukabza, 2019), highlighting a universal trend towards greater male participation in care activities and new forms of identification with the role of caregiver.

The differences between the two countries are also visible in the distribution of care activities and those that are more specifically health and nursing activities in the strict sense of the term. For example, when comparing the use of different types of external help for the elderly, it seems that our French respondents use more home visits by health specialists such as speech therapists, psychomotor therapists, and physiotherapists than their Japanese counterparts. This can be explained by the fact that these services are covered by public health insurance and the mutual insurance associations in France, whereas only the LTCI system in Japan covers them. Thus, in Japan, the use of these health care services competes directly with the use of other care services (for intimate hygiene, daily health care) in a context where the services available are often insufficient to cover all needs for the financial reasons mentioned above. Even if we find among some French caregivers an account of difficulties in access to all the services deemed necessary for adequate care, the lesser recourse to these specialists in the health field seemed to us more common in Japan.

The care systems in place thus play a central role in the analysis of practices in both countries. In both countries, we see the development of private for-profit and not-for-profit actors, both in the disability sector and in the sector of support for the frail elderly (Hirata, Makridou, and Matsuo, 2017).

The Japanese care system relies heavily on the involvement of women, mainly mothers and daughters-in-law. The language of family guilt is still present in France, whether in terms of support for elderly relatives (Weber 2010) or children with disabilities (Eideliman 2010). The French care system is a mixed system involving the state, the family and the private sector in varying proportions depending on the period, but in which the level of public facilities in several sectors – early childhood, health, and disability – remains higher than in other continental European (Letablier, 2001) and Asian countries, such as Japan. These configurations make it possible to reflect on the systems of constraints in which respondents and their families find themselves.

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[9] The implementation of an electronic bracelet systems for people with Alzheimer's disease relies on the neighbourhood involvement in the surveillance of the elderly, a protection that also goes hand in hand with increased control over their lives.

In the second section of this article, we will present our methodological choices in order to develop a better understanding of the plurality of positions of care providers from a comparative perspective.

2. Language of caregivers or the difficulties in making a comparison

We reconstruct the trajectories of carers using variables and categories from an analysis based on the sociology of work – employment status, educational level, and social origin – as well as from an analysis in terms of social policies – the type of vulnerability of the receiving person, the duration of care, etc. We also report on how those involved in these care activities reported this experience. We focus here on their interpretation of their life as a caregiver, focusing on material and moral elements of their involvement. This perspective on caregiving situations has given rise to in-depth methodological reflections.

2.1. Difficulty of international comparison based on qualitative research

In this section, we will explain the steps that we have carried out in comparing the two corpora of interviews and giving an account of the significant moments of the comparative approach. From the outset, we noted a great variety of carers in each country. The carer-figure appeared as fragmented into numerous heterogeneous, irreducible interpretations. What common characteristics do carers who argued throughout the interview for successful care organization and intensive mobilization of institutional resources for their elderly parents, have with those who insisted on their discouragement and inability to help their child with a disability? Or with those who neither sought nor refused the aid offered? Or finally, those who invested in the role of carer by reducing outside intervention? A situation that could be "coded identically" from the family caregiver's trajectory is thus expressed and experienced in a very different way by the individuals who are confronted with it.

This heterogeneity has led us to explore some questions that can guide the comparison and analysis of the caregiver's subjective expression: what might be the relevant dividing lines? What, on the contrary, are the possible points of convergence?

We will try to answer these questions, at least partially, with the following analytical proposal.[10]

2.2. Constructing a Care Orientation Diagram: a review of the method used

The first step is to work on each of the interviews. The aim is to identify and list the passages that seem to us to best express the definitions of the situation.

The next step is to compare these provisional results in order to gradually identify attractions and similarities or repulsions and dissimilarities within the corpus of interviews analyzed. These classification operations are carried out by successive, more or less provisional codings, which are further refined based on two movements: on the one hand, the comparison of singular cases; on the other hand, the dialogue of emerging categories. These correspond to different ways of expressing care, of putting into

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[10] For this, we relied on the method developed in Demazière et al. (2013).

words the situation of being a caregiver, which are transversal to several interviews. Thus, each of these identified categories recounts the orientations which the respondent attributes to their situation, condensing the argumentation explaining their journey.

The third step consists in going further in the analytical procedures, situating these categories in their relation to each other. Usually, this phase leads to the production of a typology. We did not follow this path, because it appeared to us that the collected narratives were marked by a high degree of tension between several polarities, by recurrent and even structuring narrative ambivalences, and by possible changes of orientation, so that it became too simplistic to attach them to this or that typology pole. We have therefore carried out this analysis with a twofold objective: firstly, to show that these categories are neither fixed nor watertight, but that they are caught up in relations of tension. Secondly, we have mapped these orientations, identifying the dimensions that organize these relationships, which has allowed us to situate each interview in this space.

This method was invaluable to us so as not to organize *a priori* the content of the interviews by country. Indeed, in each of the two countries, the ways of interpreting one's situation as a carer are very diverse. It thus seemed heuristic to avoid postulating that this heterogeneity was necessarily specific to the societal context, but to recognize the possibility of proximity between these two very different countries. This approach allowed us to discover specific categories of analysis beyond those available by major "cultural areas" (Geoffray et al., 2012). Likewise, we did not attempt to gather caregivers' narratives based from the outset on the care recipient's vulnerability type. This also seemed to us to be reductive in terms of our objective of understanding the caregiver role in the domestic sphere (Damamme, Paperman, 2009).

To organize this exploration of care orientations for the respondents, two lines of interpretation seemed relevant to us:

1) The first interpretation was that of reporting the respondent's position vis-à-vis external resources, whether material or abstract, institutional or network, including family networks.

Thus some interviews are organized as activity narratives, in which the subject is intensely busy doing things – organizing care, setting up an association, and engaging in activist activities – but not in a way that is easy to understand. Others present accounts of closure, trapping the subject who appears as isolated in his closed world of home care. In one case, care is described as a trigger for a set of overflowing activities that turn care provided to the loved one into one of the components of the situation. In another case, care is experienced exclusively as a lack and deprivation of other activities, and it becomes an invasive component of the situation. Thus, to illustrate the positions that can be identified as those of intensive research for external resources, the emblematic terms and expressions are: "*I search a lot on the Internet*," "*We're getting by, it's okay because we have a lot of help*." These are in contrast to expressions that put much more emphasis on the difficulty of mobilizing external aid, expressing either the ability to help oneself: "*Care is difficult… you have to learn, and those who don't live together won't be able to do it.*" Or the position of withdrawal concerning others: "*I'm very lonely, and it's hard for me to ask for help*"; "*If it's about care, I can do it*"; "*I can't trust the establishment.*"

Thus, some interviews are organized around researching external care resources, whether successful or not, while others appear as narratives of defense against "invasion" of their privacy. In the first case, external resources are seen as entitlements, a right to care, while in the second, they appear instead as threats to be avoided.

2) The second structuring logic, intertwined with the first, can be related to the caregiver's evaluation of his or her satisfaction or dissatisfaction with the organization of care. In France, for example, we note the following expressions: "*I can't count on them*"; "*I do according to… it gets better, I manage*". In Japan, we find expressions such as: "*It was my decision alone*"; "*Why is it me?*"; "*Now that the dementia is advanced, I can take care of her as I wish*"; "*It is from that moment* [when he obtained the support of his superior] *that I was able to deal with the care situation*."

This analytical grid shows the central place of the evaluation in care activities, an evaluation which is ongoing and always subject to change, but which nevertheless takes on a particular color with one interview, and even more so with two. It is important to remember that this evaluation is strictly subjective and is not considered equivalent to an evaluation of the well-being of the person receiving care. The evaluation's moral dimension is always already there, i.e., the situation's description is intertwined with that of the assessment. The care perspective makes this double presence visible (Paperman, 2013). Following the care process described by Tronto (2009), it appears that the situation's evaluation is linked to the presence or absence of dispositions at each stage of the process. Thus, the evaluation can be positive when the caregiver is not alone in assuming responsibility for finding solutions to take care of a loved one (the "taking care of" stage).

On the other hand, many carers express dissatisfaction with the fact that they did not receive useful guidance in this stage of identifying the necessary actors in the organization of care. This can be seen in France as well as in Japan in the accounts of parents of disabled children, especially when there are diagnostic uncertainties (Beliard, Eideliman, 2009). Another stage in the care process that is widely mentioned by caregivers is that of evaluating the quality of care provided, whether this evaluation concerns the care that one can provide oneself or that of the professionals who are mobilized. This stage of caregiving involves the notion of competence, which is also very present in the sociology of work and refers to the ability to provide the appropriate care. The last stage mentioned by Joan Tronto (reception of care by the person receiving it) is not very prominent in the accounts, appearing above all when care is not provided, confirming here Pascale Molinier's analysis on the discretion of care work (2005).

By crossing these two structuring logics of the majority of interviews, four poles or cardinal points can be described. These four poles do not exhaust the orientations of being a caregiver but mark out space where they can find their place. We present this in the "Care Orientation Diagram," on which we have placed the various interviews with carers (see diagram below).

3. How carers express themselves concerning resource mobilization and the evaluation of the organization of care: a Care Orientation Diagram drawing new lines of inquiry into care situations

We propose to detail the different poles identified by illustrating them with Japanese and French situations where appropriate.

3.1. Care, an ordeal successfully overcome by a high level of resource mobilization (in the upper-right of the diagram)

The active organization of care manifests itself through its ability to deploy many external resources (reflected in the open attitude towards external resources on the y-axis). This situation leaves the carer relatively satisfied (reflected in the "positive appreciation of the care organization" on the x-axis).

We find respondents approaching this pole in both countries.

This is the case for Jean in France and Atsuko in Japan.

> Jean is 58 years old. He is retired from the civil service. A former executive, he currently has a small independent business with a partner. For the past three years, Jean has been coping with the onset of his mother's Alzheimer's disease. He moved her and installed her in an independent apartment in the municipality where he lives. Jean has tried to understand the situation and to mobilize as much advice and help as possible, including by joining the France Alzheimer association in his department of residence, where he quickly took on responsibilities. Jean runs a memory café there twice a month. He has set up help for his mother, around the intervention of a life assistant and independent professionals (physiotherapist and speech therapist) to maintain her motor and cognitive capacities as much as possible. Finding his way through the "labyrinth" of home help structures, he also supports his 90-year-old mother-in-law, who lives alone, 250 kilometers from their home, but this is essentially a moral and telephone support and relies primarily on his wife. However, the couple regularly travels to the North to visit her. Their children (a son and a daughter) live nearby and can intervene on behalf of their grandmother, especially the son who lives in the same building. The weight of concerns related to his mother's illness, compounded by a relationship breakdown with his brother due to disagreements over his mother's care, has disrupted his investment in his self-employed activity. At the same time, he still considers work as a highly valued activity through which he manages to forget about the worries caused by his mother's condition and can "fulfill himself professionally."

Jean's positioning seems symptomatic of the positioning of a caregiver with an attitude of seeking control over things and relationships. He seems to have invested himself in caring for his mother as he has always done in work, seeking to (self) demonstrate his effectiveness. In a short time, he understood who were the actors in the medical and social care of Alzheimer's patients, and built a set of help and services – including medical services – around his mother which seem to be effective, while requiring a relatively significant investment of time to regulate and manage the whole thing.

Although Jean gave a positive assessment of the organization of care (justifying its position in the upper-right in the orientation diagram), he seemed to be less convinced of this in his evaluation at the end of the second interview (almost a year later). Whereas at the first meeting, he was working on ideal plans to enable Alzheimer's patients to stay at home and live out their days in optimal conditions, he is now considering the possibility of sending his mother to a retirement home, if necessary. For his mother-in-law, the retirement home will undoubtedly be a solution to consider even sooner, because of her age, her weakening condition, her isolation, and her distance. Also, he has begun to feel the physical health consequences of his intense involvement in care, with some hypertension, which he associates with the stress that the care situation generates. It is interesting to note that his own health concerns have led him to ask for his mother's situation to be re-evaluated by the competent services and for an assistance plan to be adapted. Jean explains that without his intervention, this re-evaluation would probably not have been carried out.

Atsuko is a 49-year-old woman, widowed, and living with her 18-year-old son, who was diagnosed with autism with a significant cognitive disability. Professional home care workers intervene four times a week.

Atsuko started her career as a caregiver very early. Indeed, when she was seven years old, she started helping her sister, who had a learning disability, as well as her mother, who also had difficulty reading documents. During our discussions concerning the setting up of care for her son, she reviewed the complicated circumstances of the diagnosis. During the compulsory medical check-up at one and a half years, the doctor told her that her son had developmental problems.

The same year, her husband was diagnosed with stomach cancer. He was hospitalized and had an operation. Faced with her son's behavior, hyperactive and insomniac, Atsuko researched her son's disorders herself and concluded that he had autism, which was confirmed by a medical diagnosis in 1996 when he was three years old. Following the diagnosis, Atsuko withdrew into herself off for a month before realizing that "*it didn't change anything because I loved him*." She even states that in the end, "*this month was very precious for me. For the first time, I was able to find out what was most important to me*." Her career path is marked by frequent changes in employment status, as is the case for many women in Japan. She started working young, generally holding part-time jobs. Later, she was full-time self-employed for two years and then stopped working in 1996. She found a friend with whom she started her activist activities. She explains that she did not give up her job because of external pressures (family or social) "*I told myself that this was not the time to waste time* [by working]." In 1997, her husband's cancer recurred. He was again hospitalized and returned home before his death in 1999. Atsuko says that activist volunteer activities gave her the legitimacy to be active without feeling guilty. After being a volunteer worker for the association she founded between 1996 and 2004, she became its paid director in 2005. She explains that she became involved in these activities not only for the sake of her son, but to be part of civil society. Her struggles have provided her with new resources to deal with her son's difficulties. They have even led her to take the position of director of the association. Her situation is also quite revealing of care itineraries that are marked by a change in the evaluation of the situation, going from a condition of dissatisfaction to one of relative satisfaction.

Jean and Atsuko thus seem to correspond to very dynamic and voluntarist caregivers. In the face of difficulty, they both react actively. However, this seems to have taken longer for Atsuko and required the help of her counterparts. She went through a difficult period before she started to engage in activism, a situation that can also be explained by the prospect of the long-term help needed for her son. Jean already had managerial and organizational skills from his previous professional experiences, while Atsuko acquired her skills gradually through her activist involvement.

For these situations, it is essential to identify the value of the know-how and skills required to provide care for a relative, whether this involves transferring skills acquired in the professional world to the field of care – as Jean has shown with the skills of coordinating the various care players – or the acquisition of skills from the practice of long-term care, as in the case of Atsuko.

These two situations illustrate what one generally observes for the carers in this area of the diagram: the creation of reliable networks, generally involving professionals and relatives, ensuring more availability for their family members, and even enabling them to maintain a professional activity (as in the case of Jean) or to engage in an associative activity linked to their family member's situation (as in the case of Atsuko). These activities are generally a source of recognition and also favor their positive assessment of the situation in terms of organizing care for their loved ones.

If we follow this same axis, we can then identify another pole: that marked by carers who are "open" to the outside world but for whom care remains a mainly unsatisfactory ordeal.

3.2. Care experienced as an ordeal despite the mobilization of significant resources (in the upper-left of the diagram)

For those respondents who approach this pole on the Care Orientation Diagram, active attempts to mobilize external resources have only been partially successful or have even failed. They see care organization as incomplete or unsuitable, and, as such, generate many difficulties in the daily life of the carer, leading to bitterness, anger, or despair.

It is interesting to note that among these cases, there are several care situations for children with disabilities, for which the paradigm of promoting the autonomy of the disabled person is present in both countries, and influences the organization of care. Thus, parents (often mothers) show the same attitude of openness towards all available resources, in an approach that could be described as "pro-active." They seek to obtain as much information as possible in order to take into account their relative's disability situation. Their dissatisfaction is generally accentuated by the uncertainty that may surround the care deemed appropriate, as is the case for parents of autistic children who, in both countries, report particular difficulties in obtaining a diagnosis for their child and then finding suitable care. Moreover, the existence of the controversies around autism may reinforce their relative dissatisfaction with the organization of current care, which increase the pressure on parents, and in this case on mothers, to find the establishment that will provide "good care for their child" (Chamak, 2009; Courcy, I., and des Rivières-Pigeon, 2013).

Finally, several respondents emphasized the decisive role of family associations in the organization of care by providing information on reception centers, financial aid, and providing resource centers for exchanging experiences. This role attributed to the associations often reinforces the carers' impression that professionals and public authorities have little consideration for them.

3.3. Care experienced as an intimate and satisfying ordeal (in the lower-right of the diagram)

Here, in contrast to the type of positioning analyzed below, we find respondents for whom the organization of care is centered on their own role as carers, mobilizing few external resources. The value placed on the caregiving role by the respondent gives them some degree of satisfaction, even if it leads to a reduction in the volume of professional activities, or even wholly stopping work.

For France, we will present the situation of Cyril, and for Japan, the situation of Sachiko.

Cyril is a 42-year-old man. In the first interview, he was the head of a small business taking care of his father, diagnosed schizophrenic, without treatment, living in a family home, and of his grandmother, who has cognitive problems and is also weakened by cancer. She had been in a retirement home since 2011. Cyril is his father's guardian and follows him very closely. At the time of the second interview, the small business of which he was the head had just gone bankrupt, and his grandmother had just passed away. Between the end of his (short) studies and his current situation, Cyril has changed jobs and places of residence many times. Cyril has a girlfriend with whom he does not share the same roof. He explains this situation through a desire to not "settle down" as well as his responsibilities as a caregiver. Responsibilities that he also analyzes as a new political imperative of a "*society of intergenerational solidarity [...] a society in which there would be no fear of the old and the insane*".

Cyril has an attitude that could be described as very willful. He assumes responsibility for these situations, whether it is for his grandmother, with whom he has maintained a strong emotional bond, or for his father, for whom it is difficult to get any help. Despite the difficulties of the situation, Cyril derives personal satisfaction from it. He has a relatively closed attitude towards external resources because he is very divided on the institutions of the psychiatric world, which he considers globally insufficient and inefficient. Cyril considers that the professionals at the *Centre médico-psychologique* (CMP) (psychiatrist, nurses) are not sufficiently attentive to his father's situation, do not in any way meet his expectations, and that no medical-social services are available to help his father manage his daily life. As much as the retirement home was a recourse, a place of help, advice, and support in helping his grandmother, he feels deprived concerning his father. Cyril says that he can never feel like he is on vacation, always fearing that something might go wrong.

Sachiko is a 60-year-old woman, married with two children, who has had a professional career with many responsibilities. She became the director of a home for the dependent elderly, a job she left in 2002 when her mother-in-law became dependent. "*There was only me* [who could take care of her]." "*It's my own decision*." "*As soon as I got married, I told myself that I would have to take care of my in-laws.*" However, Sachiko recalls one incident that influenced her decision to leave her job to care for her mother-in-law and keep her at home: "*The president of the shelter [where she worked] was old-fashioned... When a family came to ask for admission, he said, 'one more person abandoning their parents... I thought that's how people see it....*". Thus, Sachiko explains well her resignation to her duty as a daughter-in-law. Japanese society continually reminds her of this sense of duty that encouraged her to leave her job, which was a job with responsibilities. This decision was not based on emotional ties: she did not get on well with her mother-in-law. Sachiko developed angina in 2002 and has been undergoing treatment since then. Her entourage was aware of the fragility of the care organization that rested on Sachiko's shoulders, but there has been no change as a result of this crisis.

At present, Sachiko considers that the help of her husband, who has been retired for five years, and the advanced state of dependency of her mother-in-law make it easier for her to organize her care, as Sachiko is facing less resistance from her mother-in-law. Sachiko accepts the interventions of professionals for medical care, but not for care activities. She is even used to performing medical procedures such as catheterization and explains that she does not really need a nurse at home, but that she hires one so that in an emergency the doctor can facilitate hospitalization. Sachiko has been a member of the caregivers' association for a year and a half, where members share their experiences. She did not want to join because she did not feel the need, but the members of the association insisted that she join.

Sachiko cannot be considered as totally closed to external resources. Medical professionals intervene at home, and her mother-in-law uses the temporary residence facility. However, she considers that she can take better care of her mother-in-law than the professionals, thanks to the experience she has acquired in her day-to-day care. Sachiko is suspicious of establishments. The feeling of duty and the confidence she has acquired in her abilities pushes her to wholly and entirely assume her role as caregiver.

In this case, positioning concerning resources is also strongly conditioned by the way one perceives the vulnerability of the loved ones receiving care. In many observed situations, caregivers feel invested with a mission, even if it is restrictive in terms of the organization of their professional and personal life. They consider that they can cope with the vulnerability of their loved ones, that they have developed skills or dispositions, but that it is their responsibility to be present, and sometimes even omnipresent when external resources are deemed inadequate.

Finally, although these carers express a particular satisfaction with the care organization they have set up and do not necessarily seek other solutions, it seems to us that this balance is often fragile, resulting in health problems and particularly demanding professional careers.

Let us now consider the last pole of the Care Orientation Diagram, the one that combines both the difficulties in coping with the situation related to the support of the family member and the low level of mobilization of external resources.

3.4. Care experienced as an ordeal to be avoided (in the lower-left of the diagram)

Care is portrayed as an ordeal to be avoided: few attempts to seek outside resources are observed, the intimate sphere is perceived as a zone in need of defense, and the situation of the loved one being cared for, although often presented as painful, may seem to have been downplayed for the interviewer hearing the narrative.

There are several Japanese situations in this case, but no French ones. Several explanations can be put forward for this. Among these are the significant difficulty in identifying French caregivers who would not seek help from institutions and facilities. It is essential to identify this methodological bias, including in what it can reveal about the organization of care in the two countries. For example, a tighter network of Japanese carers' associations would help to shed light on the greater diversity of social profiles. The participation of larger-scale associations and host institutions makes it more challenging to contact carers who do not consider themselves open to external resources.

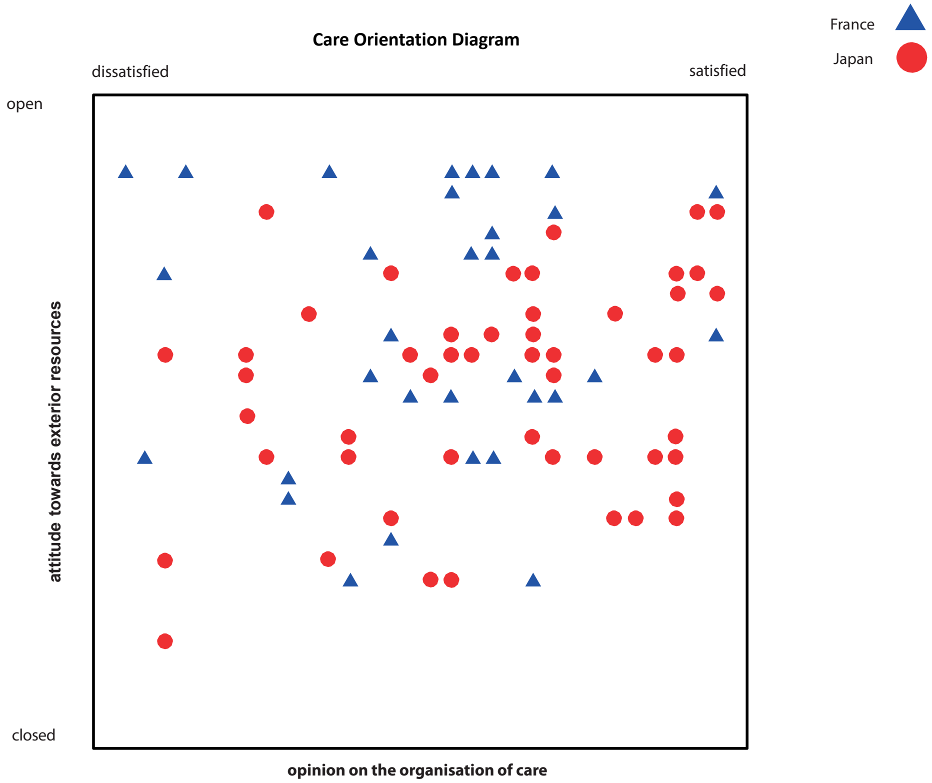
We will present Yukie's situation, which leads us to a consideration of those care situations for which the difficulty of recognizing the vulnerability – at least temporary – of the person receiving care makes such care complex.

Yukie was a 62-year-old woman at the time of the interview. She has two sons, one of whom is 40 years old, is schizophrenic, and lives with her and her husband. Her own parents and her in-laws are deceased. She no longer works and has had a very fragmented career path. The household income comes from her spouse's retirement pension and real estate income.

She says she has free time for herself quite frequently, as her son works in an insertion program, and she does not feel isolated. Her son is no longer using the care provided under the 2006 Disability Act, as his condition has improved, and he is in a program for the integration of disabled persons. He left home at the age of 21 to take up his first job. That same year, he started having hallucinations. His parents took him to the hospital away from home for fear that his condition would become known to those around them. In this respect, Yukie's attitude towards accompanying her son may seem ambivalent. She objected to his employment as a coffee server in the work integration program because she did not want him to show up in public. When she recounts the first appearance of her son's illness, her account reflects her uncertainty but also her reluctance to seek medical advice. She shared her search for information about the illness, while also noting her difficulty in taking further steps to seek outside help and, more generally, her mistrust of professionals who might also make visible the situation of fragility that could reflect on the whole family. The confusion that this situation caused is thus perceptible in the narrative, which is itself difficult for the respondent to follow.

Eventually, her son met with various doctors, but his condition deteriorated, and he was hospitalized. Later, he was able to benefit from the help of a reception center on a part-time basis and then began a professional integration program. Yukie explains that she did not want to hire a professional home helper, even in the most challenging times, because she thought it would be challenging to bring strangers into the home, people who would not have a trusting relationship with her son. Also, her house was "upside-down." She did not want to show this mess to strangers. Her son has now found a job in the maintenance and gardening sector of an institution for mentally and psychically disabled people, and Yukie explains that she is beginning to come to terms with the situation.

Yukie is close to this pole of the Care Orientation Diagram because she took a position of relative closure to outside resources that seemed to stem from her difficulty in accepting her son's diagnosis of schizophrenia, as well as her fear that this stigmatizing illness would be known to others. Her ambivalent attitude reflects the difficulty that many caregivers have in coping with the scrutiny of others, a theme that is particularly well documented for mental disorders.



4. In conclusion

The analysis of the caregivers' narratives revealed a diversity of positions of the people surveyed on their care activity. The different lines of analysis used to understand care situations do not all seem sufficient in accounting for this diversity of positions. Some of these positions may even seem paradoxical: care is not necessarily harder to organize for a highly dependent person, nor is it necessarily accompanied by extensive recourse to outside help. Likewise, providing care for a relative can give rise to general satisfaction without this necessarily being synonymous with a friendly relationship with the person receiving care. In order to understand the complexity of these positions, we have identified two main lines of analysis: their attitude towards external resources and their subjective evaluation of the organization of care. Several configurations emerged, questioning the fact that the mobilization of resources does not necessarily lead to an attitude of satisfaction towards the organization of care. Similarly, people who mobilize limited resources can declare themselves relatively satisfied with the organization set up.

More broadly, putting the situations of carers in both countries into perspective made it possible to highlight the points of convergence between them, despite the significant differences in institutional organization and social values. The responsibility of caring for a loved one is emphatically affirmed in both countries. It is interesting to note that among the diversity of carers encountered, relatives of people with disabilities produce narratives that are relatively close in terms of positioning on the Care Orientation Diagram. Thus, they tend to be distributed more towards the top of the diagram, adopting an attitude of openness to external resources, soliciting more professional help. This tendency is more accentuated for the French respondents. Caregivers of family members with disabilities are also numerous in producing a critical discourse towards professionals. In any case, they express a degree of dissatisfaction, by declaring that they are committed to a more positive degree of recognition of their loved one by society, whether it be in support of an independent life or the offer of more adapted care.

Paying attention to the caregivers' views also highlights the importance of thinking about time frames in the survey, both in terms of the role of successive assistance provided to relatives and the duration of the assistance provided, two factors that modify the trajectories of caregivers. Thus, almost all of the carers with more than 25 years of experience in providing care are in the right half of the diagram, i.e., expressing relative satisfaction. This trend is present for Japanese caregivers as well as for French caregivers, although it is less pronounced for the latter. It can be explained by the acquisition of more significant experience in providing care, but also for Japanese caregivers by a greater acceptance of the social role of caregivers, who are less confronted with contradictory orders to reconcile "family and work" than French caregivers (Nicole-Drancourt, 2009).

In addition, we find it interesting to note the relationship of caregivers to the support systems present, from a gender and class perspective. Our survey seems to support the results of other research showing how upper-class men seem to take on the status of caregiver more easily than lower-class women (Banens, Thomas and Boukabza, 2019) and can then more easily mobilize the caregiving resources that are designed for them. The place of kinship is also very interesting to document. The role of siblings deserves more investigation concerning this ability to be involved in assistance schemes. The preferences of the assisted persons for one of their caregivers, even if it is not the caregiver who provides the most care, is also an element that needs to be studied in greater depth, to reflect on the role and effects of elective choices in care (Martin Palomo and Tobío Soler, 2018).

Finally, despite the existence of various aid mechanisms, the complexity of the organization of aid is noted by the majority of the French respondents. This mainly affects those caregivers who say they are less endowed with economic, social, and cultural capital.

5. References

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