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New Kinds of Families, New Kinds of Social Care
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WORK AND CARE IN DOUBLE FRONT CARER FAMILIES

A qualitative comparison of care arrangements in Finland,
France, Italy, Portugal and the UK

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Summary of main results

The first main result of our research is that in double front carer families the emphasis is on the elder care, whereas the care of children is in general described as less problematic and more "natural". Not only does this latter one seem to involve less fatigue and stress but also, it has been presented as a resource to recover from the main burden of eldercare. These results are grounded in our data. They do not derive from a bias in the interviews but do really express the views of the carers.

It may appear that such an imbalance could derive from a different definition of family obligations towards elderly members, a field where several countries of our sample have no legal enforcement comparable to parents' responsibilities for their children. However, the greater attention given to elderly care can be recognised in the words of our respondents in all countries. One reason for this imbalance can, rather, be that such care arrangements involve complex and often disappointing negotiations among the members of the extended family of the elderly person. Even if the existence of viable alternatives in residential services of higher quality (in France or Finland) may alleviate the sense of guilt of adult children when institutionalising a parent, in any circumstance, this is a difficult decision to take. Usually family members recognise the right of the old person to refuse institutionalisation in nursing homes (or long stays in the hospital).

In fact, the larger part of the care burden for a dependent elderly person is faced in all countries by informal carers. This is testified by the many family stories of long years of care involvement told by our respondents. The real problem, then, is how such bulk of informal care can or cannot be complemented by other resources.

The common typology helps to observe variations within comparable care arrangements. But it is absolutely necessary to go beyond the simple hypothesis that national policies fully determine the care arrangements. In fact, even if negotiations among siblings are performed everywhere, this does not mean that networks of help are always formed. This affects the quality of life of our sample families deeply.

The two main types of networks in our sample are those composed of 'weak ties', where the network is minimal or even absent and care-giving falls on one person. More than half of our sample (56 cases) is included in this first type. This second main type, instead, has relatively rich and polycentric networks. A third of our sample (32 cases) is included in this latter type. In these families, the main caregiver — if there even is one — knows that she/he can count on other family members for practical assistance and second opinions. The number of cases in a third type which a specialised sub-division of tasks between at least two care givers, with or without the support of services, is much smaller.

All the three types of networks exhibit connections with professional and non-professional services. The range of professionally provided services is vast, ranging from less intense health related services and home services, to "total assistance", such as nursing homes or assisted living centres, where the elderly person has around-the-clock access to help. There the institutional mandate covers both health and social needs. Families in Finland, France and the UK mostly use combinations of informal and formal care. Only Portuguese and Italian families use mostly private and third sector care facilities.

In Italy, France and Portugal, the informal, non-professional paid sector is wide and varied, offering a range of types of assistance. In France it is framed by the *Prestation spécifique*

dépendence, becoming thus semi-public. Some types of this non-professional care like paid companions are “light” and temporary, limited by their nature. Others entail assistance delivered daily or several times a week, such as housekeeping or help with bathing and personal hygiene. In some occasions operators of the latter type even live with the elderly person, often providing around-the-clock services in exchange for room, board, and a stipend. These workers are usually women, and in Italy and Portugal they are typically immigrants from outside of the European Union. Not having had any formal training, they can in the EU labour market only rely on personal experience, accumulated with their own families. Their working conditions are inadequate. For the Italian and Portuguese families, this solution is less expensive than an intensive formal home care service or a residential home.

In any case, there are marked differences between Italy, Portugal, and France in the relationships we see between families and paid services. In the former two countries, private assistance, especially for the elderly, is hired to substitute for — and not to complement — public services. In contrast to the above, in Finland and Britain, where access to formal services is easier and more generous, informal, non-professional and non-familiar work is mainly provided by volunteers, usually free of charge, who offer their services individually or through voluntary associations.

Everywhere the centrality of the family and the main caregiver in the general organisation and control of the care arrangement remains the most important resource. It is s/he who, even in the richer and more co-operative networks, assures the “synergy” and co-ordination of the various activities. However, if too scarce help — or none at all — is available from the outside, this fundamental resource tends to become quickly exhausted. From this point of view, formal and informal serviced need to be combined in a complementary way. Often both of them are necessary.

In conclusion, the need to think in terms of a *system* of care, compatible with paid employment, emerges ever more clearly from the words of our participants. By thinking about the networks between families and services as a system of care, we are able to depart from a logic that envisages either total delegation of care or the myth of specialisation. In the first case, the asymmetry of the relations is in favour of services that have the power to “govern” the network. In the second case, according to the model of health services, services deal with only small components of user’s needs without examining how they interact with and affect the bigger picture. Indeed, the growing recourse to non-professional services in every country, whether paid or voluntary, can be interpreted not only as a strategy to meet an unsatisfied need but also as an effort to find more flexible and personalised solutions. Such solutions, above all, leave the “government” of the care for family members to the family itself.

1. Introduction

1.1 Methodology and theoretical framework

This report is mainly based on the secondary analysis of interviews conducted in the preceding workpackages of the Soccare project. These interviews have been supplemented, however, by additional interviews aimed specifically at collecting information on the special challenges some families face in confronting care burdens on two fronts: the care of children, and the care of dependent elderly relatives.

The project originally envisaged this theme as a targeted study of the 4-generation families that we had interviewed previously. At the beginning of the research, we had identified this family type as being at the forefront of the new transformations in family structures. Our research interests evolved with each wave of the study, however, and it is thus necessary to demonstrate how they changed and why it now seems more opportune to us to highlight dimensions of a phenomenon of which various interesting and unexpected aspects had already emerged, but that were different from what we had initially hypothesised.

The report is divided into six chapters: in the first one we are presenting the methodology and theoretical framework, the characteristics of the context of long-term elderly care and economic benefits and we introduce the types of double front carer families found in our sample.

In the second chapter we analyse the processes leading to the assumption of the role of caregiver through life trajectories, considering the main differences between the “stories of their careers” as caregivers.

In the third chapter we deal with the problem of constraints and resources for families facing double front of care, with a special attention devoted to networks of care. Network analysis gives interesting information on the relationship between formal and informal care, which is one of the main topics of the Soccare project.

In the fourth chapter we try to understand how this blend of formal and informal care is organised and perceived by families, how they use public and private services and facilities, what is the user’s perception of their quality.

In the fifth chapter we analyse cases where children and elderly persons are mutual resources in the same family, even when the elderly person has health problem limiting his self-sufficiency. We’ll see how this relationship may become mutual care of dependent ones, with unexpected consequences improving the quality of life of all members, grandparents, caregivers and grandchildren.

In the sixth chapter we draw conclusions, suggesting some implications for care support, like the need of an evaluation of coping capacities of families having “poor/rich resources of care”, the development of counselling in ‘first aid’ points, the growing demand of help in accepting decline and death of elderly relatives.

In the following of this chapter we present a detailed reconstruction of the samples of families included in the two data bases (most of the families appear in both data bases) we constructed and used for this workpackage. The first data base contains the objective data on all of these types of families (the collection of original and recompiled 100 data synopses). The second database, composed of information from a reduced number of cases, contains qualitative data gleaned from the original language interview integral transcripts (with the exception of the interviews with Finnish families, which were already translated into English before being analysed by a computer package for textual analysis).

In our original research project, we identified 4-generation families, along with single-parent families, dual-earner families, and families who had recently immigrated from another country, as an emerging family structure that probably faces an overload of caring problems and general

difficulties organising daily life. However, following cross-country comparisons across family types, these latter families did not seem to organise daily caregiving in similar ways.

Because of longer average life spans, 4 generation families have become a statistically more frequent phenomenon throughout Europe. What this trend might mean for the future, however, especially in terms of intergenerational equity, has been puzzling researchers for nearly twenty years (Laslett and Fiskin, 1992). Many researchers, worried about the possible social ramifications of this transformation, also acknowledge that knowledge in this field is still far too limited (Rossi 1993) and that most research has been conducted in U.S. (Dautzenberg 1998).

Despite the relative lack of specific information on these transformations, it seemed that one would be able to trace, merely from the increased number of years in which more generations of the same family co-exist before being separated by death, a necessary redefinition of the expectations concerning the 'normal' life course of family members. Such a shift would in turn alter the relations among them (Hagestad, 1982; 1995; Facchini, 1992; Attias-Donfut and Renaut, 1994). In addition, we would expect that the co-existence of many generations would also affect the timing of the transfer of resources necessary for educating the younger generation, and above all the older generations' expectations of support for when they themselves become dependent. Indeed, the image of old-age itself might change, given the increase in the number of negative ageism's and degenerative illnesses (Bengston, 1993: 5, 21)

These transformations in turn should call into question the traditional rules of the inter-generation solidarity pact. The most wide-spread line of reasoning on this issue argues that with increasing dependency rates, states will no longer be able to sustain the levels of health and social security services for the elderly that they offer today (or will take it as a useful excuse), thus leaving vulnerable the generation that now supports this burden (Thomson 1992; Walker 1993; 1996). As Bengston himself has already observed (1993, 13), however, this kind of thinking tends to confound the issue of inter-generation relationships within families with a more societal-level phenomenon concerning the relationships between age groups and cohorts. Moreover it does not consider the dimension of gender inside generations (Arber and Attias Donfut 2000).

The most frequent hypothesis suggests that the 'sandwich' generation, or, rather, those women—and to a lesser extent—men, in middle-age (around 50) and 'in the middle' of requests for care from two generations (Dautzenberg, 1998), will inevitably be overloaded. In the case of a four generation family, it is easy to imagine members of this age group having simultaneous caring obligations for both their grandchildren and their extremely aged elders, who at this stage are more likely to be dependent (Treas and Bengston, 1987). In our own research, however, we have had to deal with the fact that the cases we identified are not always comparable, though they reflect these macro-level demographic trends. It was already clear from the second workpackage and the first wave of interviews with single-parent families that the mere existence of four living generations of a single family does not in itself necessarily produce discernible patterns of behaviour in daily life—independently of whether or not the various generations lived together or near enough. Above all, the mere existence of four generations provides little basis for predicting the form of the network of support concretely exchanged among family members.

What have been confirmed are the demographic features driving the phenomenon, which is highly correlated with the average age of women at first child birth. In Portugal, where the average age of mothers at first child is still less than 25 years (the lowest in Europe), 15 4/5-generation families were identified in the national sample. These types of families exist not only where it is more common for diverse generations of families to live together or near each other, as in Portugal, but also in countries such as Finland, where, in contrast, it is very rare for elderly parents and their married children to live together, and where household exit and autonomy from the family usually happens at a younger age (only 8% of Finns between the ages of 25 and 29

still lived with their families of origin, compared to 17% of their peers in the UK; 18% in France. In Portugal and Italy, young people demonstrate an opposite tendency, with 52% and 59% of in Portugal and Italy, respectively). In Italy, though we had expected to find a fair number of multigenerational families - since residential proximity is the rule and extended families are more common - in reality they were quite rare.

Though it was a challenge for all research teams to include, as was requested, a certain quota of 4 generation families in each package, we found it no coincidence that this was especially difficult to achieve in Italy and France, where, in the sample population of single mothers, we were able to locate only 5 4-generation families in Italy, and none in France.

At the same time, it was very clear to us that the families of 4, and even 5 generations in Portugal (15) and Finland (12) had little in common. While the Portuguese families usually could be characterised by a certain amount of residential proximity, the various generations of Finnish families were instead so spatially dispersed that their relations were often sporadic at best. Among these 12 families, the oldest generation was regularly assisted by the middle generation in only two cases, but not necessarily by the same person in the family who cared for the youngest generation. In one case it was the great-grandmother herself, along with the grandmother, who took care of the granddaughter from the last generation. In other cases, we saw irregular instances of care provided by the older generations (who often lived hundreds of kilometres away), or no substantial exchange of care at all. This naturally reflects the patterns of residential autonomy exhibited by the very old in Finland, which is the highest in Europe on the basis of the Europanel (42% of men and 80% of women above the age of 75 years live alone)¹, as well as the relative generosity of its welfare system. Portugal, the other extreme of our five countries, reflects the second lowest level (only Spain is lower) of elderly autonomy in Europe: only 16% of men and 33% of women over the age of 75 live alone. Though the relatively lower number of years between each generation is a feature that favours multigenerational relations of care, it may be counter-balanced by the younger average age of elderly people in Portugal, who may be less needy than their generation counter-parts in other countries.

Nevertheless, it is still the case that neither residential proximity nor the smaller age gaps between generations that are evident in Portugal necessarily produce a high concentration of caring demands on the middle generation: of the 15 4/5-generation families, most of them did not see any appreciable exchanges of assistance, except for those cases in which the help, mainly of an economic nature, flowed from the older generation (the grandmother, or a great-aunt) directly to the single mothers we interviewed. In these cases, the support provided by grandparents substituted for that which had been withdrawn by the mothers' own parents because of disagreements or conflicts between them.

Contrary to expectations, an overload of caring demands on one specific generation instead emerged in the UK, where we usually assume relatively weaker networks of family solidarity. Importantly, however, it was not the 'sandwich' generation to be most heavily burdened by the needs of both young children and the elderly. Instead, it was more likely to be the single mothers themselves who had to provide care on two fronts: to their own children on the one hand, and to their grandparents on the other. These mothers tended to 'skip' a generation in a way that is probably characteristic of their condition: in three of the seven 4/5 generation families in the British sample, the single mothers had broken off relations with their own parents while sustaining more or less demanding care relationships (in one case cohabiting) with their maternal grandmother, with whom they had never broken. We saw at least three similar cases in Portugal, although the direction of care flowed in the opposite direction, and at least one and maybe two among the five Italian 4-generation families.

¹ Corresponding percentages for the other three countries are: Italy, men more than 75 living alone 22%, women 69, France, men 22, women 59%, UK, men 30 women 58% (Eurostat 1999).

These observations lead us to believe that, compared to the cases examined in early studies on inter-generation solidarity, which were predominantly located in Anglo-Saxon countries², the family networks of the Mediterranean countries may have a greater capacity to redistribute the burden of care in a way that the generation responsible for small children is spared the obligation towards the oldest generation, and vice versa. These countries thus manage to avoid that all of the care-giving stress of the family falls on the same person, since timing may be articulated (cf. Boyd and Treas 1989), even when it does fall on one cohort alone. There is also an interesting element of free choice, recognisable in the capacity to find surrogates or substitutes for gaps in the kinship network which in the past has demonstrated a trend towards ever fewer carers for ever more individuals in need of care. Many studies, the most well-known being Riley and Riley (1996), demonstrate this elective element in how families manage the obligations they acquire through marriage, a phenomenon also revealed in studies on divorced families, which show that obligations are not necessarily suspended, as was previously thought, upon the break-up of a marriage. (Finch and Mason, 1990; Thompson 1999).

In recent years a series of studies conducted in various European countries both in and outside of the Mediterranean area have clearly demonstrated the new centrality and generosity of elderly grandparents who are still in good health (young-old) (Attias-Donfut and Segalen, 1998), as well as the importance and redistribute capacity of generous transfers from the sandwich generation, consisting of cash, caregiving, and *inter vivos* gifts (Attias Donfut et al., 1995). This theme, which in the past has been overshadowed by the fear of a possible increase in inter-generation conflict, illustrates well the necessity of evaluating public transfers within the context of the informal, private transfers exchanged across generations (Attias-Donfut and Wolff, 2000). From this point of view the Italian case is paradigmatic. Here, the generosity of the pension system is unusually lopsided, with the cohorts who worked in the second and third decade after the Second World War being especially privileged. In reality, however, this system has functioned as a *de facto* social shock absorber for the structural youth unemployment that has plagued the country since the 1970s, because the generous pension benefits get redistributed within the family.

The theoretical framework that seems most convincing to us is that recently formulated by Attias-Donfut, Lapierre, and Segalen. These authors suggest a 'new family spirit'; a re-launching of the extended family in new forms, characterised by strong and gratuitous affective ties that 'ebb and flow or are reborn through the renewal of the generations and in particular through the relations between grandparents and grandchildren or great grandchildren' (Attias-Donfut, Lapierre, and Segalen 2002, 248). This family spirit is capable, among other things, of transcending time and geographical distance, reaffirming itself through family rituals and stories. It differs from the past, however, in the free circulation of positive debts and reciprocities between generations that go in both directions following needs, which the authors have efficaciously termed a family spirit of 'variable geometry' (2002, 251). In our opinion, this new family spirit is not only applicable to France, for which it was formulated, but also more or less to all of the five countries we studied for this project. It is probably no accident that France can be located in an intermediate position among these five, given its characteristics of a rather high average age at first childbirth, but also decidedly generous family policies.

Moreover, in the mean time, the results of the third workpackage on two-career families demonstrate that there is a much greater likelihood of finding extremely old, physically dependent individuals in three-generation families with post-adolescent or adult children than in four generation families. Only Portugal presents a partial exception to this trend, where, because of narrower age gaps between generations (discussed above), very young children can also be found in families with dependent elderly members.

² Characterised by a greater prevalence of single-parent families.

These theoretical innovations, combined with what we learned in previous workpackages, lead us to adjust our research objectives for our study on multigenerational families in two ways. On the one hand, we widen our analysis, examining all families confronting care demands on two fronts for young children and dependent elderly or adults, regardless of which generation the carers come from, or the degree to which they are involved in the care. Indeed, in all five of our countries the most problematic situations for double-burdened caregivers arose most frequently in families of three generations, rather than those of four. At least this resulted from our selection criteria demanding for respondents in active life. At the same time this brought to light a very difficult situation worth better studying and undervalued in present debate. Most of these couples, in fact were employed, and had to face different constraints connected to the double responsibility of care and work duties with a limited network of resources. On the other side, the mere effect of the 'verticalization' of the kinship network often means that the 4-generations families are actually richer in personal resources than the mean family (Laslett and al.1993).

Our analysis is thus not a cohort study aimed at researching a particular trajectory characteristic of a certain age category, which is typical of work usually done on intergenerational relationships. Such an approach would have been mistaken in any case, given that differences among our countries in the average life span are still quite significant. For example, the upper threshold identified for the middle generation (40-54) in Dautzenberg is relatively young compared to that calculated for the middle generation of Italy, which, in order to capture individuals in the same circumstances, would probably include individuals over the age of 60 (Rossi and Bramanti, 1994; Sabbadini 2002). Moreover, among classic studies in sociology of the family one also finds research that identified the double front of having to care both for one's own parents and adolescent children (Rossi and Rossi, 1990; Miller 1981) or, in a more context-bound way, those who mainly explored care-giving for very old family members (Qureshi and Walker, 1989) found many other ways of combining care duties. In fact, the meaning of care for adolescent and post-adolescent children itself assumes extremely different connotations in Italy and France than it does in the UK and Finland and it may or may not constitute an usual doubling of care tasks (cf. Brannen et al. 2002).

Given the variation in this phenomenon across our five countries, and because of our small sample size, it seems much more fruitful to investigate the *sociological* characteristics of the phenomenon that we are interested in learning about, and that seem to truly pose a series of challenges for social policy. In fact, a double front of care could be extremely problematic even for those who do not come from the 'sandwich' generation, but, if the services are adequate, often could be no less foreseeable on the basis of a series of easily recognisable subjective and objective symptoms. Likewise, the ways these families utilise services can produce a series of obstacles or access problems that are certainly less expensive to remove than it is to address their radical deterioration. In no country are the services able to 'see' the overall picture of the needs associated with complex care arrangements, that, to the contrary, probably merit the planning of 'emergency' social support measures, also in the case of short-term needs.

This last phase of in-depth study, consisting of additional interviews with new cases, as well as targeted follow-ups with previously interviewed individuals, was planned with the understanding that these additional interviews would provide a core set of cases which are uniformly burdened with care responsibilities and that serve to define, in detail, a *extreme case* of the complexity of dealing with care giving on two fronts. Starting with the far extreme of four generation families where no single caregiver appears particularly burdened with requests for care, we gradually progress to those caregivers who provide sporadic, episodic, or long-distance care, and end with those who must tend to more tiring and problematic care burdens.

We also find it worthwhile to uncover the similarities in the diverse typologies we gather *before* addressing how they differ across cultural backgrounds or according to the relative wealth of the

welfare state in which they are situated. While we are convinced that this approach will also yield significant patterns within single countries, our objective here is not to provide a systematic definition of cultural differences or the informal welfare regimes in each country, but rather to use the extreme case as a sort of rough application of the method of difference.

In this case, the richness of the spoken testimony and the sincere input of the participants open windows of meaning that very often bring together personal accounts and experiences of the above-described transformation, thus providing us with a picture of the interaction between the micro and macro dimensions that we have never before observed in terms of the supposed intergenerational conflict. For example, the deep relations developed among women of different generations by virtue of having lived and known each other for so long, along with the rich interweaving of reciprocities that constitute its warp and weft, provide a glimpse of the transformations of the gender contract. Moreover, the verticalization of the kinship network explains the difficult negotiations within families with few descendants concerning the care of their elders, and the heavy burden that falls on the shoulders of only children. It also highlights the inflexibility of the mechanism by which the main caregiver is designated, and some of the pathological tendencies that arise in relationships between caregivers and people being cared for. Above all, it seems to us that the greatest advantage of this approach consists in shedding light on the *transitional aspects* of growing old, and on the slow process of meaning construction that each family member experiences with the ageing of a loved one. The most extreme example, with respect to the supposedly measurable threshold between self-sufficiency and dependency employed by social services, illustrates how the definitions of self-sufficiency themselves shape reality and influence people (cf. Bould et al. 1997)

1.2 The context of long-term elderly care and economic benefits in the five countries

It is not our task to provide a detailed description of the generosity, coverage, and actual implementation of social policies for the elderly in the five countries of our study. There are already excellent studies that provide information on the European context, including the descriptive analysis by MISSOC, targeted studies on long term care (European Commission 2000; Bettio and Préchal 1998; Pacolet et al. 2000), and interpretative models of change (Rostgaard and Fridberg 1998; Rostgaard 2002b). However, there remain some important differences that do appear to be attributable to variations in welfare regimes. These differences came to light notwithstanding the particular research approach that we chose to follow: a study of *the similarities in the daily lives* of our participants that cut across all five countries. These observations could be equally useful, however, in thinking about the institutional practices of each welfare system, as *families perceive them in different ways*. What surprised us most, initially, is that families are generally satisfied—though not with everything—with the way economic assistance is organised, *no matter what level of quality or generosity* they provide. In other words, it appears that families reason within a national standard of viable alternatives and measure their own unsatisfied needs with respect to what their welfare system could easily cover. Our participants only rarely viewed their own situations through a comparative lens, criticising the national standards of their own countries with respect to those reported in other countries. For this reason we found their reflections on how to improve public services, which were often quite feasible, just as interesting to discuss as the common challenges they recounted. Indeed, interesting convergence seem to emerge on certain fundamental problems regardless of the relative generosity of each welfare regime.

For example, as a matter of social equity, nearly all of the families we interviewed believe that their fragile, elderly relatives should be able to pay for the care and assistance they need, whether from pension benefits or elsewhere, so as to maintain at least a modicum of economic autonomy. Equity also demands that families with children to support--whose economic costs are evidently much more obvious and uncalculated—should not be so impoverished by the expenses of their elderly family members that they are unable to sustain their ‘natural obligations’ towards their children. Indeed, this is the point on which the economic burden imposed by the elderly family member might be seen as unacceptable in terms of generation equity. Finally, above all and in all five of the countries we studied, we found the greatest agreement on the blame upon the lack of social recognition of the dignity of elderly persons who have worked their entire lives but are then left economically dependent on their own adult children for even the most basic services.

"If they needed services I think that as my Dad has worked all his life he should have a right to anything that is on offer." UK - MC08 FU³

"Well, it's okay in the sense that you would then have money for these, if there are any day care services available, or other care forms or home helpers or such services. 'Cause if you're on national pension, you really can't afford these" FIN - MC20 DB

From this point of view, however, it makes very little difference to families if the income of the elderly person or couple comes from a simple social pension, or from a more substantial contributions-based pension. It also doesn't matter if the pension is supplemented or not by additional disability benefits (whether contributions-based or not); if the right to pension supplements is evaluated according to the level of dependence; or if the supplement is in the form of a housing allowance, such as that offered by Finland to support elderly peoples' capacity to remain in their own homes, or in the form of a nationally or locally provided care allowance. In the end, what really counts is the total amount of monetary resources that can be put together based on that particular elderly person's recognised social rights, and how far those resources go in meeting the costs of necessary healthcare and care assistance. In fact, our families were unanimous in citing as their chief concern the procedural difficulty of obtaining recognition for almost any of the rights due to their elderly family members. However, if, as in Italy and Portugal, a minimum social pension is adequate for covering the relatively low costs of hiring a companion, or if, as in Portugal, an average pension would allow for a private home aid or privately purchased meals, family members do not pose further questions about the lack of recognition of other elderly family member's rights.

"Thank God he's got a pension that allows him to pay for the services they need, if I had to pay for them I wouldn't have enough money for me and my son. It's an issue that doesn't depend on what people want, but rather on the world we live in... the day centre that brings them meals, that takes care of their baths, that tidies up...it's the same system [paid for by your father's pension?] It's all covered, for the both of them". P - MC06 DB

"The care allowance really helps me because my mother has her extra costs, in the sense that she has particular...she can't eat everything, because she has a stomach hernia. She has her own needs, and then for her medication, many of her medicines aren't covered...For me this is the most important assistance". IT - MF27DB

³ Quotations come from the transcripts database (F= France, FIN= Finland, IT= Italy, P= Portugal UK= United Kingdom); if they have been collected in a previous workpackage they are recognisable as SP= single parent families MC= Multi career families MF= migrant families+number+DB. If they are follow-up interviews they are equally SP, MC or MF+number+ FU; only if they have been expressly collected for the last workpackage they are named Country - DB/number.

Nevertheless, it is clear that in terms of the elder care resources provided by the State, our five countries fall along a very long continuum of generosity. Finland and France are nearly equal at the most generous extreme. Finland, in addition to granting a pensioners' care allowance based on a sliding scale of dependence, provides assistance to families who must institutionalise an elderly family member--a solution that appears socially acceptable and within the reach of many families (though the quality varies by location). In-home services are also well-covered, with about 12% of all elderly receiving assistance of this type⁴. The most remarkable support for families, however, are the means-tested caps placed on family contributions towards in-home or institutionalised care (older couples or persons pay no more than 80% or 90% of their revenue for the costs of each form of care, respectively). Expenses can thus to a certain degree be expected and calculated, *because the revenues of no other member of the family will be affected*. Finally, our Finnish respondents also recognise the inequity that exists between elderly men and women in couples, especially those from earlier generations in which the women qualify only for the minimum national pension and cannot afford the expenses of in-home assistance, or else become poor when their husbands, the recipients of more generous pensions, must be institutionalised.

"...very often these couples are still the kind that the wife has stayed at home and the husband has worked, and then the man has a good pension, while the wife only gets national pension, so they take the man's pension just like that, almost every municipality does, they're not interested in adjusting very much, they do take all they can get. [...] ... and economically it of course means, since it all goes, all of my husband's pension goes to institutional care" FIN - MC20 DB

In France the 1997 reforms of the *Prestation Spécifique Dépendance* seem to have satisfied both our participants who take advantage of in-kind benefits, whereby a State-assigned an *aide ménagère* or an *aide soignante* provided by an accredited agency provides a certain number of hours of in-home assistance, and our participants who ask reimbursement either for the hours of assistance they provide themselves, or have directly paid someone else (from the informal market, but regularly employed) to provide⁵. In any case, the most important feature of this scheme is that the number of hours awarded for each type of arrangement is determined by the elderly person's position on a 'dependency scale', which is calculated using absolutely transparent and objective criteria⁶. Such transparency implies that the criteria are rather uniformly applied (Le Bihan et al 2000).

"What I think is unfair—it's true, but it's just a sign of the injustices of our society—even though we are in a country that is trying to make up for this inequality with assistance to the needy. They are initiating programs that don't exist in other countries, so you can't say that the society doesn't care... It is true that it keeps getting more and more expensive. And that poor people have to pay proportionally more of their income for these services. " F - MC04 DB

Unlike Finland and France, the UK is located at an intermediate point on the continuum, offering a series of non-contributory benefits on a smaller scale that more closely resemble those found in Southern European countries (Attendance, Disability living and Invalid care allowances). Home care services are generally good, and based on a 'care package' that is determined by local authorities. The hours of assistance provided, however, are rather limited, and the authorities

⁴ In Rostgaard's typology Finland is described as a bit different from other Nordic Countries in that it approximates a real right of choice between care services and cash benefits (Rostgaard 2002b), which, we will see is of paramount importance for families.

⁵ Of course the selection of our respondents does not tell anything about general coverage, but only about the satisfaction of people covered

⁶ Which makes that France, even its system is still developing and the coverage not yet large, has already the highest number among 'generous' European countries for average weekly hours of home help (Rostgaard 2002a, 62)

also assess the share of the costs that must be contributed by the users. Even so, at least some of our participants find the in-home assistance program to be timely and efficient:

"We had a package set up. The Social Services then stepped in and the social worker was the first person to come and she set the package up and it was amazing. She just completely did everything". UK-DB02

Finally, Italy and Portugal are at the least generous extreme of generosity, and elderly people in these two countries are at the greatest risk of finding themselves unable to afford the care they need. Access to publicly provided in-home assistance in these two countries is much more difficult, as is the potential of receiving support for long-term or permanent institutionalised care. Nevertheless, for institutionalised care, the criteria to be certified as 100% disabled, which in Italy is a prerequisite for what is still a very difficult process in qualifying for the service, appear to be interpreted at the discretion of service operators in Portugal, and thus lack the transparency found in France's *Prestation Spécifique Dépendence*. Finally, in Italy, the proportion of expenses that families must pay for nursing home care is calculated on the total employment income of *all* of the children. There is no 'cap' on family co-payments, such as that found in Finland (except for some little cash granted to the institutionalised elderly person), and families thus have no means to anticipate the amount of expenses they might be burdened with. As illustrated by the words of one of our participants, it is the unpredictable level of expenses that is most upsetting to families:

"In terms of Social Security, assistance with the costs of nursing homes also is practically zero. It's something that we're going to face in the future. If a more economical hospice costs as much as 140,000 escudos, how on earth can we afford it if my father-in-law's pension is only 50,000? How can we come up with that kind of money without being sure that Social Security or the State will contribute part of it? My husband already went to see, and they want to analyse our whole financial situation. I think it is outrageous that they can do it. Why should they ask *us* for this information. If someone has worked his entire life, has paid taxes for his entire life, and now his children are obligated to pay for everything their parents need because the State takes absolutely no responsibility for him" P - MC09 DB

"...they count how much my mother gets from her pension, what I earn, what my sister earns, what her husband earns, and what my husband earns, and they add all of it up, and so it appears that we are extremely rich, but in reality we can't spend all of our money paying for a nursing home, because we also have our own families...so a nursing home is out of the question, we can't afford it" IT - DB04

A difference that we noticed in the accounts of our Southern European respondents seems to concern the general attitude that supplementing an elderly person's pension benefits to pay for nursing care, in addition to other expenses, is 'obviously' the responsibility of the family, or that calculating it in this way is the natural solution. Such attitudes clearly reflect the specific climate of the welfare regimes in which they are located. Unlike their northern counterparts, who are accustomed to the recognition of specific rights to assistance for certain kinds of needs, the participants in these countries appear to be responding to an environment in which assistance is based on arbitrary and subjective criteria.

"Well, my mother has a pension, but it isn't enough to pay for this woman (private companion), so we use my mother's pension, and we also applied for a disability benefit from the S.S.L. and we also have the attendance allowance that is provided for people who aren't self-sufficient, that comes to about 400 euros every two months, and that's how we pay for her *badante*⁷. It's not a

⁷ In Italy, 'badante' means, in practice, an immigrant who is paid, or given room and board, to give around-the-clock care to an elderly person.

lot, but it took a load off our shoulders, even if we always end up with just enough money at the end of the month, because there is everything else to take care of, well, my mother owns her house, so there is no rent, but we have to pay water, gas, electricity, local property taxes, all of the taxes." IT - DB04

In contrast, a respondent from Northern Europe notices even the smallest expenses that come out of her own pocket.

"There are always some expenses, you can't avoid that, but I'm not counting them so much, as I'm an only child, so eventually, if I will live, if we go from this world in the expected order, there will most probably be something left for me eventually, but. But there certainly are some expenses, and like when I go to see mom, I don't withdraw money from mom's account for that purpose. I take her some soda pop and bananas and we go to have a coffee at the K.'s nursing home cafeteria and stuff, so there are always some expenses". FIN - DB06

"Nothing other than gas expenses for driving the car. And when I buy medications for mom, I of course use her money and I pay her bills from her account. She has her own account and I have mine, I only have the right to use hers". FIN - DB10

Participants in Italy and Portugal also use a different tone than their Northern and French counterparts when describing the forms of vouchers, care allowances, and fiscal credits that are available to them. In the latter countries, these forms of assistance are seen as helps that do give caregivers more room to manoeuvre, often with the consent of the person being cared for, instead of simply covering necessities. They allow families to adjust their consumption of paid care in a way that supports the specific family care arrangement:

[Were you paying for the services?]"Yes, Mum had carers allowance, I don't remember how much but money doesn't mean anything. The package gives you a certain percentage off and you only end up paying 25%, I think, but don't quote me. I think it's 25% and Social Services pay the rest. [Rate of payments depend on means testing]. And as I say she has her carers allowance which enables me to have carers in to baby-sit when I go out. Because of course she goes to bed in the evening. I was involved with the village hall at that time and the school Parent-Teachers Association". UK - DB02

"because my mother has a dependence subsidy (*allocation dépendence*), because she isn't self-sufficient, and it has to be used to pay someone to assist her. So I get paid for assisting her, I get 3000 francs a month for 50 hours, but if I were retired I wouldn't have a right to it" F - MC08 DB

1.3 Types of double front carer families

It may be useful to give a picture of the different type of care our families of both databases - the synopses and the interview transcripts - are involved in, also in order to describe how much a single country is represented in each situation, given the different way each country has collected its sample.

We distinguished five main types of caring patterns in double front carer families:

1 light care involvement

2 care involvement of the classical 'sandwich generation'

3 medium to important double care front

4 organisationally difficult or periodical double front of care

5 very heavy double burden of care

The five patterns were identified on the basis of the following two main criteria:

1. the position of the family in the phase of the life course
2. the resulting organisational constraints deriving from the type of needs children and/or elderly present (by age or disability degree) or which can derive from distance or difficult transportation conditions: in a sense this dimension is intended as a measure of how much the two fronts of care present contemporary requests or may, on the contrary, be articulated in time.

The first criterion was essential to distinguish between several types of double front carer families, those whose care arrangements involve a classical sandwich generation as described in most literature: middle aged people in the middle of grand-children and elderly parents or relatives, against the more burdened carers of their own children and other heavy dependent relatives we identified as a new emerging type (cf. par 1)

The second criterion was mostly connected with the first one, but it was combined in the 5 types we describe as they are grounded in our data.

These two dimensions were intended as independent from 1) a subjective sense of burden and 2) the different formal and informal care resources available to share the task. We will address these latter dimensions in depth, but, in principle, they can support or worsen each single type's daily life.

1.3.1 Description and explanation of the 5 types (and subtypes)

1. light care involvement

This type is characterised by weak levels of involvement of the main caregiver with the daily care of elderly, s/he is usually much more involved in child care of his/her little kids; even if s/he calls every day for emotional support, s/he usually does not visit them more than once or twice a week. Elderly members of the family, by age, are often still in couple and living independently, even if often one among them is already really dependent. However the help needed is mainly for external mobility (medical controls, even when the cared for is already alone. The caregivers are usually aged from 35 to 45, except in some cases (subtype 1.1). in which the main caregiver is a grandchild

2. care involvement of the classical 'sandwich generation'

In this type of model the main caregiver (aged over 48) takes care of a dependent person (an elderly relative or a very dependent husband/wife) and - usually not on a strictly daily base - also of grandchildren. Their adult children may sometimes help and support a form of partial reciprocity. A subtype 2.1 common in Southern Europe is the one with grown up but not autonomous children (a double front of care themselves instead of grandchildren) (cf. for U.S. Miller 1981)

3. medium to important double care front

In this type the elderly member of the family needing care is usually alone and more dependent, s/he may cohabit with his/her daughter or son's family or be recovered in a sheltered home requiring an almost daily supervision by the main caregiver. Age of the caregiver is a bit higher than in type 1 (37 to 54)

A subtype 3.1 is the one to be seen in migrant families coming from cultures where cohabitation with husband's parents is common and therefore the age of the main caregiver (usually a

daughter in law) is younger (24-41). Some caregivers are also younger because they care as a grandchild (usually in single parent families).

4. organisationally difficult or periodical double front of care

With this type of model a difficult organisation of mobility is the characteristic feature of the care of a dependent elderly person or couple, either on a daily basis, requiring tiresome daily journeys on a few miles (20-50) basis or periodical long-distance journeys, involving the absence of the main caregiver (aged 42 to 63) from his/her own family for several days. In this latter, however children are usually no more so young and may sometimes help. We considered in this type also the families in which a dependent elderly person spends short periods in the homes of several children (in these latter ones the main caregiver may be younger).

5. very heavy double burden of care

In this family type children of tender age (often from late births) have to be cared for together with a very frail elderly person needing daily and often continuous supervision. This latter is usually cohabiting or living next door. Mean age of the caregiver is usually from 37 to 47, only in Portugal and in migrant families we can find even younger ages. Younger ages of the main caregiver may be observed also in the subtype 5.1 in which the cared for person is a severely ill husband or wife.

As a first result of our research we have to underline that our typology of double front carer families, as well as the description of their daily life which follows, are clearly biased towards elderly care: such an unbalance - something we are perfectly aware of - is in fact *grounded in our data*. We tried to evaluate the daily organisation of these families from our respondents' perspective, giving back their world of meaning as it has been revealed in their own words.

We do not maintain that bringing up children is never described as tiring (especially when mothers describe their children's mobility needs), but we want to stress that in their general equilibrium double front carers view elderly care as the paramount problem, polarising attention and energies, whereas childcare appears as something more "natural", in which the quality of life may be recovered. Mothers' and fathers' involvement in childcare may even require long hours or inflexible timing, but, in fact, it is much less *described* in terms of fatigue or difficult managing of a complex organisation, than it was by the respondents of former work-packages.

In the following tables you will find the distribution of our sample by country and type of double front of care (table 1) and the same distribution for the transcribed interviews we quote in the text (table 2).

As you will see from the data, more than half of the families (59) face an important double responsibility of care, and a smaller number (one fourth) are involved only in a light double front of care.

The greater number of interviews were made in U.K, Italy and Finland, a smaller number were transcribed and utilised in an in-depth analysis by N-Vivo program.

Table 1. Double Front Carer Families by the type of care burden: all the families

	France	Finland	Italy	Portugal	United Kingdom	Total
Light double front of care	3	4	5	1	11	24
Sandwich generation	4	6	3	-	4	17
Medium to important	-	4	6	3	3	16
More Important or Periodical burden	2	5	4	1	7	19
Very heavy double burden of care	3	5	9	3	4	24
Total	12	24	27	8	29	100

Table 2. Double Front Carer Families by the type of care burden in transcribed interviews

	France	Finland	Italy	Portugal	United Kingdom	Total
Light double front of care	-	-	3	1	-	4
Sandwich generation	4	5	3	-	2	14
Medium to important	-	4	4	3	1	12
More Important or Periodical burden	2	5	4	1	-	12
Very heavy double burden of care	6	5	8	3	2	24
Total	12	19	22	8	5	66

Table 3. Work arrangements of all double front carer families

Work	Regular working hours				Irregular working hours				Weekly working hours not available/ not able to define		TOTAL	
	Full-time		Part-time		Full-time		Part-time		Men	Women	Men	Women
	Men	Women	Men	Women	Men	Women	Men	Women				
Employees/ Subordinate Workers	1	32		23		2		3		5	1	65
Semiautono- mous collabora- tors/ Free- lancers					1			6		2	1	8
Profes-sional Workers	1	3		1		2				5	1	11
Seasonal/ Occasional Workers				1		1					-	2
Sub total	37		25		6		9		12		89	
Not working at the moment of the interview	Men								Women		11	
	-								11			
TOTAL												100

It may be interesting also to describe the working hours of the main caregivers by their sex and how they are affected by the involvement in the care task, even if diverse arrangement may be found in each type. In table 3 the distribution of the different kinds of works by the characteristics of working schedules is shown. One of the main evidences is the disproportion among the workers with irregular schedules: 13 on 14 are women and only 1 is a man. Another remarkable difference is the gap between full-time and part-time workers. No man has got a part-time work and of the 34 women part-timers about $\frac{1}{4}$ have got irregular working hours. With respect to other aspects -- like, for instance, the conciliation between care and work -- the distribution appears too much differentiated and randomized to allow us to risk some hypothesis. In the following table (table 4), instead, you can see the distribution of our sample by working schedule and type of care burden.

Table 4. Working time patterns in Double Front Carer Families by the type of care task for female caregivers working

Type of care burden	Regular working hours		Irregular Working hours		Weekly working hours not available/not able to define	Total
	Full time	Part time	Full time	Part time		
Light double front of care	9	6	-	2	4	21
Sandwich generation	7	4	2	2	2	17
Medium to important	5	4	2	1	1	13
More Important or Periodical burden	8	7	-	1	2	18
Very heavy double burden of care	5	4	1	3	3	16
Sub total	35	25	5	9	12	86
Not working at the moment of the interview	11 (of which 7 have an heavy Double burden)					11
						97

2. Attitudes and negotiations around the main caregiver role

2.1 Trajectories towards the double front of care

Unlike with childcare, the care of elderly or dependent adults seems to be characterised by greater involvement and negotiations by family members across a much broader network of relations, especially when the potential overburden of a double front of care is recognised by the members of the network. In other words, the need to provide care for elderly relatives seems to trigger a whole set of unique mental and psychological reactions, resulting in a higher number of active or potentially active caregivers, no matter if these complex negotiations may end in designating a few among them or even in accumulating all tasks on a caregiver only. This characteristic emerged in single parent families, dual career families, and immigrant families in all five of our country case studies, independent of the type of ‘informal welfare regime’ in place. It was not only evident in so-called residual welfare states, such as the UK, where we saw families shouldering particularly heavy and challenging care burdens, but also in highly articulated and extensive systems of social protection such as Finland and France. Finally, it was also just as prevalent in countries characterised by ‘familist’ welfare regimes, such as Italy and Portugal. In these cases the final result is more often the designation of a main caregiver, directly responsible of the organisation of the care network, but others can be activated in “shifting involvements”. As a matter of fact, most families interviewed, from Finland to Portugal, show a clear preference for informal and family care *before* asking for help to public or private services. They all seem very concerned by the elderly’s acceptance of outsiders, especially when they resist admitting that these latter are no longer completely self-sufficient.

A first interpretation, then, of the trajectory our participants follow in covering a double front of care is that it is characterised by greater familial involvement (whether symbolic or concrete) when the family member needing care is a dependent adult. In fact, in our case, the ‘double front of care’ refers not to the classic theme of the reconciliation between paid work and work done in the home for one’s family, but rather to a double burden—care on two fronts—that must be reconciled with employment. These families must not only arrange care for their young or school-age children, but also that for elderly relatives or dependent adults. Usually, the latter type of burdens are those that ultimately polarise the care arrangement.

2.2. Forms of Elderly and Adult Dependence: crisis and emergencies

There are a number of circumstances that leave families responsible for the care of a dependent adult or elderly relative. These circumstances might be sudden and unexpected, or else the foreseeable culmination of a difficult and more or less long series of events. In other cases, however, even the caregivers themselves have trouble identifying the exact moment when the difficulties associated with a double burden of care became perceptible.

At times, the transition to a dual care burden is sudden and abrupt. These cases are those in which a health problem (almost always of a physical nature) unexpectedly sets off the beginning of a prolonged period of care. In these emergency situations, families must confront the immediate care needs and have little opportunity to ask themselves what alternatives are possible.

Sometimes, as in the following case, the crises accumulate, and family members must put the rest of their lives on hold while they try to manage the emergency:

“Well, it got really bad, we went a through a really terrible period when everything was happening at once, there was my mother who was immobile with severe arthritis, and because she had a problem with her knee, and we asked ourselves if she had...I don’t know...well, to make a long story short, something that, in fact... (incomprehensible) ...but that anyway... And

so she was not able to get around, and my father, I think, he was trying to do too much. He went to look for this...well, there were a lot of problems. And from the time that no one wanted to bring in outside help, someone from outside the family, well, having overexerted himself, all that worry, all of this, his own problems, his age, he's got diabetes, he ended up having a heart attack. My mother called my brother, she was frantic...(incomprehensible) ...I, at that time I didn't go back to my house for 10 days, it was a Saturday morning. Just like that, I went out, I walked out on everything just like that! I was gone for 10 days". F - DB03

In other cases, the primary caregiver finds herself having to make important and dramatic decisions without having anyone else to consult, or else responsible, by default or delegation, for managing a difficult situation:

"(It was in) November '92 when my father-in-law was sitting in a bus and had a heart attack and was taken to Meilahti Hospital, and when I found out about it, my husband was of course out of town. And, well, I took his organ testament with me and left immediately to Meilahti Hospital. And there I stood by his bedside, he was attached to all these tubes, me and the doctors reflecting whether to make the final decision to disconnect the machines, or what. So, the following three weeks I took the train every third day and went to the hospital and saw to it that all the systems worked, and then reported to my husband about how things were, while he was abroad and all over". FIN - DB01

In other cases the shock of finding oneself responsible for a dependent adult is not the result of the unexpected worsening of an illness that is known to lead to decline, but rather of the young age of the newly dependent person. This is evident in the testimony of a young woman who remembers the first undeniable signs of her husband's degenerative illness:

[referring to husband] "It was sort of, like a shock really, you just kept sort of putting it off until he started getting these seizures, he said he lost, sort of lost consciousness, so I got really scared. Because he drives and is on the road a lot, and I said that good gracious, how, how does it. He said that they are only kind of short, short flashes. This was the first thing, you know, that I remember and have thought about now afterwards. But then when he was 52 he became, I came home from work and he was there and, you know, just stood on the kitchen floor and said that he didn't know where he was". FIN - MC20 DB

The sudden and unexpected nature of the emergency usually leaves no time to evaluate decisions and makes it impossible to do more than 'just go on and improvise', as one of our participants puts it.

"Well, my father got sick about four years ago, it was then that he really became senile; now, his arthritis isn't that bad, but it was because he went blind. He lost, he had already lost, he lost an eye in the war and then he got glaucoma in his good eye, so he went completely blind. This is what upset him so much, because, with respect to the eye, because, that is [...] in effect the blood doesn't arrive in his brain, but the doctors, his doctor who took care of him, they said that maybe he doesn't realise it, he was already quite old and he didn't understand that he had lost his sight, and that's why he's so confused now. Well, it was a little bit overwhelming because it all happened at once, he'd never been sick before... it wasn't at all gradual, it was all in the span of two or three months...it was a...a tragedy because he had always been so lively, an extremely vivacious person ..." IT - DB01

"They had just finished eating lunch when my father had a blot clot, he fell, he passed out and hit his head on the counter, it was my mother-in-law who called me, she called me at work and told me: hurry, come, the kitchen is full of blood, your father fainted" P - MC08 DB

"They reckon that everything started about 3 years before the diagnosis which obviously was having an effect on his outlook and our family life, but we didn't know. Then he was diagnosed

in March/April last year. And since that time everything has happened so quickly. *There hasn't been time to do anything, just go on and improvise*". UK - MF12 FU

"Oh, but I did have agency staff but that wasn't set up straight away because Mum had just come out of hospital in London.... I went up there (London) on a Bank holiday and she had just had a massive stroke leaving her in hospital for 7 hours of tests at the end of which they said she would need 24 hour care. [.....] But *it all happened so quickly* because I had to". UK - DB02

In this, as in other examples, the precipitance of the crisis cumulates in a grave lack of support, and in almost all five of our countries, regardless how generous the welfare regime, we found individuals who had experienced similar 'savage dismissals'.

"I don't understand the health policy in Vantaa [municipality], and it's probably the same way all over but. He spent a day at the clinic and was sent back home. 'Nothing's wrong with you.' Just back home the same evening, he hadn't eaten or drunk anything the whole day and they send him back home, and there, as it's the kind of service apartment unit where they don't have night-time care, and that's the reason why he wasn't able to live there anymore. Right, and he just made it there before, so that there was someone to receive him and put him to bed. So that Peijas [hospital] didn't care one bit, the person was in the same kind of stupor after a day there as he was when he came in. And they don't even try to find out if there's anyone to receive him and to what kind of home he is going. Go home, that was all, and this happened three times". FIN - DB04

"I couldn't leave her there, she would have climbed the walls there. I brought mom home around midnight and had a pretty tight situation, how could I go to work in the morning and leave this demented person here all alone, you see, mom had started to wander away from home" FIN - DB06

"... Then maybe this general thing that no one bears responsibility, it sort of annoyed us most, that no-one took the trouble to consider... ..all the doctors in my opinion.... So, well, it was all shifted onto the family members, many times in a very rude manner, so that even if society does have health care resources, it was still so that in every acute situation we were, it was never their business..." FIN - MC21 DB

"the lifespan is increasing, they go to the hospital for therapy now, not to be placed in a geriatric ward, like before...they go to be cured, and they are treated like that. They go and whatever medical condition is giving them problems is taken care of and then, like that, they are sent back home. The problem is that they aren't regular patients, and the specific problems of the elderly aren't taken into consideration" F - DB03

2.3. *Characteristics of Caregivers*

Independently of the level of care demanded by the elderly family member, or the exact configurations of the 'double front' caregivers must cover, four distinct patterns emerge in how caregivers come to be responsible for their role. In some cases, caregivers assume caring obligations on two fronts because they see no other possible alternatives. In other cases, caregivers are personally selected by the person in need of care. A third pathway leading up to the role of primary caregiver is shaped by family history, or the preferences of other relatives. Finally, some caregivers assume their role voluntarily, as an individual choice. The last three, especially the second and third ones, are examples of 'designated caregivers' (see Finch 1989): here, the caregiver is chosen, either by the elderly person him/herself, or by other relatives. This designation may seem counter-intuitive when the caregiver already has other caring obligations, such as to his or her own children, and 'unnaturally' trump justifications to be excused from the

care-giving role. Although the borders between the four types are not immutable in time, the patterns are clear enough to serve as organising vectors for the vast archives of documents and testimony that we have collected.

2.3.1. Caregiver by default: 'chosen' by the circumstances

In these cases, speaking about a relative lack of alternatives does not mean that no practical alternatives actually exist. Instead, these alternatives are either not seen or are found unacceptable by the caregiver. In effect, the caregiver and her/his family--if they are present--accept, endure, and even perceive the situation as it stands, but never really make a decision about it. It is instead the circumstances that decide. These circumstances might include physical or geographical proximity, whereby it is taken for granted that an occasional caregiver would become, when the time came, the principle caregiver. The degree to which families do not question this trajectory is very interesting.

"Because we live the closest. Whenever they have to go to the hospital, I always take care of it because my sisters live in Rennes, and since they both have jobs, they are not very available".
F - MC08 DB

Over time, this same participant appeared to have so thoroughly 'rationalised' her role that even the most minimal feelings of injustice had disappeared by the second interview:

"Q. Were there any particular reasons why your mother came to live at your house, instead of with your sisters?

R. No, I was close to my mother. No, I don't think so, no.

Q. When you say that you were close, do you mean that you have always got along, that you understand each other?

R. Yes, yes yes.

Q. Because you also lived near each other...

R. Yes, yes, that's how it is, yes". F - MC08 FU

Other considerations, in addition to geographical proximity, also come into play (such as a specific sense of obligation or duty to previous generations) that 'trap' the caregiver into immediately assuming responsibility for taking care of the elderly person, aside from objective circumstances that might have also made it inevitable. This was so for the following participant:

"It just went so, because I was the only close person. There wasn't anyone else around to resort to. Except for those you can get against payment. That was the principle anyhow, if we take into account that, that, well, both my parents and my parents-in-law belong to the generation who is, you know, who think differently. [...] If I think about things in retrospect so, so, well, yes, I have, too much. I should have been more selfish. But it was, it was so much dictated by the circumstances, it would have been awfully difficult to act in another way". FIN - DB01

Accepting the role of exclusive caregiver as the only possible alternative is an especially common situation for immigrants, as other family resources are often unobtainable:

"Well, that's how it will be then. There's no one else. And if you think about it, mother is in Estonia and they can't get there. They'd need a visa and everything and it all costs money. And since they don't have money. It's only me who's taking care of mother". FIN - MF25 DB

In other cases, the caregivers seem to avoid fixing a precise moment in which they were designated to handle the double front. They instead recount it as a series of choices that they

took for granted and that appear as inevitable only in hindsight.

“When we finally had to confront it I had to go sleep there because the aid wasn’t there during the night, there are also other periods when she’s not there; and if my brother can’t go I have to. I also have to take care of emergencies, there’s no discussion about who handles the medical emergencies, for example, going to the hospital in the ambulance, the four or five times that she’s had to be hospitalised, or talking with the doctors, that’s my job”. IT - SP01 DB

“I was the one who had been looking after her and we had been living with her”. P - DB01

Obviously, only children are particularly caught in these types of care arrangements, and the effects of the horizontal diminution of the kinship network are already visible in Southern European countries:

“I didn’t have a choice. I am her only child, and she was an only child” IT - DB04

2.3.2. The ‘chosen’ caregiver: caring on two fronts at the request of the dependent adult

In these cases it is the preference of the elderly family member that carries the most weight, despite other possible alternatives. This arrangement typically plays itself out in two ways. In the first, the person needing care behaves as the decision-maker, tout court, over who is established as his/her caregiver. In the second, the person being cared for is actually a quite difficult and demanding charge whose intractability interferes with the execution of even small daily tasks and makes the care arrangement even more complicated for the caregiver. Often the expectations of the elderly family member are implicit in, and more or less encouraged by the circumstances:

“Certainly, she decided that she would never live alone when she was 56, she was widowed at 52, when I was only 13. I was the youngest of four sisters, and as time went on they all got married and went off on their own, and I was left alone with my mother, we were terribly poor, really desperate. I was working in a chemistry lab, and my paycheque wasn’t enough for the two of us, and my fiancée, who was absolutely devoted to the both of us, the two of us decided to join forces and get married. [...] I did it because it is important to her, and it makes her happy, but it cost me a fortune, I didn’t think about it, I did it gladly, because I know it pleases her, I thought that it was right to give her this gift, my sisters instead they’ve not been at all involved”. IT - MC20 DB.

An elderly person’s refusal to compromise and accept alternative care-giving arrangements is often in relation to the prospect of involving strangers in his/her care. This reaction can be seen as a defence of what little autonomy he or she has left—an autonomy that could be seriously compromised if someone from outside the family assumed the role as main caregiver.

“It is difficult to bring someone in who she doesn’t know. So for me it’s...for me it’s [?]” F - DB01

“Right, and they won’t go to any place where they would be cared for. They want to cope by themselves. [...] [I: Right. In other words, your father probably has a pretty big impact on the decisions that are made?] R: Yes, he does. Right”. FIN - MF26 DB

“On the other hand there’s the fact that she doesn’t want people around who aren’t part of the family, who she doesn’t know, and so we have this problem of finding someone to help, we’re struggling because she refuses she would refuse to have someone, an immigrant or a person,

even if we could find someone who would stay there from morning 'til night, which is what we are afraid we are going to need". IT - SP01DB

More explicitly, family members recognise the right of the old person to refuse institutionalisation in nursing homes, or long stays in the hospital:

"(She) doesn't want to end up in a nursing home, and that's understandable...It's better in her own house, and [...] And then...I was saying, we could always put in a 'bip' or something, but that wouldn't make much of a difference. [...] She doesn't want it, she just doesn't want it. She's not exactly easy to convince, no! ... (smiles) Oh my no, oh no!" F - MC01 DB

"Mum was sort of clinging on to me and saying 'oh, don't leave me here.' So I signed the form and brought her home". UK - DB02

In other cases, when in addition to physical health problems the elderly person also suffers from psychological disturbances, the demands of the cared-for can grow quite severe and inflexible:

"For example, feeding my father, no, no, he is really [...] only us, because, or a nurse or, because, that is, he can tell; maybe with...him (refers to her husband who goes to feed his father-in-law) he's better at it than the rest of us because my father is extremely touchy, and if he senses a hand, a hand, or a manner, because he does have moments of lucidity, and he gets angry. He gets upset with me the most, I, I...{Husband}: Of course, since he can't see us anymore, he just instinctively, at this point it's mostly instinct, the person who is there with him becomes fundamental; so, if that person is nervous or tense by nature...[Wife]: Yes, I'm tense. In fact the nurses have commented about it, no, because in general, to feed him, yes, I do it, my sister, and him. Because even my brother-in-law, being a bit older, he has another...another mentality; he, being younger, it's as if, that is, with him my dad is... he's the best of all. I don't know why; and then after he's eaten he'll even say 'Thank you, Michael'; he'll say thanks to him, to me, no." IT - DB01

In other cases, preserving the elderly person's right to choose ultimately seems dysfunctional and self-destructive. The same participant notes this, but this time in reference to the other elderly person she cares for, her mother:

"[Wife]...I say, 'but mother, don't you want a woman to take you out?' 'Oh yes, and who are you going to bring into my house, a Peruvian? what, I don't want anyone in the house'; I don't want anyone else here'. This is the problem. I suggested 'an hour, just for an hour you could do it', because the doctor told her 'Mary, don't just sit there at home; get out of the house', there's a social club nearby, 'go there,' even on foot, just to get out of the house. But nothing doing, she's stubborn, hard-headed, like this, look, [knocks on the table]', just like that, hard as wood, no? I say 'mamma, look, you're becoming an invalid, if you don't walk a little you'll become an invalid'; but she won't listen." IT - DB01

As time passes, whether the elderly person is aware of it or not, these kinds of attitudes can become signs of extreme and authoritarian egocentricity:

"From there I stop to do the daily shopping, I go then, that is, because my mother wants it fresh, so every day I go to buy her bread. Never mind that I also make it at home, but you know, even if I bake bread once a week she always wants it fresh which means I have to go shop for it, I have to buy it for her. Nothing, afterwards I get there around 10:00 or 10:30, I go out just before 9:00 to take my little boy to school, I leave around 8:40, 8:45 to get to [an infamous neighbourhood in Bologna] because he has to be at school by 9:00. It depends, I get here, then at 10 or 10:30, I have to make her tea, because she, it's one of her[...] she has to drink her, we

absolutely have to drink tea, she calls it her second breakfast, I have to make tea with something else that she wants to eat. Then, well, I start preparing lunch". IT - MF27

This happens, sometimes, even when the caregiver has his/her own health problems. This is the case of a Finnish woman, suffering from heart disease, whose parents didn't accept her gradual retirement from their care:

"...University Hospital social services arranged it. So they had to accept home help then. But that was their reaction, they didn't even consider, they simply blocked out the whole idea that I could be ill, they just insisted that I should continue it" FIN - DB06

Some dependent adults or elderly persons, though not being excessively authoritarian or tyrannical, sometimes create rigidities in the care arrangement because they prefer one caregiver to another for certain types of assistance, such as personal hygiene. The following testimonies illustrate this point:

"He would rather have my husband. Because he still has days when he is completely lucid, he would be very embarrassed if I were the one to bathe him. For him he always wants his son". P - MC09 DB

"[...] Well she is kind, she seems like that kind of woman but it's also true that...well, there are certain things, she doesn't want to go in a nursing home, she doesn't want help walking... There are things that she refuses. It adds up, you know... [...]... The washing machine (for example), she doesn't want anyone but us to run it". F - MC01 DB

In a second interview several months after that cited above, this participant stressed the difficulties of managing not the practical elements of care-giving, but rather the challenges of handling her mother's difficult personality:

"Yes, but I don't know if she really understood that is; and then she said 'I'm not leaving' and we told her: 'You know you don't have a choice'. [...] She didn't want any more of it. Then she went for a check-up, and we had trouble getting her in there. She said 'I'm not going there.' Fine, I said. 'Where will you go now? To (Stock?)?' 'Oh no, I won't go there'. Aha! ... My brother and I asked each other 'what are we going to do?' [...] Alright, we agreed, 'We'll take things into our own hands, and then we'll see how it goes'. And so I said 'Do you want to go into a nursing home?' And she replied 'Ah, well, this, no, definitely not!' (the interviewer laughs) [...] [...] But look, it would be simple to arrange if she would just let us take care of it, if... I'd say when you're dealing with an old person that lets you...that lets you make the decisions that, well, you can even manage to organise things very well. And so I said to her: 'Give me the shopping list and the laundry bag so I can wash your clothes'. But she never has her things ready, do you understand? So every time I stop by it takes at least half an hour to [...] Yes, this is the problem, it's easy...from a practical point of view it would be easy to manage. The problem is that you also have to put up with her character, and she has always resisted our taking over these things' F - MC01 FU

2.3.3. The negotiated caregiver: caring on two fronts at the wishes of others

In this case, the main caregiver is 'chosen' by other relatives who, though being present, are not involved or are only minimally involved in caring for the elderly relative and cannot be considered as viable alternative caregivers. Unlike with the first type of caregiver, who assumes her/his role for lack of other alternatives, it is understood that the principle caregiver in this case is designated after a certain amount of implicit or explicit negotiations with other family members.

At times the final outcome of such negotiations is a smooth and peaceful transition based on 'objective' circumstances, such as personal affinity with one family member or personal conflicts with another, the ease with which the caregiver can reconcile the care-giving with her/his job, or particular family arrangements. In other cases, the agreement is only formulated after much discussion and compromise:

"...but of the seven who remain, no one...well...no one wants to hear about it (smiles) and none of them can stand her. Because, well, my brothers and sisters are... I hear from them more often, now, ever since I bought the house...but they can't stand our mother, because mamma, she's got a personality..." F- MC22 DB

"There is also my brother and my sister, but they aren't involved. My brother lives in the Chianti and my sister is in Florence, but she works all day and doesn't have much time to take care of mother. I work, too, but three days a week I only work mornings, and my mother lives alone and I call her to make sure everything is fine". IT - MC25 DB

"Well, ever since mom died and even before that, I've tried to visit him twice a week, but pretty often it now shrinks to just once a week, which does bother me a little. But I do go on Sunday afternoons always, it's a regular thing, and then I try sporadically, or I try to go on Tuesdays in the middle of the day, but I don't always manage to do it. But it's all I can do, I can't go more than twice a week, so that that's my share. And my sister visits him twice a week too, 'cause she's alone, she may drop in more often, a third time. And my brother's wife goes there occasionally, but not in the way, she can't right now take part in the way we'd like to ... my brother's been ill a lot so we've decided that the matter's clearly between the two of us". FIN - MC21 DB

When other family members offer little or no help to the 'chosen' caregiver, the care-giving arrangement can become extremely burdensome for the main caregiver, and fraught with conflict:

"My mother-in-law has lived with us for the last year, before she was living with her daughter in a rented flat, but then they bought their own because they had to leave that apartment. Since they couldn't afford a big house, she moved in with us, we have an extra room, the one where we usually store the bicycles, all the things that a family accumulates, we slightly remodelled it and put the grandmother there, but it's really not a very good situation... [.....] We haven't received any help from our relatives because my sister-in-law has two other children; they've shifted it all onto us..." IT - MC14 DB

"Very indignant of course. As I usually say it really disgusts me, but, as I do not want to become upset, I try not to think about it, but there are times when I feel like shaking them. I can't understand, because my father at this time needs all his children, why should be just one caring for him ". P - DB02

"[Referring to one of his brother] ...And well, and last summer, a year ago when I didn't seem to get hold of him, he has a cell phone, but I didn't seem to get hold of him on that either and, and, well, and we didn't really have any way to talk with each other and. And he's sort of a hermit anyway, he doesn't like to be disturbed. So a couple of times I decided that I would send him a text message, he would read that anyway. And I sent him a couple of text messages, telling him that, hey, since you've been seeing dad for ten years, and dad has pampered and adored you and, well, and, and the rest of us, we have sort of envied you for being pampered by him like that and, well, so could you at least visit him, because he keeps asking for you. He had by that time moved to that old people's home. [.....] So I sent two of these text messages, and then I accidentally saw him a year ago in July at dad's, he had suddenly appeared there and, surprisingly enough, I happened to come at the same time, so he said to me that, listen, if I get one more of those harassing text messages, I will send the cops after you". FIN-DB04

2.3.4. *Choosing to care on two fronts: the voluntary caregiver*

Finally, some of the principle caregivers we interviewed explained that they had freely (and sometimes happily) chosen to assume exclusive responsibility for their caring obligations. Among the various intervening factors, the element of individual choice is that which prevails above all others. Here, the factors that determine the conditions of the double front of care are less related to the wishes of the dependent family member, or other relatives, than they are to the personal and subjective characteristics of the caregiver herself.

In any case, care-giving arrangements in which one family member holds exclusive responsibility are sometimes the result of nominal negotiations with other relatives (who do somewhat participate in the care arrangement), and in general resemble the ‘classic designation’ even when the participant couches it in terms of a personal choice arrived at over time and in certain senses, enjoyed:

“I think I was a kind of mediator, you see, in the family, in my childhood family, it's totally. And the others probably thought that it's good that she's taking care of things, so they don't have to so much. But we didn't talk about it ever. [...]

And I was a mediator between mom and dad and I felt that I little by little became a sort of, so that when I still lived at home I already started to take on the role of mother more than the others, even my mom used to say that it's time to buy a new coat or hat for mom and. And my sister is ten years younger than I so, so I somehow took care of her too and took her to her activities and to the dressmaker and ...to school and stuff ... in a way I liked it”. FIN - MC16 DB

In other cases, it is portrayed as the outcome of important caring decisions made many years prior:

“No, rather, I think that we had...that we had prepared everything for this baby, so I told myself that somewhere there was probably a child that also needed us, I on the one hand I needed him and on the other hand maybe there was a little boy who might need us. So we applied with DDASS to become foster parents. We had agreed after a lot of thought, because it seemed strange to them. At that time my husband was teaching, I was a psychiatric nurse, we didn't have children, we had just lost our first child, so then we asked ourselves ‘my God, what are we getting ourselves into?’ It wasn't at all obvious. But in the end we did it. So, well. [...] William has autism. The psychologist at C., when we visited him, warned us ‘you know, I think that you are taking someone who will be sickly for the rest of his life.’ Fortunately it hasn't been that way. I think that together we have made important progress. It's still not enough, in my opinion, but... And then, in fact, it's true that William has absolutely monopolised our attention, I was so caught up in him, that I, well, so I forgot that I could actually get pregnant again. Then, when I found out that I was expecting, I was more concerned with William than the child I was carrying’. F-MC23 DB

Some participants expressed a clear and explicit desire to not delegate care to anyone but themselves:

“I wouldn't like to include any outsider in this, stirring things up. Since this has started to, this system of ours works well, so that, so that it feels that an outsider wouldn't fit into this. As long as I'm healthy and my condition is this good”. FIN-SP13A DB

The following examples illustrate how care is sometimes understood as a ‘private’ and familial activity that precludes delegates—in so much as it is possible—and is based on a clear conception of family exchange relations:

“[Do you think caring for the elderly is a family obligation or else the responsibility of public

institutions?] Of the family.[Why is that?] Because in the family you are bound to each other, by affection...I don't think there is much support for the State to provide all the care and then I don't believe that hospitals can become collection zones for old people...the elderly need to stay with people, at home.. there's not [support] I don't think there's support for that" IT - MC 01 DB

"I think I'm a great believer in family values and feel it should be the family for a lot of reasons. I think there are occasions when society falls down because it hasn't got a lot of those things in place or they are not accessible. I think there are a lot of services that are available that people don't know about and unless you what to ask for you don't find out what they are. If a Mum, a single Mum, is ill and doesn't have anyone around to help there are ways that Social Services can help, but that Mum probably doesn't realise it. So she's not aware that she could get some help whether to take her children to school or someone calling in to do something for her. There is all sorts of things". UK - MC08 FU

In some extreme cases these caregivers end up leaving their own paid jobs so that they can better care for terminally ill family members:

"When my mother came out of hospital, she was very unhappy there, and I knew she hadn't got long to live. I wanted her to be happy for the little time she did have left so I had to give up my job. It was the only way possible really if she was going to be able to come home" . UK - DB01

Other caregivers locate their greater responsibility in the particular position they have historically occupied within the family:

"My mother was already 46 years old [when I was born], she had health problems then, she had angina, and she was obese [...] when I was very small she used to take me to work with her, she was a maid and she took me with her, I went to work with her [...] I've taken care of elderly people for my whole life...because my mother, compared to me they are much older, it's a very big difference, you know. Because they've always been very dependent on me..." P - DB02

In some cases, the crises associated with the worsening health of an elderly relative can be predicted and the challenges of caregiving on two fronts are foreseen. In this sense, the health problems of the dependent adult/elderly person might entail the worsening or intensification of a degenerative process, or the emergence of new pathologies (often in the form of psychological disturbances or depression) in the person being cared for, or his or her spouse.

The following illustrates a typical case where the person being cared for, after a long period of unstable health, suddenly exhibits signs of rapid decline:

"She's hanging on fairly steady but in terms of her mind, there's a little...a little...she's gone a bit downhill there, too. It's as if...well, now I notice...I was telling my husband the other day...uhm...it's like she waited to turn ninety to... [.....] There was a decline right after her ninetieth birthday. Time goes on, I don't care. It's ...it's... But I really do see that she's not her old self anymore...she's a little senile. My sister said to me once, the last time that I saw her she said 'Oh, she got old all of a sudden!' She's lost her edge, you can really tell in the photographs. There are some differences. The picture from her ninetieth, she's still straight on her... Oh yes, you can really see the difference. The day that we brought the bed in, I told myself: 'Well, here it comes...We can't go back anymore.' Because she already had been bed-ridden once before about twenty years ago, maybe ten, I don't remember, well, she's quite old... and we knew that time that it was only temporary because well, she had had phlebitis, we had to be sensible, so we had already got the bed back then. So I, I sensed that this was coming. I was aware of that moment, and I said, alright, this is it ..." F - MC22 FU

In some cases the worsening or the beginning of true decline in the physical and/or psychological condition of the elderly person begins immediately after the loss of a dear one. This is often seen in elderly couples who have long depended on each other for emotional and physical support,

even when their own self-sufficiency is limited. One of the two might find him/herself unexpectedly alone and without any apparent reason to go on. In this way the death of a spouse marks the beginning of a rapid decline and produces, for the carer, a series of one caring obligation after another. The characteristic regularity of this rapid transformation is striking, but the warning signs, often evident in hindsight, are usually ignored.

"[...]...because ever since my mother died I think that he...to me he seems depressed. I think that he suffered a very deep depression. Now it is like he's at rest...He had been so overwhelmed. All of his time had been taken up caring for my mother, taking care of her illness, all of the many problems, that when he suddenly found himself all alone, overnight, there was a huge void...[...] And then, he had this episode in which he lost consciousness, and there didn't seem to be a physical reason, he went into a coma, but they couldn't figure out why. I had gone home for lunch, and I saw, from a distance, I got there and I saw the ambulance, the SAMU parked out in front of our house. [...]...I had just got home from work, and I found my father like that... the General Practitioner that we know well, we've known him for a long time, took me aside and he told me 'listen, we still don't know very much, but evidently he passed out, he's in a coma' [...] My father didn't have any health problems. His cholesterol was a little high, like everyone else's in the family, but nothing really serious [...] He was in the hospital for five weeks, they examined him, they gave him so many examinations, but there was no clear reason for why he had fallen into a coma. It could be that it is Alzheimer's. It must have started about two and a half years ago. What I want to say is that I was so wrapped up in my mother that I didn't realise that my father was starting to deteriorate." F - MC23 DB

"Oh yes, definitely. She was more self-sufficient. But when my father died, she became more psychologically dependent. So it's already been [...] The last time I went to Rives she wouldn't get out of bed, the doctors didn't even feel like coming any more, she was completely...well...and then her apartment was on the second floor, and so on. Her sister-in-law would go and she asked—the one who had a tumour—but why is she like this? Well, at that point I tried to make sure that...that there would be someone who would prepare her meals for her. Fine, or at least someone who would go to give her something to eat but...humph...she refused to eat half of it. So it wasn't possible, she wasn't feeding herself anymore, and like that, not eating, she became unreasonable. No, we have to watch that she eats, keep an eye on everything, you see." F - MC04 DB

"My grandfather was 88 years old and he would still get up every morning, wash himself, get dressed to go out, and then take a walk, or stop by the print shop that used to be his, to see how business was. But from the day my grandmother died, he went completely downhill. A year later he was dead." P - MC01 DB

"... after my father's death the situation worsened. Surely my mother, who had always been an housewife, she worked and worked but always in the home, she lived in my father's shadow. When he died the situation collapsed, my mother missed everything" IT - DB04

In other cases, ever more frequent health problems and physical weakness, or the worsening of pre-existing conditions, often send the elderly person spiralling uncontrollably into irreversible decline.

"Well, illnesses in the sense that father had this he's always been a bit of an invalid in the legs he had to have a knee surgery, as his knee became worn out and he had to have it replaced by an artificial joint. And then things have happened little by little, he's had accidents, like he fell when his legs failed him and he never recovered fully, so he had to use a wheel chair. So, he's been confined to a wheel chair then, or more or less confined to a wheel chair, let's say, the past three years..." FIN - DB08

“Thing got worse last year, because in addition to all of my mother’s other problems, she also had to have an osteoma, which psychologically, in terms of her morale, was really a blow... Last year she weighed thirty-eight kilograms, now she weights fifty-one: she’s really a fighter. She’s also got rheumatoid arthritis, it’s in all of her joints; she spent two years in bed, when I was young: she’d move from the bed to the sofa, I remember that I went through a rebellious stage, when I was about fourteen, and so I really understand what kind of life my father had.” IT - MC07 DB.

“She was in hospital and she had operations, then she came home then she went back again. [...] ...I thought my mother would live to be a 100. Her mother lived to be a very old lady and was as tough as they come [...] How did it come about. Well she had what she thought was a tummy bug. I can remember it clearly because we were going on a day trip to France and on the day I had a call from another relative to say that my mother didn’t want me to know in case I worried but the doctor had been called as the tummy bug hadn’t gone away. It turned out to be cancer. What happened was that the cyst on her ovary got stuck to her bowel so the tummy upset was the first indication. [She died in hospital?]Yes. In fact she got back into hospital because I was on the point of collapse.” UK - DB01

The cases in which psychological equilibrium begins to decline, or in which there are actual neuropsychiatric disturbances, are different. In the following, a participant recounts the slow transition of her father towards what appears to be senile dementia. Her testimony illustrates how these changes pose more challenges in terms of relationships than they do in terms of practical care, though being just as difficult to confront.

“...He does, in the same one, yes. And well, he’s having the kind of phase that we don’t know if he’s becoming demented too, or, or well, if he’s just having these delusions, but he ... already before Christmas started to think that we are stealing money from him and, and he kept calling me at first before Christmas, saying that he’s lost a hundred thousand so can you come here, in the middle of a working day. And well, one time I then took a cab and we went straight to the bank, right, nothing’s missing and he ... he has been ... he’s been reflecting on me, that I have taken money from him. He’s started to have this kind of ... and so. Some time ago ... distance ... Let’s see if it’s like this that, that it’s only a delusion, or if he’s becoming demented. So that it will again, again be such an unreasonable ... not another one any more. But he is really old, so that it’s clear that the brain is sort of anyway, but he has been very alert, alert up until now, even though he is ... So that I always say that I have two very different ageing parents, one, mother was 82 when she died and father is already now older, and been so sharp”. FIN - MC16 DB

For others, handling elderly family members’ mental problems, which require constant attention and usually worsen with time, is such a challenge that they must seek out external assistance, which in these cases is very difficult to procure.

“D. Have you always been able to find these people, the women you’ve paid over the years to watch the children and your mother, have you always found them yourselves, through newspaper ads or by word of mouth?

R. No, we’ve always found them on our own, it’s very complicated, it was very difficult. Well, for the children I wouldn’t say that it was that hard, sometimes I just put the word out with my friends or the woman that I had before this one I found her through our parish, I asked if they knew anyone and they sent me this girl. But for my mother it has been an absolute tragedy, the hardest part about finding help for my mother is the lack of information, that is, you don’t know where to turn, who to ask. [.....] It was such an ordeal for me. I must have made 100 phone calls to find something out.

D. Did you try these employment offices?

R. No, I only found these day centres run by Caritas, but even there...because since I work days, I try to take care of things via the telephone, and maybe that’s why I had such a hard time

finding someone, I don't know, but not having time I should have taken some days off to look and so I went about it in a very round-about way, it took a very long time.

D. How long did you look?

R. Well, it took some months, I remember that it took a long time, maybe a couple of months, I couldn't find a suitable person...." IT - DB02

The following example also helps us to illustrate how caring for someone with deteriorating mental faculties is different than caring for someone who simply needs help with the normal activities of daily life, such as bathing, cooking, and enjoying social activities. Once more, the involvement of the caregiver is more psychological than practical:

"We'll talk about K's Mum and she said she wouldn't be surprised if she hasn't got senile dementia starting. So we are going to have to look at that now. She is, apparently, showing classic symptoms, repeating herself, not remembering things that happened yesterday or last week but she's remembering what happened years ago. For the moment she's quite mobile and able to cope at home with lunch club once a week and Age Concern twice". UK - MC08 FU

Finally, there are several incidences in which pinpointing the exact beginning of the caregiving crisis, or even diagnosing the illness leading to the crisis, was far from easy for our participants. Often, the main caregiver has a sudden realisation that even though the situation had been serious for quite some time, all of its signals had been dismissed. It appears as though some episodes constitute a sort of 'socialisation' to the dependent state of the family member.

"You can't really say when it really started. I myself realised it when Manon was born, but [participant reflects] before that, there had already been some problems. [...] my mother ran off one time, we searched for her for the entire night. The police were looking, the police dogs...." F - DB01

For other participants, the indefiniteness of the beginning of the crisis, along with the problem of correctly managing care for the older person, stems from a bad relationship with the health system. At times these caregivers do not even have an exact diagnosis to work with.

"Do you know, I can't really tell you the name of his illness. They've run test after test after test on him. And stuff. Let's say I have the flu, so everyone knows I have a running nose and a fever and a cough, but he's paralysed, and he never had a stroke. He just lost his ability to move in two years". FIN - DB04

In these cases, it is not only the physical and mental health of the elderly person which is at risk, but also the psychological well-being of the caregiver. These individuals, such as the immigrant woman below, risk deep feelings of frustration and impotence.

"My mother has had some tests, well they said that she is, that she has amnesia, because she doesn't remember things. She doesn't believe me when I tell her that I am her oldest daughter[...] Then after we'd take her two or three times a year we'd take her for tests; in the end they told me: your mother, it's that your brain begins to.... unfortunately we've just left her at home, I haven't taken her back to the hospital, because they always ask me, they say that the problem is with her mind, there's nothing they can do. When she got here, she could walk, she could walk very well, she was fat, healthy, just right. Her mind was still clear, she could understand things, respond; but the problem is that she doesn't recognise that I'm her daughter; she says 'my daughter, they are all dead, I don't have any children'. She has lost her mind. No. Then I said 'I am desperate, my mother doesn't recognise me' I took her right away, immediately, to the hospital. Yes, and then she was even worse. So then she went back home, and then she came back, she doesn't take any medicine, why should she, she sleeps well, what good is medicine?..." IT - MF31 DB

Another recounts the difficulties encountered with her father-in-law, who suffers from Alzheimer's:

"My father in law has Alzheimer's. He was diagnosed with it in November. After all of these years we finally know that it's Alzheimer's Disease [...] It's a very light form. Let's just say that we started to complain, and we told ourselves that it must be arteriosclerosis. Back then they thought everything was arteriosclerosis. What were the signs? He started to talk about his mother a lot. I knew that a person with that kind of illness goes back in time, often very far back... And he started to forget things like if he had had lunch or not, and he would get mixed up about where he had put things... Then I started to realise that he was behaving differently, it was strange, the things he was saying and all and then I heard about these special clinics for the very old. I decided to schedule an appointment, because given all the things I had noticed and after talking about them with some friends at work, it seemed to me that he had Alzheimer's Disease. But since I didn't want to just rely on my own opinion, I went to our family doctor, and I told him how he had been behaving, and he agreed, yes, that we should have some tests done". P - MC09 DB

As is clear from the testimony, each case is quite unique. Thus, information on the forms in which the care crisis manifests itself, or even the characteristics that define the state of dependence of the person being cared for, do not greatly facilitate the development of a clear typology of the trajectories caregivers follow towards a double front of care. What is evident, however, in every case, is that the inevitability of caring for elderly family members, along with the specific connotations of 'elder care', restrict the range of options caregivers have in deciding how to meet the double front of care. Importantly, these restrictions are not just logistical, but above all highly symbolic. Here the difference between elder care and child care is stark. With child care, the support network is much richer in alternatives and back-ups, especially external to the family, and care arrangements can shift without causing too much disruption to the family. In contrast, the need to care for an elderly relative seems to reduce the possible solutions to two: 'I'll take care of him/her myself', or 'Someone else can take care of him/her'. But the range of alternative care arrangements available to these 'delegates' (within the family network) is much more limited and often has greater consequences for the individual autonomy of the person left with the responsibility. The choice between *exclusive care* and *delegation of care* (even partial) often produces serious problems of reconciliation between paid and unpaid work, and in some cases leads to the sacrifice of a significant element of the caregiver's own personal and professional life. Furthermore, the extent and duration of the caregiver's obligation is not well-defined beforehand, but is instead wound up with his or her own sense of obligation and duty and the urgency of the circumstances leave little room for postponing any decision.

So we could say that the main sources of stress in the family caregiving are the nature and quality of the relationship between the carer and cared for, the range of behaviours from the cared for (manipulative, overdependency etc.) and the adequacy of financial resources. (Nolan, M. & Grsnt, G. & Keady, J. 1996)

Caregivers' ambivalent feelings about temporarily sacrificing themselves to care for elderly family members who may not have much more time to live is well-expressed in the following:

"For her I think it is the best solution but for us it is the worst... But we also take into consideration that we still have many years to live, and no one knows how many she has... so we chose the best solution for her, thinking of her, not of us. It's a nightmare for us having those two here at home". P - MC01 DB

All of the above takes us back to the theme of the designation/destination of the caregiver, and leads us to the next section, where we will attempt to better explain them through their trajectories and activating mechanisms.

2.4 Ways of accepting the designation as the main caregiver

As we anticipated, (par.2.1,2.2), a number of the mechanisms previous literature has identified as part the designation of the main caregiver emerged in our sample, and we sometimes observed that ‘once a particular relative has taken on the responsibility for the care of an elderly or handicapped person, they get rather limited support, if any from other relatives’ (Finch 1989, 27).

If we examine the classic hierarchy of obligations that seems to regulate ‘who does what for whom’ in the care of elderly relatives (Qureshi and Simons 1987; Ungerson 1987), we see that, even if in our case we cannot observe the well-known role of unmarried daughters, because all of the families we interviewed have children, the importance of the spouse and the children—especially those still living in the home—is regularly confirmed by our participants. In addition, gender imbalances in the care of elderly relatives is also evident, perhaps most clearly in the Portuguese case, where sons often tend to delegate the care of their own elderly parents to their wives. Interestingly, however, there is great variation across the five countries in terms of the relationship between birth order and being designated the main caregiver. When birth order is mentioned as a factor, it often seems more a justification in hindsight for much more complicated negotiations.

"[Q: How did it happen that you decided to take him in here, and not in Piedmont or...] Well...*because I'm the eldest, I've already raised my family, the others have smaller children,* a more recent marriage, so it seemed right to me that he would stay with us, and then he just adores my husband, they get along really well, really better than a father and son would..." IT - DB02

"As the *oldest daughter* I suppose I feel responsible for carrying the burden of caring for them in some way". UK - SP02 FU

"*Being the youngest...it's like, we've shared more;* of course she loves us both, but my sister is a lot older than me, she's 14 years older than I am. So she wasn't in the house as long, instead, I, partly because I got married late, partly because she was with her, well, in practice...it just ends up that I do a lot of things for her" IT - DB01

"I was so close to my Mum and Dad *being the youngest and being 10 years younger than my sisters, I was the baby* and they were protecting me as a baby". UK - DB02

There are other cases in which the designation seems based on completely objective criteria. Only-children, for example, or people who cannot count on the availability of enough resources to use private, paid services are obviously confronted with such responsibility.

"She's been sick like this for 23 years, I, I was still single when the symptoms first appeared, then, because I am an only child, and she owned the house, but my mother needed help, so when I got married I decided to stay in the same house with her, in effect I never left home. But it seemed normal, we both wanted it " IT-DB06

"I was married and already had my little girl [you still lived at your parents'?] Yes at my parents' because she [the mother] needed my assistance. And I never went out". P - DB02

In other cases, there might be one sibling who, being more available than the others (for reasons such as physical proximity, age or greater free time), finds himself or herself assuming the caring obligations almost "by default".

"...It's probably because mother was there in the country and none of the other siblings even went there [...] That's probably why it became my task, because I was the only one who went there and saw the situation". FIN - DB10

As we already highlighted, in these later cases the caregiver has little choice but to understand the 'legitimate excuses' of all the others (Finch and Mason 1993).

It seemed more interesting and useful to us to try and trace the trajectory by which main caregivers explain not the objective designation, but rather the perceptions that they have of it, and the ways that they describe it, in their own words. In many cases, as we have seen and as we will see, the psychological burden and stress associated with a double front of care is much greater, and much more difficult to bear than the material obligations, when the caregiver is isolated. At times, as in the example that follows, just the thought of such exclusive responsibility for the commitments and duties of care is enough to cause significant anxiety and worry, even in a child aged 9, who already worries about her mother's future and can imagine herself as the designed caregiver :

"So what about, what will happen to me if something happened to mom? My sister had moved away from home at that point and my brother had just got married, you know. What I concluded in my little head at that point was along the lines that neither one of them might want to take care of me if I was left alone. (...) It was this kind of fear, like small children often have the kind of fears that they don't dare to share with anyone, not even in their dreams. I just kept worrying about it in my mind". FIN-DB12

As we will see, if we examine the psychological attitude of the caregiver in greater depth, the perspective changes. There seems to be a gap between stories of clearly difficult situations where the respondent has been abandoned by others to manage a double front of care, and the subjective interpretation given by the respondent herself. The attribution of a formal designation is much less certain, especially in cases in which the main caregiver asserts that she doesn't experience her obligation as an exclusive and burdensome responsibility.

From a specifically psychological-relational point of view, without taking into account other external variables (such as the presence and availability of other family members or services), and independently of the *designation* (whether real or presumed) and of the perception that the main caregiver has of it, the factors which have the most impact on the caregiver's balance and ability to handle stress seem to be the following: the subjective representation of the pathology and/or of the loss of self-sufficiency; the relationship between the caregiver and other family members; and the history of the relationship between the caregiver and the person being cared for.

Every caregiver elaborates a representation of the critical event, that is, a portrayal of the pathology or form of dependence that struck her/his family member. This might be described and experienced as a progressive, chronic illness whose course precludes the possibility of a recovery, cure or improvement. Alternatively, the representation might instead suggest a dramatic process of steady decline. The weight and tiresomeness of the care burden and personal frustration with the physical impossibility of being able to guarantee an adequate level of assistance to the family member often accompany these perceptions of the loss of autonomy. As the following participant indicates, mental strength and a lot of time are what are needed most:

"I: What things in particular are required?

R: A lot of mental strength and a lot of time. I work and every week I give up one evening to go and see her. And at the point when I cared for her even more, I always gave up one day every weekend to go there and take care of everything. It took one whole day. And then if there was a need to see a doctor or take care of some affairs at an office, so those things had to be taken care of during the week, you couldn't do them on a weekend." FIN - DB12

The risk of burn-out or break-down is also higher when, in addition to genuine physical exhaustion, the caregiver is aware of the irreversibility of degenerative illness. This is illustrated in the narration of a woman who cares for her mother, who is sick with Alzheimer's disease:

"You do what you have to do, because the last time that I went to visit the social assistant, I really couldn't take it anymore, I said 'I can't do it any more, this is impossible', because she's always in the bathroom, when the colitis flares up she spends more time in the bathroom than she does out of it. I had to continually clean her room, and it came to a point where I said "I can't do it anymore"; in fact, I took her to the doctor on 13 November [...] I wanted to have her put in the hospital because I didn't know what to do anymore. (...)... I had got to the point that I couldn't, 'I can't handle it', I had to admit to myself, and I was crying because I couldn't handle it any more..." IT - DB08

The inability of elderly family members to recognise their loved ones, and their incomprehension of their own actions are two other sources of difficulty that caregivers often describe. In what follows, the woman mentioned above, who we found very close to burn-out, emphasises not only the psychological and emotional stress associated with the loss of all possibilities to communicate with the person being cared for, but also the difficulty of managing an unfamiliar illness:

"Ever since the disease started, because, because I didn't realise what was happening, and then the sadness of seeing a person who didn't used to be... well, she would lose money, and blame it on me; she said that I had come to the house and taken it myself. And so I was also really suffering at that time, because I didn't know, not, not knowing what was wrong... I never thought about this illness (...) We even found her standing in the bathroom sink. Yes, she climbed up onto the toilet and then she stepped into the sink, she was hanging onto the light fixture, for which... the bathroom is very small, too, if she had fallen she would have bumped her head or something". IT - DB08

We can find a similar situation in the following case:

"You can't live like that, it's impossible, with these constant... even if he didn't come right out and say them, these insinuations 'you took advantage of the fact that I was confused to sell the house', things that weren't true at all, that would have been done anyway... And then to see him always...so upset...oh, no, it's very difficult, it's a terrible situation. Even when he was calm, the atmosphere was unbearable..." F - MC23 FU

The quality of the relationship between family members is also of great importance because it influences how caregivers see their role, and shapes their capacity to effectively carry out their functions, even if the negotiations regarding his/her designation took place long before. Even if the caregiver cannot count on concrete help from other relatives, the stress and depression to which caregivers are subject seems notably reduced when they feel themselves surrounded by positive symbolic exchange, or at least embedded in a flexible kinship network whereby roles might change, if necessary, with the evolution of the disease. It can also significantly attenuate the risk of conflict and resentment on the part of the caregiver.

"...I mean, my brother and sisters are up there are they are really good. My brother spends a lot of time with Mum and Dad, he keeps me informed of the true story. You get a made up one from Mum and Dad because they don't want to worry you." UK - MC08 FU

The past and present relationship between the caregiver and the person being cared for is even more decisive, obviously, for the effectiveness of daily activity and the endurance of the caregiver. The dramatic, and often unexpected, transformation of primary relationships represents the main source of stress for the caregiver, and, in the most serious cases, can lead to

burn-out. When the caregiver perceives that the difference between the needs and requests of the dependent family member and the resources available to meet those needs is too great, she/he may fall victim to a growing and unbearable sense of impotence. These feelings stem from feelings of powerlessness to change the situation and eliminate the mismatch between what she/he believes her/him charge expects from her/him, and what she/he is able to actually offer. Such exhaustion manifests itself in various ways: physical reactions (chronic tiredness and insomnia), psycho-somatic illnesses (allergies, eczema skin conditions, lowered immunity to illness), psychological difficulties (senses of guilt or inadequacy, low self-esteem, irritability), and behavioural problems (defensive attitudes with others, detachment from relationships). Often times, the caregiver is not able to see when the stress has become too great and that she should take a break. On the other hand, families do manage to mobilise themselves to meet even the most difficult challenges. Absolute, total, and stable adjustment does not, and cannot exist, and every personal and family situation is located on a gradual continuum that might range from a negative extreme of deep crisis and disruption to a very high level of stability and satisfaction.

The role the main caregiver originally played, and how this role is transformed with the progression of the illness is also an important element in the relationship dynamics. Being the caregiver for a parent or spouse radically changes the interpretation of the relationship. For couples, the relationship between the partners is transformed by the illness not only by the symbolic and material weight of finding oneself having to care for someone who up to then was completely autonomous and self-sufficient, but also by effort of learning new skills and responsibilities. These individuals discover that they have to invent a new role for themselves with relation to their own partner. In the following passage, the challenges of this are illustrated in the dramatic narration of a young wife:

"...there was this stress. It was there, in my head, I , well, it was imprinted on my mind, so that one day, I always heard when he went out, so that I sort of, it was like, I suddenly said to a co-worker that oh my goodness, my husband has gone out, but he hasn't come back in, and why, why is that? It's been an hour I think, so I, well, I said then that this bothers me so much that I must go home. So I took the car and drove home, and right, he had left, he didn't have the key and he was out there on the back yard(...)

...it would be great if there were a kind of crisis centre that you could contact when the situation suddenly arises, well, that you could sort of take for a day or two. That would be the most important thing in my opinion. And since these ill persons are so, they are so strange, you felt yourself a total fool so many times. (...)

...And then there is this thing that you can't be in a hurry ever and that you can always, I mean , you can keep on this, it's totally unbelievable. (...)

Well I started to wade through these, these things that were going on, there were all kinds of stuff along with this, totally, totally shocking things, so that I, it was completely so that I only lived one day at a time". FIN MC20 DB

When the relationship is between an adult child and his/her parent, the role transformation can be even more challenging because in this case it often takes the shape of an inversion of roles. Becoming "the mother/the father of your own father or mother", and being forced to watch the progressive deterioration of an ill loved-one requires adjustments and redefinition that can be extremely painful and exhausting; if most of the care burden falls on one person alone, the problems are amplified and the weight can become unbearable. In these types of relationships, the original quality of the relationship can be decisive. If the relationship had always been a good one, it is more likely that the adult child's sense of debt and gratitude might lighten the perceived weight of the caregiving responsibility:

"Yes, yes, yes, extremely: as I get older, I feel more and more that I've been very fortunate, to have had such generous parents. Really generous, not in an economic sense, but generous in

terms of all the affection they gave us, their free time, the time they spent playing with us, without ever complaining. They managed all of that, even though they had serious financial problems, and life was actually difficult. We were six, I remember nights when I couldn't fall asleep, and my parents would be going over the bills, after we had all gone to bed, and it was really a desperate situation because they didn't know how they would make it to the end of the month. Even so, they were so GENEROUS! I have SUCH wonderful memories of my childhood, and for me, this is what matters. So I really have to do the same for them". F - DB02

If, vice versa, the memories of the past are negative and describe conflicted and difficult relationships, taking on the caregiving burden becomes much more problematic, and is lived with greater stress and displeasure. The relationship between the caregiver and the cared-for can become even more tense, and the probability of episodes of intense crisis and breakdowns is much higher. As in the cases that follow, this could happen in the moment in which the caregiver must make a decision about the eventual institutionalisation of the dependent adult, or when the caregiver needs to take a break from caregiving responsibilities.

"We have all cared for her, until Mothers' Day, when I took her to the health clinic, after she had fallen at home. And she was in the hospital for a month and, well, then somehow she collapsed mentally, so that she's been very depressed and she's angry with me when I try to take care of these things, like where will we place her if she can't cope at home. Like when I took an application form to an old people's home to her, she, well, she said she'd rip it into pieces, that you can't throw her just any place. The fact is that her mind is so lucid, but her body is failing her. She was discharged from the hospital two weeks ago and was at home. And it was totally hopeless, it didn't work at all". FIN - DB01

"It has been very exhausting, it's been totally, I noticed it was so tightly scheduled already when, and especially last summer when mom was in one hospital and dad in another, and mother's affairs were so wrong as can be, and we couldn't, we couldn't make any sense of it and then it was actually so that I drove between the two hospitals, went home in between and dropped in at work, sometimes here and sometimes there. So that last spring and summer and fall, it was all such a big hassle so that, so that that tightness, it was hard, all the time you had to squeeze your work in between it and try to cover it up in there that things were so tough, and I had such a hard time trying to find the time to do it all. The work was waiting here, it didn't go away and you couldn't take days off for something like this or anything. So that everything was extremely tight. It was probably the lack of time that was so distressing about it, all the time you were in a hurry, in a hurry away from very place, and late at every place, so that I had this feeling...where should I be now. It was a felling of huge hurry, hopelessly huge hurry and anxiety, they were the topmost feelings. And this was specifically, as I said, this was from last spring, from the end of spring to, say, to mid-September, so that that's when the biggest hurry was by far". FIN - MC21 DB

In other cases, care givers manage their personality conflicts with their dependent relative by assuming an attitude of detachment:

"Yes, I've always had that sort of caring role but I do still find it difficult being in that role with my Father. Because our background, our personalities and we've never got on particularly well.... But at least I can detach myself emotionally from it more". UK - SP02 FU

From a social policy point of view, these accounts highlight the importance of recognising that not only might there be individuals with no family to care for them, but that not all individuals with family will be helped by them. Some family members can't, or *won't* be available as main caregivers. The lifestyles and interpretations of those who are designated as main caregivers, and the reactions or 'rationalisations' that they adopt can give rise to extremely unfair and different outcomes. As we partly anticipated, main caregivers appear to react to their

designation in three general ways, regardless of how complex and drawn-out the negotiations actually were:

1) In some cases, assuming the role of main caregiver appears to be a genuine *designation by investiture*. This type of designation can be further distinguished by that which is self-selected (“self-designation”), and that imposed by others (“hetero-designation”). The caregiver can thus either feel invested with an exclusive role and compelled to carry it out ‘alone’ based on his/her own preferences and personal characteristics, or else invested with the role by others, and thus enjoying less autonomy. Family roles that are already in place, along with the responsibilities and reciprocal expectations within the family can be decisive in determining which family member will become responsible for the dependent adult, and in what ways. On the one hand, among various external circumstances, decisions based on the personal and individual choices of the caregivers appear to prevail, for which we can thus talk about a sort of ‘self-designation’, or at least the illusion of it:

"Because it falls on my shoulders, that is, because it couldn't be any other way, and then maybe because in the type of relationship that there is between the children and my parents is so..."
F - DB03

"But perhaps not the kind of thing, he hasn't taken part in taking care of things for example, and stuff, so that they have all been my responsibility, like after mom died, the funeral, the estate inventory et cetera, they were all my, my responsibility to take care of them". FIN - DB08

On the other hand, the external imposition of the designation of main caregiver (or the “hetero-designation”), also might be the preference of the person being cared for:

"(...) Because I, that is, my sister she is... Well, with my sister... The problem is that with me she's... she's a problem, now, a personal problem, let's say, I, well, because I am the youngest, being the baby of the family she (her mother) she's more comfortable with me, let's say... My sister also helps out a lot, but she (her mother), with me, let's say, she expects more, you know, when they get old..." IT - DB01

"I have when I was little, I took care of my mother's mother 'cause, 'cause, well, she was, she was probably already ninety at the time and she didn't accept anyone else to help her in the sauna, for example, I don't know what the cause was". FIN - MC20 DB

"Instead I am involved with all of her medical needs, I feel like that's my responsibility because if there should be a problem, a stomach ache or something, if we have to call the doctor or some tests or analyses to have done, I take all of the health related things. Then on Sundays, that's the day when the woman who cares for her doesn't come, so I have to go myself: if there are two or three days of holidays in a row, that means that I have to go, it's all my responsibility. Then, for every day things, now, for example, not being able to go on Sundays, I have to go and bathe her, that is, take care of her physical needs like washing her hair or cutting her nails" IT - SP01 DB

This approach might also be the result of explicit promises made in the past, for which the caregiver feels deeply responsible:

"My uncle, before, it was something that I inherited from my grandmother, I, *it was a promise that I made to my grandmother*, she asked me to take care of her son who for her was a real torment, the fact that he isn't completely normal for here was a real sufferance. So this promise, when she passed away, we kept it, even if my mother's brothers, that is, my uncle's brothers, said that it really wasn't necessary and that he should stay in his own home with a woman who could keep house for him, who could keep him, well, because he has to be managed, a little, it's not like you can... he has to be watched, it's not that he's done anything, but we have to keep

an eye on him. So that was the situation, and it went on that way for six or seven months [the attempt to leave him with a housekeeper] and after that his older brother called me saying that it wasn't working out, and that it would be safer, if it was alright with me, to have him with us, and so we took him in". IT- DB02

"And it happened that, I'm sure I will remember it until I die, there were occasions when mom totally panicked over there and called me and said that she was feeling so bad, that she couldn't stay there anymore, that she was being abused and didn't get enough to eat and. I wasn't always sure how true her claims were. But she was in her right mind then. And she didn't get enough to eat and she was being shouted at and stuff and I remember telling her that I promise to take care of you until you die. And it is of course a matter of heart to me that I will do it. I have promised to do it". FIN - DB10

Caregivers feel more resentment when the designation comes from other family members, or imposed in a way that is explicitly forced, and therefore, conflictive:

"What really exhausted me is that I found I was the only one giving anything, even though I'm the youngest, but I was working, I was working, and my brothers and sisters never helped with anything [...] But, you know, they, my siblings always say 'we leave in the morning and get home in the evening, we have a smaller house' they always dump everything on me". P - MC08 DB

2) In other cases, the *designation* is *described as a genuine vocation*, or at least something related to the personal character of the caregiver. Here, the designated caregiver might find an internal justification for her role, defining as a personal vocation the experience of an unfortunate destiny that is actually felt as a disadvantage. This is the case of the 55 year old woman below, who recounts her own acknowledged dedication to her mother. This woman interprets her role as in keeping with a natural quality, a vocation, conditioned in part by the sacrifices that her mother made for her and all of her many siblings. Indeed, her role nearly seems a redemption of her idealised maternal figure:

"But I, I think that my vocation comes from what my mother did for us. Because we, she was that way (already) when we were young, and so I, personally, I was ten when she started with the little ones, the little and the big ones [children in foster care]. For us, they were brothers and sisters, it was.. family life, well. It wasn't about outsiders, it was the family (...)
She has...she is a woman who has always...well...she's always needed [has always been forced to] on the other hand, because, well, she was the one, anyway, she raised all eight of us. Because my father, he was an alcoholic..." F - MC22 DB

The apparently serene consequentiality of the 'vocation' described in this account dramatically reveals its true nature, though, when, much later in the interview, we touched on more hidden recollections of family violence. Though this is not the context for discussing the specific after-effects, it does permit us to suggest that the presumed 'vocation of exchange' looks much more like a bitter destiny designed by external circumstances that probably have little to do with a true vocation. The same participant commented:

"...something else that I would never put up with from my husband is if he were to lay his hands on a little girl or boy. Because, well, something very bad happened to us, that is, my father molested...he molested all of us. My mother never knew about it". F - MC 22 DB

This particularly dramatic example is emblematic of a removal that also appears in other cases in which the participant describes herself as 'naturally called' and suitable for the role of main caregiver; a description that in fact obscures old unresolved problems with herself or other family members.

The caregiver who associates the designation by others with qualities that are part of her own personal character is well-illustrated by the following declarations, in which, at times, it becomes extremely difficult to distinguish the designation of the choice. In these two cases in particular, the mixing of statements such as *"it's my fault if I'm this way"* and *"I'm this way by nature"* reveals profound contradictions in terms:

"As a caretaker definitely, it may be my own fault, too, I am this kind of an organiser by nature_ (...) So that when this buying of an apartment became topical, it was me, I can take the credit (laughs) for the fact that they were able to buy it. So that, I am like that by nature". FIN DB 4

"It's a situation that was certainly caused by my own way of behaving, it was my fault above all because of how I am with my mother and everyone, especially the girls saw that I would make these sacrifices without thinking about it, I would put aside everything to run to her side" IT - MC20 DB

It is also sometimes evident, just when the participant wants to exclude it, that caregivers cast a certain amount of judgement on other family members who, 'simply', because of different natures and characters, leave the entire responsibility for caregiving to her:

"Yes. When I used to go up there every weekend it was me paying them back for all they had done for me. But I didn't resent my sisters for not doing anything because they never liked household things". UK - DB02

Justifications for designations based on personal characteristics can also be found in previous family stories, or in the employment background of the caregiver. There are several examples where the work of family caregiving and extra-familial caregiving overlap. These common features leave one to hypothesise a type of socialisation into the role of carer, as well as a sort of exchange by osmosis of the competencies gained in the two contexts:

"Yes I did really. My background is nursing and it's happened so many times to other people. Also, my father's father suffered really in the same way. It wasn't quite so bad but he actually lived to a ripe old age, but really I think mentally he was quite chaotic and he was a strain on everybody else. Plus I think my father's always has a tendency to be depressive and it didn't surprise me really. I expected it really". UK - SP02FU

"Well, I'm a nurse at Pontchaillou and...(....) a state diploma from...since I was 28. Well...I returned to school...then, I finished my certificat d'Etudes (degree). After that I did a secretarial course, and then I...I wanted to work with children, so I was a teacher at Bouexiere. I tried to be a teacher...well, I was looking for what I wanted to do. (...) Then I went to Paris. (...) I worked for...two years and then I went back to Rennes. I lost my father, and my brother was the youngest of the family. So, if you like, I took over...I was already considered (I became) the head of the family". F - MC01 FU

3) Finally, there are those who, among the participants, speak very explicitly of *designation as being tied to destiny and even as karma*:

"I took the car and drove there to see him, and this brother of mine, he said sort of laughingly that this is apparently your karma, like I always say that this is my karma_ I'll always be there when someone is being taken to the hospital. I'll always be the first to hold somebody's hand and to handle the affairs with the doctors". FIN - DB01

"I cared for when I was 12, for my brothers and sisters, and my Mum and dad technically. Because I was the only one at home so I've always done it. My mum worked and my brothers and sisters were younger than me. (...) [Q: Do you think you were destined to become a carer because of the way you were brought up?] A: Yes". UK - MC08 FU

Though some caregivers might allude to destiny, it does not always mean that they serenely accept the facts:

"I mean *I don't believe in destiny in that way*, but in a way, because my grandmother was in a wheelchair and I was given the responsibility of looking after her. So in a way, having to look after the physical needs of a person is not something I found particularly difficult. I have always been aware of how awkward people who have a long term illness can be. I suppose I have become a bit more cynical than is healthy." UK - MF12 FU

There are two other fundamental variables that have an impact on the experience and symbolic representation of the double front of care, and that in some way determine their 'tolerability': the *length of time* (understood as the subjective perception and the actual duration of care) and the *timing* itself (understood as the rhythm and succession of important events) of the entire career of the caregiver.

The length of time in which care is necessary, and the episodes that mark the progression in time constitute decisive elements in the determination of how the main caregiver reacts and the degree to which she accepts having nearly complete responsibility for care. As partly anticipated in the previous section, one way that caregivers manage their sense of time is by denying the future, by a rejection of future time as a period of deterioration and death. Vice versa, in some ways the future can be foreseen and shaped through rationalisations that anticipate and plan actions in preparation for changes, and the necessity to adapt to guarantee the care and assistance that might be necessary. In any case, the duration of the double front of care constitutes a reliable indicator for evaluating the capacity of the caregiver to resist, especially when she is the 'sole' caregiver. The prospect or experience of a long-term double front of care also encourages some of the more motivated caregivers to hypothesise alternative solutions to the care arrangement, as is well-exemplified in the following case:

"[husband] 'There's an old proverb that says 'la malattia che dura stanca anche le mura' (illnesses that linger even tire out the walls). Her mother, because sometimes she insists, she says: 'we can't abandon him, the poor thing...' Of course we don't want to abandon him, but time, when it's such a long time, then, it kills, that is..." IT - DB01

In other cases, the apparently cynical uncertainty about the expected time that the person being cared for has to live brings us back to the very real problem many people have of finding alternative care arrangements:

"For her I think it is the best solution but for us it is the worst...But we also take into consideration that *we still have many years to live, and no one knows how many she has...* so we chose the best solution for her, thinking of her, not of us. It's a nightmare for us having those two here at home". PMC01 DB

In other situations, the designation of main caregiver appears fulfilling in itself, even if there is no clear idea of how long the caring will last. In these cases, especially if the person being cared for does not need continuous care, the caregiver, even when relatively isolated and deprived of external support, has a generally positive outlook and seems able to draw on extraordinarily rich internal resources. Personal satisfaction with her/his own solution to the caregiving dilemma seems to cancel out the exhaustion associated with managing the responsibilities of a double front of care. As in the follow:

"I (do not) ...find it altogether very difficult because everything is beyond my control. I'm okay if I can organise myself and can fit things into my job. If I can say 'I am going to work from such and such a time and then I'm going to do that.' Then it's more manageable, and in a way it's

been much more manageable with the children at school, the regular hours, and I've been organising myself around that". UK - MF12 FU

As a conclusion to this section, I would like to present a paradigmatic example of the trajectory followed when faced with a double front of care, with its associated risks of burn-out. One of our participants, a mother of three children, found that she had to completely revamp a well-consolidated care arrangement in relation to the health problems of her elderly father, who, rendered completely dependent by a stroke, was transformed from a 'resource' into a 'constraint'. Her story is also emblematic in so much as it is an example of long-term care, for which, though starting from a relatively advantaged position, she faces the risk of an eventual breakdown. This participant is a public servant with managerial responsibilities--a job that allows her a certain amount of flexibility. Her professional career has been sustained by her husband, who knew how to play an alternate role in family care without being hindered by any preconceptions. Perfectly inserted into the service culture, this interviewee is also well-endowed with what can be called 'social capital'. Despite all of this, even she, in the face of a prolonged period confronting a double front of care without apparent ways out, began to show the first signs of a crisis associated with a strong sense of 'not being able to handle it any more'. Many parts of her testimony were striking because they seem to suggest interesting elements of reflection on the short-comings of social policy, but also some possible solutions. I will attempt here to reconstruct the main turning points through the words of the participant herself. While her employment circumstances allowed her to confront the emergency, in the end it revealed itself to be a double-edged sword:

"As for my job, I'm a public servant, I have a flexible schedule. I can take a day off from today to tomorrow, it's a flexibility that my husband doesn't have. (...) If I want to take a day, an excuse, I have that flexibility, for my father I have a right to it thanks to L. 104, to assist handicapped family members. For the protection of working mothers, the family, for handicapped persons, Italy has good coverage. You can take care of a lot of needs. I'm talking about public servants (.....) Then obviously you have to look at what kind of role you have in the administrations". IT - MC16bis DB

In fact, the gap between what the law provides for and the actual possibility of taking advantage of it is particularly clear when it comes to the elderly. As one gathers, the type of help our participants call for is more tied to the need to learn how to manage unexpected events for which, in most cases, they are unprepared. What emerges is a request for training and guidance on 'how to become good caregivers'.

"...but what I really wanted was some psychological help, because they are things that transform you life overnight, so, some psychological help for him, also to give all of us some breathing room, because being stuck in the house like this he needs some stimulation. (...) I want someone to help me, because a lot of the time I don't know how to act, I don't know if it's right to tell him one thing or another. I think there is still a lot of work to be done on social policy for the elderly". IT - MC16bis DB

Even the most motivated and seasoned caregivers, when abandoned to themselves, eventually run out of energy. With this burn-out an important supplementary resource is lost. In fact, the entire social system loses a precious resource every time that a potential caregiver burns out.

"My organisation is like a spinning top, and I'm not very satisfied...(.....) There is very little time for myself, in every sense of the word. (...) I should mention that when I have to, I can keep going, it's just when things let up that I had a very difficult time, a depression, nervous exhaustion, too many things were weighing on me. In the most difficult times there was too much to do. When all of this happened with my father, I feel it more, now, now I say: where will I get the strength? ...now I'm giving up a little. Up until a month ago, I was constantly running

back and forth between my father here, and my son, at home. *But I haven't done this part for a month, I just can't handle it, and they take care of things a little bit more; but I do feel guilty about it: to not have the time, or the inclination, to take care of everything: I just need some time off*".

In conclusion, the importance of not being left 'alone' as a caregiver should be highlighted. From an institutional point of view, this does not necessarily mean that the best response is economic support, whereby taking care of family members is considered a remunerated job. Rather, they should try to intuit and highlight the potentially positive valances of caring for family members (of exchange, of reciprocal enrichment) and try to favour the conditions under which this work can be carried out in the best ways possible. In other words, to provide for a positive balance of costs and benefits for both the caregiver and the cared-for:

"It's not even an economic issue. What I mean is if they would give me 800 liras to look after, I don't know, a child, it wouldn't be an incentive to make me do more. Of course money helps, but for me it isn't a job. Taking care of someone shouldn't just be considered a chore. (...) I don't experience it as a job, also because it isn't my job. What I consider work is what I do outside of the family. Taking care of the house, of the children, of my parents, I don't interpret that as work, even if it is a responsibility that can weigh on me. *To me it would be useful if I could work with other people, that is, to divide these chores, to exchange things, also to grow, both the person being cared for, and the one doing the caring. You grow more if you can share it*". IT - MC16bis DB

This example helps us to better understand the complexity and the variety of the elements than can intervene in the overall articulation of situations characterised by multiple burdens of care. The double front of care usually tends to fall on one exclusive caregiver, regardless of family conditions, economic circumstances, the cultural, social, and professional background of the person confronting two fronts of care, or effective and satisfying solutions to the care arrangement.

Caring for a sick or disabled person gives rise to different kinds of stress, both for the carer and the person being cared for. This type of caring has an impact on relational investments, on the time available for oneself and one's own family, and it is the source of psychological tension that has emotional and affective implications. To become the mother/father of your own father or mother, or the nurse of your own partner might constitute an extremely intense and even beautiful experience, but always with a certain weight. And the type of support most lacking is not that associated with direct care (economic assistance, relief services, or in-home helpers), but rather that which is necessary to withstand the stress associated with care and with understanding when it is appropriate to help, to stand aside, or to pass on the burden to someone else. This last aspect proves especially difficult in those cultural contexts where the task of providing care and assistance represents a traditional family value and is experienced as an act of love and intimate duty. On that account while it is true that many caregivers are constrained to assume their role for lack of other services, available family members, or feasible alternatives, it is also true that cases of "intensive caring", whereby the caregiver provides around-the-clock attention, are not unknown, and should be avoided or managed in the interest of the psychological and physical health of both the carer and the person being cared-for.

A professional and competent psychological support for caregivers should also encourage caregivers to find some freedom, to take a healthy distance (not to be confused with detachment) so as to acquire greater emotional clarity and guarantee a more effective and personally rewarding presence. Indeed, the construction of a symbolic space which separates those who provide care and those who receive it, is also crucial for the liberty and the dignity of the latter. This wish emerged in many of our interviews in a way that seemed nearly universalistic, independent of the orientations and value systems of the various caregivers.

For most of the people that we met, the theoretical distinction between families and/or *family-oriented* people and families and/or *career oriented* people did not seem sensible or applicable. Furthermore, comparisons of the different pathways to becoming a designated caregiver based on different cultural contexts and different welfare systems are also problematic. Beyond the individual stories contextualized in the five countries, the logic of action (and reaction) of caregivers on two fronts appear to fit along a continuum that extends from ‘convinced caregiver’ on one end, to an opposite extreme where caregivers manage and reconcile the double front only with great difficulty. The rare cases of the former demonstrate the defining circumstances of the double front of care or the exclusive designation of the caregiver, and the latter inevitably lead to the burn-out of the main caregiver. For all of the caregivers in our study, the real discriminating factor and that which also renders possible the continual reinvention of different combinations of care arrangements is constituted by the mix of possibilities found at the intersection between formal and informal care. In a word, it is the complex of solutions that one can realise given the particular mix of resources and constraints that, in fact, are much more context-dependent. In order to reduce the impact that illness has on family variables (economic, psychological, and relational), it is necessary to involve not only the entire nuclear family, but also the offerings of the institutional network, and services. It is this, above all, that makes the difference, and that on which we will try to reflect in the next section.

3. Constraints and Resources for Families Facing Care Burdens on Two Fronts: Networks of Care

3.1 The Transversal Characteristics of Care Networks

In this section we analyse the resources and constraints families have that facilitate or aggravate their efforts to manage a double front of care. We pay attention to family and service networks, and their various combinations, because their composition, breadth, and utility can make a world of difference in easing the daily burden of primary caregivers. Indeed, when these helping networks are absent or fragile, caregivers are extremely susceptible to burnout.

Furthermore, we will also see how the quality of relations—and thus the perception of responsibility—varies within each network, as do the models of exchange and negotiation among family members and between families and services.

As the interviews from the preceding work-packages (wp 3 on dual career families and wp 4 on immigrant families) revealed, for families dealing with care on two fronts, it is the care of elderly family members that is experienced as particularly taxing and difficult to confront because:

a) it is an unavoidable duty that caregivers cannot easily renegotiate with other family members because the elderly person has ‘chosen’ her as the designated caregiver; because of a lack of practical alternatives or other available caregivers, especially in case of emergencies, as in the case of only children; or because of reasons related to logistics, space, or geographic proximity;

b) it is not always reconcilable with the employment obligations of the other members of the network, who negotiate their own caring contribution based on the compatibility between work and care;

c) care networks for children and the elderly are not easily interchangeable, and only the people at the centre of the network, such as the caregiver and the spouse of the cared for, are simultaneously concerned with both. If there is an exchange of roles, it is usually in a single direction, where the person who cares for an elderly family member also agrees to mind a child for a few hours; it is rare that a family member responsible for child care would also look after an elderly relative. This rather rigid separation of roles between the two worlds has both symbolic and practical meaning. In fact, in the market of paid assistance and professional services for children and the elderly, the two specialisation reflect each other but remain divided by a sort of symbolic imperative to not mix the two fields. Cleaning the soiled clothes of a child seems to require different hands than those used to clean the soiled sheets of an old person, especially in countries like Italy and France, where it seems that the purity of childhood must be protected from contamination by the corporeal deterioration of old age;

d) there is also the question of choice: though children are always considered as bearing more ‘rights’, the old person obviously has more ‘say’ in the solutions the family adopts. Even so, that which is most expedient in terms of familial organisation (which, in the case of multiple siblings, also means the organisation of more families and their respective commitments) is not always the solution most desired by the people involved;

e) of the meaning that is attributed to the necessity of caring for elderly family members. In the interviews with Moroccan women for the work-package on immigration, for example, the framework of meaning they drew upon was recognised as having strong attenuating effects on the women’s senses of being ‘overloaded’ with care obligations. The comparison of the smiling acceptance of the immigrant women with the unhappy resignation of Italian women sheds light

on the importance of the internalisation of the social norms as a framework of meaning and as a fundamental resource for accepting the double burden. In family networks of care, such frameworks of meaning differentiate those who understand caring for one's elders as a private matter, as an obligation to give back what one received in childhood, from those who would prefer to delegate such responsibilities to a professional or paid assistant. In these case the respondents show an individualistic attitude, where family obligations and duties are not unavoidable, but can be negotiated;

f) the outcome of the network's configuration, photographed at the moment of the interview, is the product of continuous processes of readjustment not only of the actual concrete resources available (time, people, services, and money), but also of the progression of the elderly person's illness, and of the continuous re-elaboration and re-negotiation of the meaning embedded in the care obligation. In other words, these latter values, and not just the concrete resources at hand, shape choices and influence the delicate equilibrium among family members in the network.

In addition to the above challenges, our analysis of care networks also requires that we consider four other crucial, highly inter-connected factors that run through and influence all of the stories we collected in the various countries:

-the evolution of families' strategies for handling care on two fronts. Though the dual burden of care is studded with more or less foreseeable events, there are also priorities that must be evaluated from moment to moment, and the history of the double front of care is made of progressive adjustments. The management of this dual burden continually generates both skills and concerns about how to best respond to newly emergent needs. For the caregiver, this process involves all of the concerns that must be kept in mind and taken into account for 'managing' the care: the reconciliation of the two care arrangements, relations with public or private services, and the reconciliation of caregiving with her own (and her partners) paid employment. It also means handling changes in the network as they arise. Caregivers must deal with the reactions of their own nuclear families (spouses and children) and their families of origin, and they must confront, little by little, their own feelings about taking care of parental figures whose reality of weakness and dependence might be a sad departure from earlier, deeply internalised images;

-the management of emergencies, that, depending on their frequency and gravity, risk upsetting the network of care;

-temporality, understood not only as the duration of childcare and elder care responsibilities, but also in terms of the relationships between the past, present, and future, continually emerges in the participants' accounts. The amount of strain associated with caring obligations appears directly proportional to the length of time (months, years) a caregiver must manage them, and with increases in the latter come increases in the former, leaving caregivers with the impression that there is no light at the end of the tunnel. Over time, heavy and prolonged care burdens transform family equilibrium, and sometimes the networks wear thin or even 'unravel', as one of our English participants mused while looking at the photos we brought to the interviews illustrating family care for the aged:

"Obviously in the pictures there is a greater family unit than we have got and there seems to be a fair amount of warmth going around. Which in my case, unfortunately seems to get less and less. It reminds me that it is coming back. UK - MF12 FU'

The element of temporality also has a future dimension, and families anticipate the possibility that the dependence and fragility of their elders might worsen. These evaluations weigh in on plans to relocate, move house, or buy or sell a home:

"and when my father started talking about moving he said he wanted to return to Paris, he wanted to go away at all costs, I think he would have even run away just so he could get out of that house (...)... we had him tested for Alzheimer's disease, but in the end they decided that it was just a deep depression (...)... and so I said to him if you don't like living here, we'll find something else. (...) you understand that he worked his entire life to have that house, but then my mother got sick and there he was, inside those four walls without his wife... (...) and so I told him: it's fine if you move, but not too far away. It would be easier for you, too; this way we're within walking distance of each other. My father doesn't have a driver's license, he doesn't drive. We wanted something nearby, and we looked for a house within half a kilometer of ours, but there wasn't very much but some, yes. (...) We kept on looking, but we often went without him, because he was so anxious to move that he would have agreed to anything, or paid any price. The house that we bought for him is 150 meters from my house, on the other side of the street. (...) Well, for the loan I had to take it out in my name, because he is too old. I'm the one who bought it for him, and it is like he is my tenant, he pays me rent because I have to make the loan payment to the bank". F - MC23 FU

Timing and process are important factors because in the moment in which it is necessary to activate resources to assist ageing parents, it might come out that not all family members have evolved in the same way, and for some, the past might heavily influence evaluations of the present:

"It was a decision that we made together, my sister and I. I tried to involve my brother, but he still has an old idea of what our father is like. Our father was an authoritarian type, one who got through life with an iron fist, and our brother still has this image of him and thinks that he wouldn't be able to respond if our father expressed some need or wish. But he [my father] is incapable of expressing his needs. I think that there has been an evolution, but that my brother's family still has an outdated image of my father, of someone who took care of everything. But then they didn't visit very often when my mother's health was failing and when they did come, my father tried to make their stay as easy and relaxed as possible, without any problems. (...) I think that he [my brother] did what any of us would have done, it's not that he denied the situation, but maybe he refused to see it, because if he acknowledged it, it would have been painful for him. And once he did realise how things were, maybe he didn't want to get too deeply involved, or maybe he wanted to get involved, but he just didn't know how, how to go forward..." FIN - DB01

-Finally, the fourth factor that has transversal influence over the network is the visibility of the network itself, and the family's awareness of it. It often happens, in fact, that members of a caring network are unaware of its existence and how it works. It is an important step, especially for the main caregivers, when they begin to recognise themselves as 'network nodes', with defined resources and limitations. At that point, caregivers are better-positioned to organise themselves, evaluate problems as they arise, take advantage of learning opportunities, and make the most of what services are offered without losing sight of the importance of affective ties. In this process, the network nodes become more competent, more capable of rational action, and, in a certain sense, more reflexive or capable of reading, interpreting and reconstructing the meanings of the relations and the points of view of others, above all those of the cared for.

3.2. Networks of care

In our sample, family care networks are composed of members from the family of origin, from the family by marriage, and from the extended family. These are flanked by informal networks made up of friends, neighbours, volunteers, and aids providing either public or privately paid

services. In this section, we will go over some of the categories employed in the now classic social network analyses in the fields of anthropology, sociology, social work, and organisational analysis.

Networks, understood as a web of interwoven threads, are usually analysed according to two collections of characteristics: the structure, and the quality of relations among network members. The former allow us to map out and discuss the actual design of the network.

The structural characteristics of a network are legible through a series of indicators, which include:

the presence or absence of a nucleus, its breadth and extension, and the distance between the nodes. These three indicators shed light on the outlines of the network. It is also useful for understanding how individuals join together to confront care burdens if we know whether there are alternatives available to the members already involved, and what the underlying operative rules and models of co-operation are. In addition, we can observe the density or the number of dyadic relations or other relations between the nodes, the homogeneity (or heterogeneity) of the members (in our case, within and external to the family) and the level of mutuality (that permit us to see if all members interact with each other, or if some use intermediaries). Finally, it is also possible to identify the so-called ‘clusters’, segments of the network located around the main caregiver with particularly high levels of density and frequent contact among the members. In general, one can also individuate precise relationships between the breadth of the network and the intensity of the relationships: a loose network often has a lower density than a more tightly woven network, while high density and high extension are characteristic of rich networks. Tightly-woven networks with high relationship density tend to be closed to outsiders, and low-density networks of limited relationship extension are characteristic of situations of isolation.

In terms of the quality of relationships, the meaningful characteristics to examine in a network are the content areas of relationships—these permit us to define a relation as one-dimensional if it is mainly concentrated on one area of contents (for example, a common interest, or, in our case, the execution of one single type of caregiving) and multi-dimensional if the more areas are included (friendship, work, kinship; in our case, the taking on of different types of care in an inter-changeable way). In addition, we can consider the direction of the relations and the contacts; their symmetry (if they are reciprocal or one-way); the intensity and the co-involvement in the relations; their intimacy; and depth. In addition, the frequency (the time passed together) and the duration/persistence in time is also informative. Finally, other interesting indicators of the quality of networks include the decision-making processes and the forms of regulation of conflicts and negotiations, and the models of communication. For example, our participants often mention more or less intense exchanges of information with other family members on the organisation of the double-front of care, whether in terms of the responsibilities assumed by others, or, vice versa, in terms of unmet expectations or empty promises.

We will use these indicators to understand how the care networks of our participants function, and to differentiate the representations of quality in the relationships, especially for those concerning the care of older people.

From the point of view of the main caregiver, we will then try to highlight how they evaluate the contributions of other nodes in the network, and how the different resources of the members are represented. For example, the difficulty in reconciling time for work with time for care is a recurring theme in explaining the greater or lesser availability of other family members to shoulder part of the burden. Diverse capacities or competencies are a good criteria for the division of labour (he is better at doing this than that): some are called in for emergencies,

because they are able to maintain calm, others, who are less central are justified in terms of their ‘character’ because ‘they’re not really cut out for that’.

Table 5. Network types of all double front families

NETWORK STRUCTURE	NETWORK TYPES ⁸				TOTAL
	FAMILY-BASED	INFORMAL FAMILY + OTHERS	MIX: SERVICES + FAMILY	MIX: INFORMAL + SERVICES	
Relatively extensive, rich, and polycentric	5	6	8	13	32
Specialised, centred on two caregivers	2	3	2	5	12
Minimal or absent network, loose couplings, strongly centred on one main caregiver	15	10	17	14	56
TOTAL	22	19	27	32	100

Above is an synthetic distribution of the network structures and network types we identified in our sample of families. Of the family-based networks, five could be characterised as having relatively large, rich, and polycentric structures, while in contrast, fifteen of them appeared quite weak, with loose couplings among members, and care falling mainly on the shoulders of one, isolated caregiver. Among the mixed networks, composed of family members and aides either hired privately or provided through social services, eight demonstrated relatively strong and polycentric structures; two demonstrated more specialised networks, with caregiving centred on two members of the network with different tasks; and seventeen could be characterised by their relative weakness, loose couplings, and overwhelming dependence on one main caregiver. Finally, the caregiving networks that depended on a mixture of family members with non-professional assistance, or non-professional and professional assistance, returned minimal network structures centred on one or two primary caregivers (fourteen) or more rich network (thirteen).

⁸ Table 1: Network of care

Rich = more than couple & at least 1 person not of the family

Specialised = 2 main carers with others on the periphery, e.g.: 1 cares for everyday life, 1 cares about different tasks

Minimum = 1 carer doing most of the care arrangement (more or less helped by the other adult or children) – usually a heavy burden.

Informal = family and neighbours and volunteers.

Services = public and private

The two main types of networks in our sample are those composed of ‘weak ties’, where the network is minimal or even absent, and caregiving falls on one person, more than half of our sample (56), and that which is instead relatively rich and polycentric (32), one third of our sample. In the latter case, the main caregiver, if there is one, sometimes knows that she/he can count on other family members for concrete assistance and second opinions. The number of cases in which there is a specialised sub-division of tasks between at least two care givers, with or without the support of services, are much less.

One could hypothesise that, over time, the configuration and structure of a network can change, especially when the obligation of organising care on two fronts is of such great duration that the resources and availability of the network participants are diminished.

In the next section, we will analyse the characteristics of each of the three network structures, setting aside for now networks in which the main caregivers are provided for through public or private services.

3.2.1. The rich network

1)The extensive and rich network has at least three active members in the care arrangement, the management of which never completely falls on just one person’s shoulders. The care of the elderly person is shared with at least one other person, and child care is often shared with someone else. Even if there is one central caregiver with more responsibility than anyone else, this type of network generally tends to be polycentric, especially in terms of its modalities of relations, communication, and the organisation of care-giving tasks. A good indicator of such polycentrism is the existence of a cluster—that is, a segment of the network with a particularly elevated density that encompasses more than one node of the network. There are inter-connections and good connectivity, and communication is transversal and there is no single reference person acting as intermediary for the others. The distance between the nodes is not too high, though over time there might be negotiated movements towards more or less involvement in the daily organisation of care.

If we also consider the more qualitative variables, we note a certain level of reciprocity among the nodes that runs in more than one direction.

The ties and the frequency of contact are relatively intense (many times a week), and the content areas of the relations and care can be multi-dimensional (including emotional, physical, and material support), but also specialised or uni-dimensional (each child assumes a particular area of responsibility, which, if necessary, can be transferred to the other).

In the rich network, the nodes put together what they can offer in terms of assistance, be it time or money, constituting a sort of ‘depository of care resources’ that can be drawn upon when necessary. This is well-exemplified in the organisation of care for a partially self-sufficient elderly couple:

"Because we children have all left home, and because we have this, well, this problem, this illness now, we hired a woman from Eastern Europe, she’s Polish, who stays, who stays in my and my older brother’s old room. I am the youngest, I have an older sister, a brother who is one year older than me. We are fortunate, being in three. (...) We take turns; that means, in the morning, if my sister isn’t busy, she goes to find out, when she drops off, I don’t know, some aspirin or something, she goes to talk with this person, who speaks pretty good Italian, to see if there are any problems. I go out at noon, and I’ll stop by there around 1:30 p.m., like today, for example, I stopped in for lunch, so that I could give the Polish woman a break, who is obviously there all day long. My brother lives closer to the house, and has a more flexible schedule, so he’ll stop by either in the morning or in the evening (...) my sister, since she doesn’t have a regular job she’s the one who usually takes care of emergencies". IT - SP06 DB

In the rich network we find different types of relationships between the ‘active nodes’, that can be summarised in a typology of ‘collaborators’, as some of our participants described them. The first type, as in the Italian family cited above, are the ‘regular and unconditional’ collaborators, who are interchangeable in their roles and tasks and who demonstrate strong affective ties with the person being cared for. There is usually a frequent exchange of information among these individuals. They consult each other for important decisions, and there is high agreement among the partners on what to do and how to do it—there is, in sum, an understanding about the ‘operative rules of care’:

"There were way too many risks because of lack of nourishment, we were aware of that. Everyone kept bringing food, freezers were full of it, but she didn't eat. In other words she got this kind of occasional help but she wasn't happy with it and then, then it was stopped. There were many, even grandchildren, who then brought food, several relatives got groceries to her from the store and went to the pharmacy regularly, at least. And well I probably took care of mom's papers I had something to do with this trial and the housing corporation and other things and, and well the environment was sort of mixed, we all lived close to mom. It was five minutes walk from our place to hers, so if she had any urgent need for help, she just called. (...) And about the division of who does what, I could say that both of us have taken part in everything, there hasn't been any clear division, except for the paper work. That way.' FIN - MC21 DB

"...and we helped each other a little bit taking turns, also a lot (my partner) in the period when my grandmother was sick in the hospital, and where he [the grandfather] actually became much more independent, of course we had to wash him, to put him under the shower, but he ate by himself. Of course, now that I think about it, it was pretty tiring, but even my children spent time with him, they'd take him to the bathroom, cut his meat for him, everything seemed under control". IT - DB03

"Yes, even with the finances, the three of us make those decisions together, when there are big expenses, or certain things need to be taken care of, I don't have to manage it all by myself". F - MC05 DB

In the end, this agreement is also valid for the negotiation that takes place within the family, who agrees that it is necessary to find the best solution possible for the elderly parent, taking into account even the personal preferences and affinities of the old person:

"Well, I'm a vegetarian, I have been for twenty-two years, and I don't like anything that they like to eat, but they have a good time (her husband and father), they really have a lot of things in common and this is why we thought that it was the best solution, having him here instead of with my other brothers and sisters who, well, they are younger, and different. Each of us offered to let Dad move in with us, but he refused everyone, including us, he wouldn't hear of it, but then when I put on some pressure, well, he accepted, and that was that". IT - DB02

Q: "Who will be the one who actually takes care of your parents, when that day comes?"

R: "My sister and I." "Both of you, equally?" "Yes, equally, as much as we can."

Q: "But how come, why should it be both of you?" R: "Because both of us are their daughters".

P - MC09 DB

Sharing the caregiving tasks is even more profound and rewarding for family members when, among all participants, inshared values guide not only the daily actions, but also the fundamental choices of the members of the network/regarding the members to include in the network:

"Me and my brothers were on call 24 hours a day, so that my brother rode there on his bike last thing in the evening, made some sandwiches ready and. And the other brother then, they've

been absolutely great, both of them. Er, when it comes to my parents-in-law, no. But I must say that now that my mother and father have been ill and in this kind of situation, so, well, well, at the time mother had this cancer diagnosis and I broke down in the autumn of '99, so then my older brother, he started going there and taking care of mom's pain plasters and stuff, started to be part of their life. So I told my brother then, I told P., that I thought that it was great to have a big brother, that I wouldn't have had the energy to go on otherwise, that it was great that he had. He just said that it wasn't a big deal, that he hadn't done that much. But it's interesting to notice that both my brothers have exactly the same way of acting, so that. So that it's been in a way easier now with mom and dad, because I've had people to share these things with". FIN - DB01

But, as expressed in the quotation below, a framework of meaning that privileges the value of reciprocity above all else is not always shared by other nodes in the network:

"...for me it is important to not to put my mother into institutionalised care. Because I don't think that she would do well there, and then I feel that I was lucky to have had parents who helped us, who showered us with attention and I'll do everything possible to avoid putting her in a home, but it isn't easy [...] my sister and brother, they see how it is when she stays with them they often say to me: we should think about putting her in a rest home, because you can't handle all of this". F - MC04 DB

A second type of collaborator is the 'flexible specialist,' that is, those who make themselves available for short term scheduled periods, but who might also intervene on other occasions:

"...my sisters used to take my mother home with them every weekend, but because it is too much for them, since June they take her every third weekend. Each of us three sisters, myself included, now take turns keeping her a weekend at a time". F - MC08 DB

"We are three sisters, and we divide up the vacation periods, now that my mother is sick we have to be organised with our time, especially since one of our older sisters died and we also have to help look after her children". F - DB02

A third type of 'collaborator' includes those who participate when there is need. These individuals must be asked if they are willing to assist with certain tasks, or may be requested by the main caregiver to establish some 'organisational routines':

A fourth type of collaborator we noted in the rich care networks (and also in the specialised networks) is the 'crisis manager'. These family members, who typically have less intense affective ties with the cared for, manage to maintain calm in moments of emergency:

"My mother is certainly glad to do it, but given the amount of care that my grandmother needs, it takes a lot of energy to handle everything, and she (my mother) probably needs to relax a little bit more, even if she's never been one to travel or go places, but maybe it would do her good if she could find something to take her mind off things. (...) It has happened more than once, she gets very upset, because my mother, my mother is a worrier, and she can upset the whole household when she's like that, and so she'll come to my house because I'm here and I'll be able to take control of the situation and call, whenever we need to, the ambulance, for example". IT -MC24 DB

Finally, we would like to highlight another characteristic of rich and broad caring networks: the important capacity to develop good collaborative relationships with people outside the family, like, for example, neighbours, even for small things. In these cases we have tried to verify how the exchange of assistance can be 'generative', where there is value added in the relationship that was not there before, and that serves to alleviate the caregiver's sense of being overloaded:

"Well, I mean when you say nobody, I had very good next door neighbours. One would do the ironing, and they would call up to the bedroom window before going to bed every night and ask if I was all right. Brilliant, they were absolutely brilliant neighbours. One, a particular neighbour, would come in every afternoon and I would go for a walk just to get some fresh air. Because it was a tiny, weeny cottage, very small". UK - DB01

"And of course they helped with the yard and stuff, they helped a lot in there, I wouldn't have managed without, and then I had this wonderful neighbour, he always shovelled the snow in the winter. I didn't have to shovel snow at all, so it was also in a way a real great help".

FIN - MC20 DB

3.2.2. *The specialised network*

The specialised network is that characterised by the greatest routinized division of labour. Unlike in rich networks, where a main caregiver typically delegates certain caregiving tasks, in their entirety, to complementary or supplementary collaborators (such as administrative or bureaucratic responsibilities), specialised networks are composed of subgroups that are relatively independent from each other. In addition, these latter usually have fewer nodes, and contain strong ties to the world of services. The interconnections are found in partial segments of the network, there is less symmetry between contacts, and communication is more specialised. Indeed, it is the differences among members, who generally, except in special cases, are not interchangeable, that is recognised and valorised. Some nodes in the network are very close to the caregiver, while others are decidedly farther away, in the background.

"My maternal grandmother was widowed eleven years ago, I live in another town, she lives here in O., I take care of... in the sense that when she needs something I try to take care of it, and my uncle who lives in Milan takes care of the bureaucratic part, that is, he take care of all of her personal affairs, her paperwork". IT-MC 26 DB

"Yes. Let's say that, besides visiting them once a week, I might have called them a couple of times a week. Then I have a brother in Oulu, who phones them more regularly, so that. And I have taken care of these, as they are both sort of, so mom, I guess dad must have taken care of these health and bank and other affairs, like he still takes care of his bank affairs. FIN - DB08

Sometimes it is difficult to arrive at an equal division of labour, and competition between siblings might even arise with regard to who does the most, or who manages the overall care

"My brother is the youngest one, the baby of the family. They've always protected him. But every once in a while he says to our mother: I could do it myself. There are some things that I do and others that he does, but it depends on what time of year it is, because he has more time than I do during the holidays, other times it's me, some times we work together, for example, with the bank, we both go with her...well, we do what we have to". F - MC01 DB

Having two persons specialising in diverse aspects of care also carries certain advantages; it can be an important resource when one of the two approaches burn-out. The specialised pattern can, in some cases, become more flexible and lead to shared and interchangeable roles in caring:

"at times when one of us can't take it anymore, the other goes more often. My brother really broke down in June, he couldn't handle it anymore, he was very tired, not just mentally, but also because of his work. Usually he is very patient with our mother, but he just couldn't go on, one day he stormed out, slamming the door behind him, he was really "going crazy" and he told me 'I can't take it anymore!' And so I told him that he had to take care of himself, set some limits, and that it wasn't worth it to get so upset, and so he took some time off" F - MC01DB

"Because she started with Alice [the sister of the interviewee], except for the time when I was living with her, it was decided that each of the children would take turns keeping her (the mother). Right now José. can't because he doesn't have a regular schedule, a regular life. She started with Alice., and stayed there two months, then she stayed with me for two months, (my sister) Imelda. couldn't take care of her because her husband is always travelling. And so Alice and I agreed that we would continue on together like that" [alternating every two months] P - DB01

In this type of network the principle caregiver usually is the one who mediates among the other participants

"I think I was a kind of mediator, you see, in the family, in my childhood family, it's totally. And the others probably thought that it's good that she's taking care of things, so they don't have to so much. But we didn't talk about it ever.

And I was a mediator between mom and dad and I felt that I little by little became a sort of, so that when I still lived at home I already started to take on the role of mother more than the others, even my mom used to say that it's time to buy a new coat or hat for mom and. And my sister is ten years younger than I so, so I somehow took care of her too and took her to her activities and to the dressmaker and to school and stuff in a way I liked it". FIN - MC16DB

In terms of the kinds of collaborators who are engaged in this network, we often find family members whose limited participation is justified by their geographical distance from the cared for. Family members who live far away are also involved in rich networks, but they seem to have a greater degree of affective involvement, despite the distance:

"But perhaps not the kind of thing, he hasn't taken part in taking care of things for example, and stuff, so that they have all been my responsibility, like after mom died, the funeral, the estate inventory et cetera, they were all my, my responsibility to take care of them. (...)

Because I live so close by, much closer, that's it. I don't think there's anything more to it, I'm sure if my brother lived here the division of labour would be different. So, it's purely because of these geographic reasons". FIN - DB08

In this network we also find 'fixed-term participants', or rather those who help when asked, but whose participation is generally more limited because of a lack of time or resources:

"I have a sister in C., then I had two of them there because the one who was living in Switzerland, her husband retired, and they came back to C.. But they have, they also have a lot of, not a lot of problems, well not problems because it would be extreme to say it's a problem, that's a strong word, isn't it? But they have all of these commitments, two daughters, the one here, she works, she works too; and so, it isn't that, you can't really ask them to help out, so if you do ask them...if you ask, it's just for a small favour, not a regular thing". IT - DB01

More atypical, in this kind of network, are those members who we might call 'the competitive inconstants'. Even though they are not always present to lend an hand, they compete among themselves to appear us "good sons". These types of members also exist in the other networks. The problem in these cases is that it is difficult for the caregiver to be certain of their reliability and the possibility that their assistance can be counted on:

" I have a sister, she can be quite supportive sometimes and that goes in periods of being very supportive or giving no support at all. (...) There will be an element in the conversation that will make me feel guilty in some way. And almost competition really, between my sister and myself, so if I don't go one day my mother will say 'Your sister's been at the hospital today. I didn't see you there.' But she fails to realise, or maybe forgets, that my sister doesn't work and I work full-

time, and that is a totally different situation. (...) I'm more constant, my support is more constant than hers which is periodic, she will either be there or she won't.' UK - SP02 FU

"But all the economic matters are my responsibility, for example. And this younger brother of mine, this Mr Overactive has been very indignant about the fact that he isn't allowed to handle them. Why is it that I can have his ATM machine card and, and, well, and stuff, that he'd like to, couldn't he do it for a while? And I've told him, by the way, that it's no fun really, that we get enough bills of our own, that they would suffice for me any day, but dad doesn't want, he doesn't. He wants, wants that his bills are paid on time, not so that they just might, because my brother has so many other things that he can't remember which bill is due when". FIN - DB04

Network members also mention family members who refuse to help, or who make themselves scarce or unreachable. These cases also come up in situations where the caring network is quite weak.

"[referring to the care of her elderly grandmother] We take care of it among ourselves, me, my children, and my husband. From a financial point of view, I can count on their help, but if I am gone for a weekend there is no one else on whom I can depend. Our relatives haven't helped at all, because my sister-in-law has two other children, so it all gets dumped on us, I asked them if we could send her [the grandmother] to their house at Christmas for a night, but she said no, not me". IT - MC14DB

"I have a brother who has been extremely difficult: 'in any case, I don't have a mother anymore'. And I said to him 'without your mother you wouldn't be here, my boy...' he was really the most spoiled one, too, my mother paid for his studies, more than she did the others, she made sacrifices for him (...) he could at least give her a call!". F - MC22 DB

It also happens that those who make themselves inaccessible are also the ones who can't deal with the decline of their parent, and they disappear because of this decline, or without any other explanation:

"I have two brothers. And well, and, one of them stopped completely, he lives in a village not far from here too, and it wouldn't be difficult for him to visit dad, but he stopped altogether at the point dad was hospitalised. Not once has he been to the hospital to see dad. I don't know. I really don't know what kind of break he's having. After mother died, for ten years, he went to see dad every day, as long as dad was well. He went there every day. They had dinner together and everything was just fine and, and then the day father fell ill, then no more". FIN-DB04

These absences are strongly-felt, and give rise to feelings of abandonment, resentment, and frustration with unmet requests for help:

"He had by that time moved to that old people's home. So could you please, as dad keeps asking things like, what about Temuu, how is Teemu and why can't he come and see me? And it's a pity that the cell phone doesn't work and, and, could you please go and visit him, since you don't have a family, you only have your work that starts in the afternoon, so you would have all the mornings to do it and, and all the weekends, and it would help the situation of the rest of us a lot. So I sent two of these text messages, and then I accidentally saw him a year ago in July at dad's, he had suddenly appeared there and, surprisingly enough, I happened to come at the same time, so he said to me that, listen, if I get one more of those harassing text messages, I will send the cops after you". FIN -DB04

The specialised network is rooted in a fixed nucleus of a few people who confront the double burden of care with a strong division of labour and reliance on external services. It is a network

that in most cases exhibits rather static routine characteristics and a certain physical and affective distance between the members of the nucleus of care and the other members who occasionally offer assistance. Compared to rich networks, it is relatively closed and limited, with high density of relations mainly around the fixed nucleus.

3.2.3. The minimal network

The minimal/absent or loosely coupled care network is composed of few persons, and is strongly centred on the principle caregiver, who has few choices and care alternatives, and very few sources of assistance to count on. If other family members are involved, they offer only complementary assistance at best, and in any case keep a certain physical or affective distance from the central nucleus.

"Well, the older brother and my husband, but their help was minor. It was so that my husband had just barely enough time for a short visit. But then it was me again and again". FIN - DB01

The structure of the network is highly centralised, with high relationship density around few people, who might even find themselves responsible for the care of elderly family members who live far away, in other towns or cities, abroad, (as in the case of the Estonian immigrants in Finland), or of institutionalised old people. This type of network is very common among immigrant families, regardless of whether or not their immigration was recent. Apparently solidarity between generations is made more difficult, or even weakened or broken, with the emigration of family members.

"We take turns to go there. We do everything that needs to be done every time. It's cleaning and going to the store and to the pharmacy for medicine. Then I every day talk over e-mail with my big sister about what the situation is and what needs to be done". FIN - MF26 DB

The relationships in these impoverished networks are one-way, and reciprocity, experienced as an obligation, is extended by very few members. Moreover, rather than finding sections of the network with high-density features, we instead see couples or individuals who take on the entire caring burden, and the management of the relations with the services. The contents of the relations are nearly always multiplex, because there aren't enough resources to develop a regular division of labour.

We most frequently find only children situated in this type of network. Some of them even find secondary advantages in this situation, though.

"When I was a little girl I always asked Santa Claus for a little brother or sister, but I don't really remember...when my mother got sick I said to myself 'I am all alone in this', but I also thought how lucky I was to be alone! Sibling relationships are packed with disagreements and discord, and we're all alone anyway. If you bring someone else in, they'd say that you weren't doing things right, there would also be these others to put up with" F - MC23 DB

The weakness of the network is sometimes the product of processes of exclusion from the network when the caregiver and the cared for create a preferential, exclusive relationship:

"I do have to admit that my brother might feel a little bit left out. This said, it's also true that he puts himself in that situation, it's a complicated situation, but I try to keep things calm for my parents" F - DB03

It is important to remember that even weak ties and connections can be activated and changed as circumstances change:

"I have a sister-in-law in Rennes who comes sometimes, she stops by during the week because she was recently widowed, and it also does her some good to get out of the house. She helps with our grandmother, and with the little girls". F - MC22 DB

In this network the interviewees often spoke about the deficiencies, about who makes themselves unavailable, or doesn't help, either because they are unable to, or because they don't want to:

" I didn't resent my sisters for not doing anything because they never liked household things. I always did, and I've always liked being with old people, probably my sisters don't. I mean it's not as though I think they are wrong and me right. Its different". UK - DB02

"Then there's my sister, she lives her own life, sometimes she comes to take my mother home with her, at the end of the period when she's staying with me. When I go on vacation my mother stays home by herself, and my sister helps her. Her [my sister's] character is different from mine, and there is some conflict between us because of it...her house is also smaller while at my house our mother has room, she has her own bathroom. My brother has a bar, he calls to make sure everything is alright, but he's no help at all!". IT-MC25 DB

When these already poor networks come undone or become smaller, or when other nodes disappear, the caregivers embedded in them often experience strong feelings of dejection, isolation, and strain.

"...so this older brother was in a way ahead of his time in going bankrupt and having all these financial difficulties. So that it was such a huge disgrace at such a small locality, and little by little the friends of my husband's parents, they didn't dare to contact them anymore, they thought that, oh my goodness, and when both of them started to be in such a poor shape too, I mean this is what happens very often that, when you become ill, people don't contact you anymore, so that even the old friends sort of disappear, they cant socialise with you because you're just ill all the time. And as it turned out, I in a way was their last straw.

then this older brother of my husband went bankrupt, and he was very young to have all these financial difficulties. And it was such a huge disgrace in such a small town, and little by little the friends of my husband's parents, they didn't dare to contact them anymore, they thought that, oh my goodness, and then when they both started to go downhill, I mean this is what happens very often that, when you become ill, people don't contact you anymore, so that even old friends sort of disappear, they can't socialise with you because you're ill all the time. And as it turned out, I in a way was their last hope" FIN - DB01

"[my brothers] aren't very close to our father. They're quite cold, in fact. They have a very distant relationship with him, so I'm the one who takes care of his health issues, no matter what it is. And they don't worry about any of it, either because they think that I can take care of everything, or because they've never had to confront problems like this, they've never had to be the ones to take care of something... because they really don't do anything at all. It's very complicated". P - DB02

In this network, we find nearly polar attitudes concerning services. On the one hand, the intensity or exclusivity of the connections between the nodes of the network often suggest that the burden of caring on two fronts can and should be taken care of within the family. On the other hand, other weak networks, whose members recognise their limited resources, seek out assistance from social services.

4. Care Networks and the Relationships between Families and Services

4.1. Formal and Informal care

In the preceding section, we focused on the informal, private networks engaged in caring for elderly and dependent family members, where family members, friends, and/or neighbours are the principle nodes in the overall caring arrangements. In this section, we instead look at those networks where care giving tasks are shared with individuals who are outside of the ‘familiar’ sphere, paying particular attention to the relationship between families and services. We will evaluate these relationships from the caregivers’ perspectives, as they are the ones who describe the contributions, as well as the inadequacies, of these other nodes in the network. In addition, we are most interested in their actual experiences and in the services that are actually taken advantage of in the care giving arrangements, and not in the overall range of services that are available through social policy.

The first striking characteristic of these networks, which is also consistent with prior research, is that the family care giver is still the nucleus of the organisational and communication network when it comes to the family’s relationship both with health and social care services. These responsibilities entail that the individual must be able to access services, handle bureaucratic requirements, and gather information on alternative care arrangements. Above all, this person must be capable of negotiating the health and social services sectors, which are quite poorly integrated in all our countries.

For our cases, we find that there is a more general, but important distinction to be made between those services provided by public or private care giving professionals, and those provided in that vast and growing grey area of paid, non-professional (and non-familiar) informal care. That which distinguishes the professional sector is the specific training and skills possessed by its workers. These individuals have followed courses or have diplomas in the specific activities which they are paid to carry out. In addition, their services are almost always organised by a public or private agency or structure. As we will see, however, the work of both types of providers border on each other, and, when provided in the home, may even overlap.

The range of professionally provided services is vast, ranging from less intense health related services (i.e. rehabilitation, visiting nurses for injections) and social services (i.e., companionship, meals delivered to the home, domestic help during the day), to ‘total’ assistance, such as nursing homes or assisted living centres, where the elderly person has around the clock access to help, and the institutional mandate thus covers both health and social needs. When the care relationship is mediated by a public or private organisation, a ‘fourth partner’ is introduced into the provider-family-user triad, acting as a guarantor for how services are provided, from the schedule to the turnover of workers.

In Italy, France, and Portugal, the informal, non-professional paid sector is wide and variegated, offering a range of types of assistance. Some types are ‘light’, temporary, and limited in nature, as with paid companions. Others entail assistance delivered daily or several times a week, such as housekeeping or help with bathing and personal hygiene. Operators of the latter type at times even live with the elderly person, often exchanging around-the-clock services for room, board, and a stipend. These workers are usually women, and in Italy and Portugal are typically immigrants from outside of the European Union. Not having had any formal training, can only at best rely on what personal experience they have accumulated with their own families, or in other similar positions.

In informal child care arrangements in which an unregistered childminder is employed, very few of the caregivers engaged actually have specific training in child care and education. These are

typically casual baby-sitters, or "au pair" young women who spend brief periods living with families, exchanging child care for room and board in their home. We find it striking that among our participants, this arrangement of care exchanged for room and board, in the case of children, was quite rare, often referred to the past (when children were of tender age).

In any case, there are marked differences among Italy, Portugal, and France in the relationships we see between families and paid services. In the former two countries, private assistance, especially for the elderly, is hired to substitute for, and not complement, public services for which the family is ineligible. In France, on the contrary, the range of home assistance available stems from an in-kind benefit (*prestation spécifique dépendance*) that can be paid directly to the public agency employing the professional home assistants, or used to reimburse the costs of a regularly employed private aid. Even families who are above the minimum income threshold can be partially reimbursed, and they also have access to an evaluation system that assesses the level of dependence. In this way, even home assistance which is completely paid for out of the family's own pocket is interpreted as a regulated prescription for care, even though our participants sometimes highlight the differences by using vocabulary that differs from the official social assistance terms of *aide ménagère* or *aide soignante*.

What follows is a typical example:

"I consider her as a *lady companion*, because that's more what we have in mind for her. She gives us moral support. She's there. She also takes care of all of the medical issues, I've delegated the doctor appointments to her, I told my mother: I can't handle the dentist and all the other appointments any more, now J will take care of them, and it has worked out very well" F-MC04-DB

This participant's phrasing is remarkably similar to how our Italian participants spoke about their private aids (see par 4.5), and the tone really differs from the more official language used regarding the forms of assistance provided by formal social services:

"My mother needs assistance practically all day long. I arranged an 'aide soignante' from the CCSA, that is a Social action centre that offers the service, one in the morning and the other in the evening. They take care of her personal needs in the morning and at night. In the afternoon there is an 'aide ménagère', every day, weekends included" F - MC05 DB

In contrast to the above, informal, non-professional and non-familiar work in Finland and Great Britain is mainly provided by volunteers, usually free of charge, who offer their services individually or through associations. Caregivers are particularly appreciative of support offered by 'self-help' groups. These provide not only concrete resources of time and skill (and often useful tools for disabled care), but also serve as sounding boards, giving caregivers an outlet to talk about the challenges they encounter day-to-day.

The results of the research compel us to provide a more precise articulation of the sphere of informal care, which is often more varied and complex than is suggested by the formal boundaries each state uses for the system of care provided for in its own welfare regime.

While some individuals engaged in providing paid, informal care are declared workers in the 'regular' economy, having been officially hired or given some kind of employment contract, others are instead caught in the black, submerged labour market. These jobs are based on verbal agreements, invisible in terms of taxation, and offer no insurance or social security coverage for the workers. In turn, the families who hire them have no guarantees that the work relationship will last.

The growing gap between formal and informal care for the elderly, in which the forms and elements of non-declared economic exchange expand and multiply (and which up to now were only estimated) is, moreover, an important sign of increasingly unsatisfied needs. In fact,

families and care givers turn to this informal ‘grey’ sector to supplement or substitute for care giving and services provided by the family and by public services.

The next section lays out the details of how families incorporate formal and informal services, respectively, into daily care giving.

4.2 Professional Services

All three types of networks we discussed in the previous section—rich networks, specialised networks, and minimal networks—exhibit connections with professional services. From our participants’ experiences, we understand that the most important factors in obtaining and using services via relations with professional providers and the public sector are:

- a) the circumstances leading up to the request for services
- b) accessibility
- c) availability and flexibility of resources
- d) evaluation of the quality of the services and how they are delivered
- e) the capacity to integrate, within the network, different kinds of services, and to consider the family itself as a resource and node in the network; this is typical of services providing case management
- f) ease of dialogue and collaboration, that naturally follow from the previous ones, above all when the case involves prolonged or terminal illness, or the various forms of senile dementia and Alzheimer’s disease.

A) The Request for Services

The resort to services provided by individuals external to the ‘familiar’ sphere may come suddenly, in case of accident or crisis of the elderly. When the health conditions deteriorate in a longer time, the request for services can follow a slower process during which family members realise that they are in need of external assistance, but also find themselves having to convince their elderly family member of the benefits of such a choice. This process can be long and difficult for everyone involved, especially those who find such a change unacceptable. In some cases, an elderly family member will refuse being bathed or assisted with personal hygiene by outsiders. Others don’t like the idea of having a stranger in the house, or else they resist admitting that they are no longer completely self-sufficient.

“We had the aid for two months. When it comes to the bath, though, my father doesn’t want anyone but my mother to touch him, and so when she also was disabled for a time it was a big issue because she couldn’t help him with those kinds of things anymore.” F - DB03

“Also because they, despite everything that I said, it was only for necessity that they moved in with us. But if you think about it, really, here we are, we have a house in the middle of nowhere, it’s like a ranch, isolated, and they missed their own room, their house, and they are cut off from the few outside relationship that they had, and so they were relieved at the chance to go back to their own house, but we said we would agree, because it was their own idea, only if they would get regular help, on this we really wouldn’t budge! We also told grandmother: “Look, either you’ll have to come back to our house, or go into a retirement home!” that we never would have done, but I used it as a bargaining chip, I’m the one in the house who really plays the ‘heavy’, but it was only to convince her, it was unthinkable that she try to live on her own. You could also see how the house was starting to get run down”. IT-DB03

“It was a very complicated phase for us, because my mother-in-law was in the hospital... and he [the father-in-law with Alzheimer’s] was left alone all day... So we looked into the Association

(the Portuguese Alzheimer's Association) to check out the possibility of getting some assistance.

Q: Because your mother-in-law still manages to watch over him, to keep him from being disoriented?

R. Exactly...but once he went out to look for her...so, leaving him there alone...it's unthinkable. But to find someone who is available, even for pay... to take care of him all day long is very difficult... so then he had to go into a residential centre for a week and a half...it was only temporary though, he had to leave because in the mean time his place had already been assigned to someone else. Only later did we find out about this adult day care centre, where they watch over the clients like in children's day cares. We would only have to drop him off in the morning, and pick him up at night. The meals are included.

Q: Does he go to this centre, now?

R: No, he's at home. We still haven't taken him, but at least we know that it is an option. In any case, it costs 3000 S a day, that would be quite a lot for them". P - MC09 DB

"But really, because my Mum is quite independent she didn't really want to accept any help. The only help they were offered was someone to assist my father getting ready, washed or showered every day. But he really kicked up a huge fuss about that in his more lucid moments and refused to have anybody in and really got very aggressive towards them". UK - SP02 FU

Sometimes caregivers must hide the fact that they have asked for and received help, even of a completely impersonal nature, such as financial assistance for care, because 'she would feel like a burden to me [the person being cared for]'. This was the case for a Moroccan family, where the traditional obligations to care for elderly family members is felt as an 'unavoidable duty'.

"Q [when the interviewer points out the option of asking for in-home assistance]

R: This I couldn't do because of my mother's character, she doesn't have, she doesn't, well, the fact that I have to hide that I receive a check, a care allowance for her, that says everything about her character. Yes, because she would interpret it, she would think that she was a burden to me ; it would bother her that if I asked for it. In fact when they came, I couldn't tell her why because it's her character, she's always been someone who would get up at 4:00a.m., she always worked, she never got tired, the things that I do for us are nothing. They worked, they worked in the fields, all that work outside, she's a very strong woman, one who never gets tired, for her these things, for them, what we do is nothing, what do we do? We have dishwashers, washing machines, compared to what they had, life is easy for us. So it wouldn't be right if I went to ask for help." IT - MF27 DB

B) The accessibility of services is an indicator of how those services work, and it is necessary, from time to time, to analyse who makes the services accessible, what services are made accessible, and to whom they are made accessible. It is important because it gives us information on a fundamental stage of the process in which a formal right is materialised. There are three levels of accessibility, which comprise the communication of information about the services to citizens (what they are); information about who has entitlement to the services; and information about obtaining them. Participants from the various countries underlined the importance of simplifying this procedure as much as possible, especially from a bureaucratic point of view.

"But with the bureaucracy, it almost seems like it isn't worth the bother. To find out about getting a disability benefit , for example, to get the disability benefit I think I lost at least at month before I finally had all of the information. Because there wasn't anyone who could tell me what I needed to do. Then things change there, too, the City is involve, the ASL (local National health office) the Prefect, and then the competencies of the Prefect were passed to the city, the City Disability Office—all of them are involved! It took at least a month to find anything out. Then what did I find out? Just where to pick up one of the forms that I had to fill in and send—when

they would let you send them—sometimes I had to go in person. And trying to take care of this, for someone who already has a job, with the opening hours of the public offices, it's a mess. Thank goodness there were some things I could just put in the mail. It's really a an endurance test!" IT - DB04

"It's a four part form, written in small letters, and complicated, you have make a bunch of photocopies, I don't know how anyone could do it by themselves, but they want her signature on it, at the bottom, that's clear, 'signature of applicant', of the person who filled out the form, and my mother signed it!" F - MC05 DB

"..my Dad has worked all his life [..]. He has applied for various allowances but has been turned down. Maybe he didn't fill out the forms right, but in that case there should be someone there to help him". UK - MC08 FU

Dealing with bureaucracy results as a specific skill of a citizen needing access to formal social care:

" There should be one person who knows both the services that the public sector offers and the private services. And he or she could then build these kind of packages, and would possibly also help in filling out all these forms." "Because a person cannot, let's say that why I did not apply for other kind of help, was because in that bureaucracy there was so much to do that I could not have coped with it." FIN-DB17

At times the bureaucratic process is so long that it may hinder the use of services, and the assistance only arrives after the person has died :

"I don't know why, but my uncle had taken care of everything, but I don't think so, and he finally got approved for home assistance not very long after my grandfather had already died. I don't know many details, because my uncle takes care of all the administrative details, even though he lives far away he manages to take care of all of these kinds of things, so from that perspective he's very present: IT - MC11

"We trying to get home assistance through Santa Casa. To tell the truth we didn't go ourselves, we heard that if the children or daughter-in-laws made the request, it might seem like we weren't interested in taking care of our family...so they discouraged us from going to Santa Casa in person, but someone else, without mentioning the children, so my mother went for us... My husband is always taking care of things for them. That's why we're trying to get the assistance. But it's very difficult. Really really difficult... My mother tried to make them understand that their case is extremely serious, that both of them, not just one, need help. But they say they have much more serious cases to take care of... We've been expecting someone for three weeks now, but so far no one has come. My mother has been calling every day, but so far no social worker has arrived. It's been three weeks since they told us we could expect someone, and we really hope they will come". P - MC09 DB

C). The availability and flexibility of resources is another useful indicator for understanding how services are incorporated into family care arrangements, which often depends on the schedules of the adults, children, and services involved in the care arrangement. Sometimes it is impossible for families to take advantage of services, either because what is offered is inadequate with respect to what is needed; because the hours of service provision and need do not coincide; or because the services are too rigidly defined. Mismatches between services and families, and the associated impossibility of adapting services to families' needs often lead to deep inconveniences or waste:

"[You said services were coming in morning and evening. Did you choose these?]No. Well the social worker came and gave us this interview, and I don't know whether, if they had given me a

choice of what was on the cards at that time it would have meant anything because I had no idea what they were like.(...) She said this place is whatever. I did though change agencies as I went along because I wasn't happy with them. Once they let me down, one night a carer just didn't turn up and they didn't apologise for leaving my mother sitting up until 10.00pm when I came home as I had broken down somewhere. And you know she frightened me because she would just fall out of the chair at that time. So after that I changed agencies. (...)

There was no facility, London was not as good as Kent they just sent me out of that hospital with no help at all, and I couldn't even physically lift her to get her to sit on the toilet or whatever. UK - DB02

"When they need to go to the doctor, my mother can still get around enough to go by herself, and my father goes in an ambulance...I call. Sometimes I try to arrange for the doctor to go directly to the house, but because they don't have to, its almost impossible to get them to agree to it". P - MC06 DB

Sometimes, if families don't have enough caring resources of their own, they must turn to paid assistance to pick up the slack, even in countries with good social services, such as Finland:

"Not really, I have managed this way, I don't expect, I'm not that way. But I did ask last winter for example, after dad had fallen, I asked then if home help services could check on him a bit and see if he needed other kind of help in addition to the meals and the cleaning up. But they didn't think he did. And I'm not sure really what they would do there, he gets the meals now and they take care of the cleaning. And the cleaning woman, as she comes from outside, I mean that it's a private service, so she does the laundry too, or puts the laundry into the washing machine and does things like this." FIN - DB08

Another inadequacy in resources, or obstacle to obtaining necessary services, is related to particular events, for example, to the needs associated with in-home recovery after a fracture:

"The physical therapists don't make home visits, except for cases that are much more serious than my mother's, if the person is paralysed, for example. There's no way around it, they don't want to make home visits, I had requested it when my mother broke her hip last April, and they came until the summer holidays started, in June, and after that I couldn't get them to come back". F - MC08 DB

In other cases, the waiting lists for public services are so long that in effect, they are 'useless and inaccessible':

"When it comes to the elderly, it's a different story, I've heard lots of promises, but I've never really had good concrete help, so I've had to resort to private aids. There are a lot of good intentions in public services, they even came to our house to evaluate my father's level of dependency. His stroke happened on November 5th, but they didn't make their visit until May. It's true that he was in the hospital for two months right after, but what was I supposed to do in the mean time? Anyway, they finally did come, and they made us a lot of promises, they said that he had a right to a home aide, and so on. Then after two weeks we got a letter saying that the evaluation of his level of dependency would be postponed for a year. And I thought to myself let's hope he's not dead by then, he's eighty years old, his whole right side is disabled, and then he just needs help with daily things, nothing really special. My father tries to respond, he speaks, he remembers things, he wants to do things, but he needs constant stimulation, you really have to push him. And from this point of view I'm really dissatisfied, because I can't wait another year". IT - MC16bis DB

D). Evaluations of the Quality of Services

In addition to the many types of financial benefits available to families for the care of elderly persons, many of which cover all or part of the costs, our participants have requested and tried

out nearly every type of public and private professional service that is available for the elderly. These range from home assistance, (from meals to help with personal hygiene), to hospitalisation or residential facilities. There are variations in their use, on their impact on the care arrangement and on the meaning of such forms of assistance have for the personal lives of caregivers, who are situated in more or less wide networks of care.

4. 2. 1. Non-residential services

Families who use non-residential services, such as home assistance and adult day care centres, note the particular characteristics they appreciate or look for most. Those who are satisfied with these services, are happy that the elderly person does not have to be uprooted from his/her home to receive assistance with daily care. They also mention the speed of service delivery, scheduling compatibility, the personalization of care, the flexibility in terms of what tasks are undertaken, and the capacity to integrate the services with the particular needs of the elderly person and the general family network of caregivers.

"From my own experience the ladies who came to give support were nice and chatty and they were making a good effort in getting to know the patient. They would have blended into the routine if the situation had been easier. In a situation where the ill person is happy for care to come in I think that the relationship would be good and one should be grateful for that kind of help. UK- MF12 FU

"Right, in the beginning of the year. And well, we were then, we had, were so very lucky that when he had been in the social services office the previous spring and inquired about these taxi tickets, he had inquired if he could get some taxi tickets, as he had heard, he belongs to the age group that does not easily go and ask for anything". FIN - DB6

"Yes, first of all I got on to my own GP and straight away he sent the district nurse up. Excellent it was, she came the same afternoon and said 'The first thing you will need is a commode,' as I couldn't get her up my stairs to the bathroom
We had to get a bed settee in there and do everything in one room. We couldn't even get her through to the toilet as the wheel chair wouldn't go through my doors, and the toilet was too small. So they brought a commode, a bedpan and they set up agencies to work with me. Morning and evening to help get Mum up and get her to bed again.
[So the nurse set up the agency morning and evening help?]Yes. We had a package set up".
UK - DB02

"No, but that wasn't even, I was going to say that it would have been awful to put her in this day care situation, but that really wasn't true because in the whole time she was going there, the van would come to pick her up in the morning, and would take her to this retirement home, they were there, they played cards, they'd visit with each other and then in the afternoon she'd take the van back home". IT - MC11

Such an experience however seems to be shared by a minority of families. Moreover, though families certainly appreciate the support provided by these 'adult day centres, which often offer more flexibility than do residential centres, the problem of costs is very real for them:

"There are adult day centres, but if you aren't able to pay for you, you can't use them, you know. Because if you go to the day centre you also have to pay for that, too, then you have to leave a deposit, that's fine, they'll refund that, they'll give it back, but if you don't have it in the first place, the rest centres are, they also have overnight facilities, they'll keep them there for fifteen days, you can leave them for a month, two months. And they keep them there, regularly. [Does it cost the same as a retirement home?] It's like a retirement home, yes, it's the same. The day centre,

for example, they ask for a 500.00 Euro deposit; so that's all money that goes, but they didn't realise that it worked like that. (...) Yes, I pay the ticket for the day centre, it's 29.00, 28.50 E. a day, something like that. Home assistance costs 5.40 an hour. Yes, the social services; it's all managed by a cooperative. And I noticed that for the home assistance, in the last two months they've given a 30% discount for Alzheimer's patients. I'm not sure how long that will last" IT - DB08

Families also appreciate when home aids are willing to do work that isn't strictly part of their role, thus taking up some of the tasks usually done by the family. This comforts and reassures families:

"Sometimes the *aide-soignante* asks: 'what can I do to help you?' and so I ask her if she would mind ironing a little, and she might do that for half an hour while she talks with my mother, they are small things, but she is really very active, she'll pick up the broom and sweep, she seems very comfortable doing things like that. She's the one who asks me if I need something done, because I consider her job to be taking care of my mother, but since I, for example, I do her laundry for her, it's like she's supplementing what I do" F - MC04 DB

When families perceive the help in this way, they feel more certain that the aid has 'taken to heart' the situation, and that they are good companions for the family member. This trust is necessary and inherent in any service relation where someone entrusts a dear one (whether a child or an elderly family member) to someone else's care. It is a trust that is renewed daily, and that is sometimes founded on the recognition and acceptance of different ways of managing the care:

"...yes, we trust her, I know that if something came up she would call us, she would tell us, when we run into each other she tells me what has happened, how things are going. Yes, I know, even if things aren't always easy between the two of them, because my mother has a rather difficult personality" F - MC01 DB

"Yes, I don't think that it is easy to live with someone else, many people couldn't handle it, of course if they live with you it's clear that they are doing everything for you, and you can't expect that they will do things exactly how you would. I tried having live-in help when the children were young, and we always managed to compromise on things, but she (the mother-in-law), instead...well, you know, these qualities get stronger with age, at least in our case that's how it's been" IT - DB03

When the relationship between the aid and the elderly person is a good one, it can become an important resource for the elderly person herself, who might feel less restrained than she does in communicating with her family, 'chained by affection and responsibility to care'. Indeed, feelings of competitiveness and jealousy, analogous to those felt by mothers with respect to their young children's caregivers, might even emerge:

" Often when people are very elderly and sick they can sometimes communicate with outsiders in a better way, because they have the freedom almost, when it's paid workers, they can talk about their relatives as well. It maybe that they feel they are a burden on their son or daughter and they are not going to tell them but they can tell the carer. (...) I think, as a relative, I could understand it, but some people may not be able to and will feel jealous of the relationship between their father or mother or older brother with a carer. 'Why aren't they like that with me,' more or less". UK - SP02 FU

Some caregivers even feel surprised at the idea that service providers care about their own problems:

“So it was sort of funny I think, when I for the very first time contacted these home help services last spring and inquired about their services, so it was funny when this person said that have you cared for your parents all alone, aren't you tired? You bet, I said” FIN - DB02

Vice versa, the frequent turn-over of home aids is seen as problematic because the elderly person must start over in terms of getting used to and trusting another aid and having someone unfamiliar with his/her needs:

“There is a departmental committee that centralises the applications and the assignments of the ladies that come to the house. There is one lady in particular that my mother really likes. She's probably in her fifties or sixties, and she's very charismatic, she does things with an authority and know-how that my mother really appreciates, and when they send her substitute things don't go as well. She's younger, and maybe she's a little too obedient, she'll do whatever my mother asks, and sometimes that's not the best thing” F - DB01

“I would prefer someone, well, these young people from home assistance already have this kind of experience, they're already used to this kind of work. Luckily in the morning we always have the same person, but they change in the afternoon. They change all the time, and this was a problem, because once she gets used to them she can recognise them, but if they change all the time she can't do this”. IT - DB08

Equally problematic are scheduling rigidities that often don't take into account the fact that the caregiver must co-ordinate a number of different needs (from work schedules to child care). In the case below, a Somali woman who resides in Italy describes her experience in this regard:

“[referring to home assistance]. Yes, they gave it to me; there is one who comes three mornings a week. That's good, I've got that in the morning, but who can I leave her with in the afternoon if I have to go to the hospital for treatment? I asked the social worker, and she had my mother put in a nursing home. Three months after I had my baby they asked me 'if you want you can leave your mother there' and I said 'no, I can't' and I brought her home. Before the children went to the crèche, now they go to nursery school, there's a little bus that picks them up, and I have to go down there to meet it. It arrives at 8:00, 8:15, and so I requested that the home aide come afterwards, if I'm not in the house, who will open the door for her? No one. I asked her to come at 9:00, but they said 'at 9:00 no one is available'. So I just said 'thanks, my mother is bedridden, anyway'. IT - MF31 DB

“This kind of flexibility is lacking entirely, I think it's the big problem, that the flexibility between different kinds of care solutions for the elderly, not to mention the fact that the co-operation between the different actors in the social and health care sector isn't always the best possible, there are lots of examples I think out there in the field, that it doesn't work yet. These kind of things.” FIN - MC21 DB

Some of our participants also comment on the 'rushed' way the services are sometimes delivered:

“So that, so that these projects always have fine goals, but they won't become reality for everyone at all, but for some they do, and it's of course important to an elderly person that some additional person comes to see him or her and the family member does also get some security out of the fact that someone from outside comes for visits. Home help is of course a good solution for those who, who need help in practical matters, but home helpers are really in such a hurry and they never have time to stay for very long”. FIN - MC16 DB

4.2.2 Residences and assisted living facilities for the elderly

The decision to leave one's own home and move into an assisted living facility or residence is never easy, and the elderly person may fear rejection from his or her family, considering themselves 'a useless burden':

"And well, first of all he was really disappointed, since he made the comment that he was in such a bad shape now that no one wanted him anymore. And we were very disappointed too of course, since we knew that he had been looking forward to getting back there and things would have been so good there". FIN - DB04

These fears also emerge even when the quality of the facility and the professional competence of the staff is certain, as in Finland, where this solution is socially acceptable, and the network of these services guarantee good qualitative and quantitative coverage of the needs.

"So, in September he got an own apartment there, a room of his own. And, well, we could then furnish it a little, we took some of his own stuff there, what we could fit into that small room, it was anyway sort of like an own place and, well. And over the summer he had sort of already thought it out that this, this is it. And the care is good and good caregivers and. The room is nice and, well, he has sort of settled in there, so that this past year has gone really well there and. And it looks like it would in future too, so that so far there haven't been any illness-related things, the illness seems to have sort of settled, the fever had perhaps something to do with the advancement of paralysation, so that it was only in the legs at first, and it has risen higher up in the body now. So that, so that, he sits in a wheel chair and, and, and of course gets the basic care there". FIN - DB04

"I felt that they had too little staff there, and, and well, for supper mostly, to see that she ate. At first I just checked that she ate and finally I fed her for a long time. So it was sort of like this, and changed diapers, because I thought they didn't change them too, or often enough. I saw to it that she wasn't over-medicated and, and you see, I did express my opinion about things like this there.

Well, it's true that they were quite negative, particularly at the stage when mom was there, because it was a 40-bed ward and, and it really wasn't one of Sopimusvuori's units, which are quite ideal, so they didn't have time for any kind of individual care really, so the nurses worked hard there, but when they went, the food was delivered, that took a while, and after that they did a round changing diapers and, and well. It was the routine kind of thing and there was no extra time. So that's how it went, you see, it was quite, well, basic needs were satisfied. Although I felt that the most important thing was to be there to feed her she didn't eat well, so they didn't care so much, so that if she said that she's not hungry, okay, you don't have to eat". FIN - MC16 DB

Both nursing homes and geriatric wards are still greatly influenced by the depersonalisation and routine of the total institution that is present in many European countries:

"We saw several nursing homes...there were some we entered where we just turned around and walked right back out the door because that was enough to understand that it wasn't worth looking at the rest of the place...the strong odour of urine. Others seemed better, but the worst was knowing about the rest" P - MC09 DB

"The patients that I saw were almost all old people, really really old people... The one in Alentejo... it's pretty good, there's a waiting list. But I didn't like the one I saw here, because I think it would have been like killing them that's to say, the people who were there, they were all so old that they were beyond communication, no..." P - MC06 DB

"[wife] Well, hmm, well. It's worse than a crèche, but you should see how many there are. The thing is, they have, but as soon as one of them dies it's just like at the supermarket, you know,

when you take a number to wait your turn. As soon as one dies, they put someone else in his bed right away, but you should see how it is...really atrocious...Really barbarian". IT - DB01

Being hospitalised itself can also cause other side-effects, creating illness in individuals who are already fragile and debilitated. This could be a result of inattention to the patient's needs, or because of too-frequent shuttling from one ward to another, or if an elderly person is sent home from the hospital, only to be readmitted immediately after.

"Well, before father was hospitalised, he was still able to take a spoon into his mouth, but then in the hospital, he regressed so that somebody had to hold the mug for him when he drank and I fed him for the very last time right before he died. The nurse was so lovely afterwards, after father had died, and she even phoned me the following day and said that it was very touching, that she had seldom seen anything as tender and beautiful as those moments between my father and me". FIN - DB02

"Well, it's been above all this constant shuffling back and forth that dad went through and then the quality of care in that Hospital and the way they handled all patients as if they were psychiatric patients. (...) all the discussions that took place, they heaped abuse on family members and so that in that way, totally incomprehensible. when we tried to negotiate the process of that continuous transporting of him in an ambulance, sending him back home directly in a very poor condition, and from the emergency room directly to ward where he was totally crippled, until we again managed to get him to the hospital where he was held sporadically. (...) And when it started to dawn on us what the quality of treatment also for our father was there, we started procedures to get him out of there. And well, actually his condition became so bad in there that he was thought of as a terminal patient. He was actually undernourished, since we didn't notice at once that no one helped him with the eating, so I don't really know how badly he was dehydrated, but when we finally realised it, we started to go there every day to feed him, and then we managed to get him a place at this hospice, the, the, what you do call it the only hospice there is, what is it now?" FIN - MC21 DB

As in the above Finnish case, an Italian participant reports a similar dynamic in an Italian hospital, where relations between the family and the staff are complicated by misunderstandings with and incomprehension from the head of the ward, who manifests prejudices towards the children of the patient, 'presumed guilty' of not wanting to take responsibility for the care of their elderly family member:

"The head doctor of the ward was inflexible about his decision to dismiss my mother, even though the other doctors didn't agree and said that she should remain hospitalised. He also made some sarcastic comments about how we shouldn't use public institutions as a 'parking lot' for the elderly, and he didn't even change his tone when I explained that my mother had been admitted via the emergency room in a diabetic coma. And can you imagine he even refused to put in a request for us that she be placed in a private facility, in convention with the Public Health System. He had an incomprehensibly punitive attitude towards us (three adult children), and in his opinion we didn't do enough for our mother. It was really his own prejudice, as he didn't know anything about us..." IT - MC02 FU

These cases of 'institutional insensitivity' grow out of the health system's impotence and inadequacy in confronting the complexity and growth of the demand for geriatric care. And it's not only this: these episodes testify to the weak capacity of considering family members as legitimate mediators for their elderly relatives, given the precarious state of patients who can't 'defend themselves alone', as was evident in the Portuguese case discussed above. The cultural matrix of these institutions recalls the traditional, asymmetric relationship between doctor and patient, where the doctor has the power to make unilateral decisions about the patient's well-being.

In contrast to the above, small, friendly structures where the medical component is de-emphasised are greatly appreciated:

“The situation has settled down now a modestly furnished room of eleven square meters and two men in it, it’s their home, the eleven square meters. Nothing extra fits into the room, but the care is good, the nurses are very friendly and, and nice and, well, it’s totally clear that dad has it quite well there, he doesn’t long to be anywhere else and we don’t think there have been any bad states of incoherence it doesn’t seem that he’d be overmedicated or anything, just enough that, he does take some medication but he’s by no means never tired because of medication or so that the conditions are good in every conceivable way.” FIN - MC21 DB

Hospices are also appreciated, where the care of terminally ill people is delivered in an atmosphere respectful of the privacy and the affective relations that bind family members. These facilities guarantee much better quality and continuity of health care than can be provided with home assistance:

“I think hospices are marvellous places. In retrospect I query whether she would have been better off in a hospice, not home care which I don’t necessarily see as the best form of care. Hospice care with better medication? I don’t know but I can’t beat myself up about that because I did the best I could”. UK - DB01

4. 3. Case management and networking

While our participants did not explicitly mention case management, or the work of the network, they did so indirectly every time they brought up the importance, from their point of view, of co-ordinating the assistance offered by various providers and services, or when, conversely, they note the absence of these webs of services, and their fragmentation into rigidly separate competencies.

Case management was first developed to support de-institutionalisation of mental patients in the United States and it was a response to the fragmentation of both public and private services. In Europe, it was mainly tied to the policies of community care, (especially for cases of long-term care) and emerged as a response to the lack of flexibility and, again, to the fragmentation of public services (Fernandez, Davies 2001). The objectives of this type of intervention are those of maintaining the individual (especially the elderly) in their own environment for as long as possible, to relieve some of the weight and responsibility of care from the primary caregiver, and to improve the effectiveness and efficiency of service use. Case managers are individuals capable of activating connections between different services; de-centring responsibility; evaluating the effects of the interactions between the nodes in the care network; and, by taking into account the autonomy and wishes of the caregivers and people being cared for, manage to shape the configuration of services so that they best meet everyone’s needs. Rather than ‘directors’ of the network, a label that recalls the idea of a centred network governed by services, it seems more appropriate to speak of case managers as activators or advisors of the network and the subjects that it consists of. Below are two examples of case management, where the caregiver describes how the network among services functions:

“So I just phoned everyone. I just made contact with every possible support group and everything. I was greatly helped by the counselling service here at the university who gave me lots of ideas as to how I could get help. And, basically it all came through the GP who referred M through the X Hospice. And obviously everything was supported by the consultants up in London. So that’s how it all got organised. They were very quick and helpful. (...) We went through a couple of meetings for the assessment purposes. There was a lady from Social Services, the district nurse and the GP was involved as well. And between all of us we worked

out what it was he needed and how it could be done. And, in fact, they organised for 4 calls a day which is more than they usually offer" UK - MF12 FU

"Well, we could say that I kept contact with the attending doctor. They did try to arrange, they contacted a social worker at the health clinic, so that in a way my role wasn't so much about arranging things at that point. The social worker at the health clinic was active and tried to arrange a care place in a care facility". FIN - DB08

The perception of the user is one of swiftness, efficiency, and personal involvement of the service providers in her problem.

In contrast are the perceptions of those who, frustrated and discouraged, feel themselves to be at the centre of a discontinuous and uncoordinated web of services, broken up by isolated institutional competencies that do not overlap or communicate, and that do not even keep individuals informed of their rights. In these cases, the primary caregiver or another family member paradoxically becomes the person responsible for putting together agencies and service workers who do not talk to each other, and co-ordinating the delivery of services. Furthermore, the user feels constrained to negotiate or insist on services that he/she instead feels are an acquired right:

"Simplify. When you're talking about the elderly, now I understand that in the past there were problems with fraud, but you can't generalise like this, it only makes life more hard for honest people like us, that is, if the ASL recognises your right to an invalidity pension, why shouldn't the public services then also do the same? It can't be that the city ignores what the ASL does, but that's how it is! Now that's just one example, but who knows how many others there are, you know. You shouldn't always have to go and complain to people to get what you have a right to, the squeaky wheel always gets the grease, and that's not right, the principle of it is wrong, you can't keep doing this. It's the same at the bank, if you want to get a better rate, and you have a right to it, why should you have to go talk to the director about it? It's the same, the same thing! This is the level we're operating one here! But here you're talking about people who have a right to nursing assistance, not to a bank account, for heaven's sake!" IT - DB04

4. 4. Information and Communication

The theme of information and communication among caregivers, their families, and services--crucial for the good functioning of almost any kind of personal services--assumes a different character here, tightly connected to the preceding themes.

There are three main points:

F) In contexts where the network of services and institutions is particularly scarce or poorly co-ordinated, being able to find out useful information is crucial for accessing services:

"The biggest problem for me are the things that I don't know about, I try to keep my eyes open, to find out things, in fact I'm always on the internet to see what the city offers, because that's my biggest problem. It's getting the information, and having time to go through it." IT - DB04

-Parallel to this theme, already noted, emerges another more tied to the specific characteristics of the double front of care: the specialisation of sectors and networks into child care and elder care. Only rarely does one find a unique point of reference that can serve as an information and service centre 'for whomever who has problems of care', regardless of whether it is care for the old or the young, as in Finland:

“Right, well, there are some, if you have a need to use them. If the children are small, for example, you have all of these services to help take care of children and the elderly, home help services for families with children.” FIN - DB08

For non-professional care work in Italy, parishes often play this role, and end up as a meeting point between the supply and demand for care giving work. Both families seeking an aide, as well as individuals, Italian and foreign, who are seeking this kind of work, turn to them.

-More information and communication is especially sought after by families who have an elderly person affected by Alzheimer’s disease. These families want more information on the course of the illness, as well as on how to care for their relatives afflicted with it.

“ From home help I would have expected that they would have been better informed. At the moment the situation is, it has changed a lot in just a few years I think. Even though I’m now, I don’t have so much to do with them, but, but in the way that we now know much more about dementia and it isn’t such a mysterious, mysterious thing as it used to be to so many people, so that they didn’t know what it was and how to take it (...) And finally I then leafed through the phone book and found a dementia advisor, so she was the first person who then understood a little what I was speaking about. It was as if, as if, even though I then didn’t want to at that stage, she would have made a home visit too and, and so, that was it. So it wasn’t more than that conversation at that point, but then, then I started to have a look at the things they were offering “. FIN - MC16 DB

“ I think the best system is if we develop this home care, home help, so that you can get help, get help in your home for as long as possible, but even that is sort of a two-sided affair when it comes to demented persons, because even that doesn’t, it doesn’t really work, this home care, because, because, well, because those home helpers are there only for a short moment. But other people, you know, can be cared for at home for long, with these, what do you call it, meals on wheels and other services. But in case of a demented person, it doesn’t work”. FIN - MC20 DB

In the growing literature dedicated to the effects of this type of illness (Censis 1999), there is growing consensus that these pathologies can be considered *family* illnesses, both for the level of care that implies a radical reorganisation of the family, as well as for the heavy emotional toll taken on caregivers by the progressive loss of identity of the afflicted person. Indeed, caregivers themselves often suffer physical and psychological upsets related to their involvement in this type of care (Quaia 2001). Family members continually refer to biographical episodes that took place before the elderly person fell ill, as if they want to be sure that the service providers understand that their loved one was really another person before the onset of the illness.

“I started noticing it about two years ago, and then after a few months, This disease was recognised, but then in the end, yes. Maybe even two and a half years, because she started to lose things, she was living alone, so I didn’t quite realise what was going on, and the doctor told me it was arteriosclerosis, ‘it’s normal at her age’, but to me it didn’t seem normal, also because she would do things that she had never done before. So I took her to a doctor, and they referred me to a neurologist, but then three, four months went by, they told me what the treatment was, “but she’s fine, she’s fine’, then, in the end, No, no, because she wasn’t sleeping at night, we couldn’t even get her to sleep, she wouldn’t even take her shoes off, she wanted to go back home when we were staying with my aunt at the seaside. Every night it was like that: on the third day I took my little boy and I said ‘we’re going home because this is impossible here’. So I went to see this doctor, I explained what had happened, and he gave me a prescription. But he didn’t say it was Alzheimer’s, he didn’t tell me anything. (...) The medicine made everything worse, anyway, the hallucinations, all of these strange things. Now she can walk straight, before she couldn’t, now she’s doing much better, (...)

[referring to the medication] At the beginning when I went they told me 'it's so we can manage them better', because she had an impossible character. She didn't want to get undressed, she didn't want to wash herself, she was really impossible; instead with that little by little yes, I was able to make them do what I wanted. But for now it's enough, because I see that now she's doing much better, and then, she's reasonable. But I still am not sleeping well myself, not even now, because if I hear a door open I get up to see what she's doing". IT - DB08

When the family member eventually does have to be hospitalised, usually because of the need for 24 hour care, sometimes caregivers feel guilty for not having known how to do more.

In fact, many structures, even expensive ones, are not prepared to take in this type of patient:

"We postponed looking for a nursing home until we had gone to speak with Doctor L (from the Alzheimer's association) because it is still hard to find places who accept Alzheimer's patients. We wanted to know how other families manage it, that the doctor would give us information on which...P - MC09 DB

Family members also yo-yo between high hopes for new medications and medical techniques, and disappointment that they still don't seem to produce appreciable results. They oscillate between attitudes of vigilance and hyper-control, to a complete delegation of all care giving to professionals and institutions. What services often do not address, however, are the troubles in the family, of the care giver, given that the problem is not only the sick person's, but also that of whoever in that moment is caring for him/her, and they must express it, live it, re-elaborate it, and communicate it to others.

"...when it comes to these grave cases, the doctor or someone... there should be someone who could explain things to us, because we are all disoriented, we don't know how to treat him, or who to turn to... I tried going to the city, even to the Church... but there's not a single thing offered to give us some direction, that tells us where we should go, that explains everything clearly" P - MC09 DB.

As we will see below, in these cases associations and volunteers can be of great help.

4. 5. Non-Professional Paid Care

That which some scholars have called 'hidden welfare' (Gori, 2001), or the submerged social market of personal services (Ranci 2001), is an extremely interesting phenomenon in Southern European countries. The notable diffusion of this form of care was relatively unexpected, but tied to the process of the commodification and externalisation of care into a low-cost and, with recent immigration, completely segmented labour market. In Italy in particular, experts were surprised at the discovery that, in early estimations, this type of work makes up about 5% of in-home elderly assistance, greatly overtaking the barely 2% coverage of formal in-home services (Gori 2001). Its relative invisibility is tied to the fact that it concerns the *private* exchange of assistance, usually in the home, often undeclared from both fiscal and social security points of view, and provided by, at least in Italy and Portugal, male and female immigrants from the third world who often do not have regular resident status.

In the words of one of our interviewees from a previous workpackage:

"Here in L, for example, immigrants from outside of the EU can only find work assisting elderly people 24 hours a day, and it's a demanding job, you don't have time to take care of your own children; so in my opinion there needs to be more opportunities to find different kinds of work. To have more free time for your own life" IT - MF14

In Italian, the term '*badanti*' or 'minder' originally referred to elderly ladies who spent a few hours each day taking care of old people who had been hospitalised or institutionalised, often bringing them meals and substituting for family members who, because of problems with work schedules, were unable to supplement and 'humanise' the services provided by the institution. Today the meaning has expanded to include younger male and female immigrants who are 'assigned' to take care of an elderly person in his/her own home. Beyond the debate about what these home aids should be called (Piva 2002)--they can't be classified as *colfs* (family collaborators) because their main responsibility isn't housekeeping--nevertheless, they carry out their activity in the home and for the home, as well as for the person who lives there (providing care, assistance with personal hygiene, shopping, meals, and companionship). They are employed expressly to help a person who is no longer capable of looking after him- or herself, and when his/her family members are unable to meet his/her needs. In some cases the job entails assistance only during the day, while in others it requires that the aide live with the elderly person, thus providing around-the-clock services, with only two afternoons free a week.

Q:[how many days off does she have?]

R: Two days, two half-days, Friday and Sunday afternoons. We take turns on Sundays...On Friday afternoon, though, it's almost always my sister who takes care of her, because she's less busy on that day; that is, this woman has practically two-half days free, but we live there... this person prefers to have two half-days so she can really have a break, a little bit more with respect to these old people, well, it's logical...like today, for example, I really gave her a break because, lately it's happened a lot that I let her sleep in the afternoons, this woman, because if she's been up all night with my mother it's hard for her during the day. Mother will wake up for 10 minutes, then she'll fall back asleep, she'll turn over, she'll move, she'll put herself, sometimes, not long ago she even tore off her dress, so, there are, that is, she has some serious pathologies, really.

Q:[Does this woman have a vacation in the summer?]

R: Oh no, no...the big holidays are still fundamentally holidays that, we, eventually she had a little...one, there was one, but another didn't stay, she went away, we gave them the day off, that day. Now, sometimes, maybe this summer we'll pay someone else for a couple of Sundays, an occasional request for an extra Sunday. She seems open to doing it." IT SP06 DB

"In the morning she started at 8:00 and worked until 5:00pm. She looked after my father, she took him out to walk, because he really wanted to be able to walk well again. She cleaned the house, and made his meals and washed the dishes. and then she ironed". F - DB03

"So every day a lady goes there, I don't know what the current agreement is but I don't think it's everyday, she goes every other day.... In the mean time one of the ladies who at that time was working in the rest home, she left but instead offered her services privately..exactly...then for meals when my father is here there's a restaurant nearby, it's a friend of his that he pays by the month, and they bring the meals to the house". P - MC 06 DB

"This woman is someone she's known for ages because her son went to school where my mother taught, and she's been cleaning for my mother and me for more than 15 years, at times she really puts up with being mistreated because my mother dumps everything on her, but she's important to us, at times I'll call her to ask how things are going, and I ask her to forgive us and to remember how important she is to my mother. She tells me that they fight almost every morning, but when she leaves they've made up again, all kisses. So I ask her to stay, anyway, and that she takes her out, also to do the shopping. She has a car and takes her around in the car, she'll take her to the doctor if she needs a new prescription or if she needs someone to go with her; it's not that I stay on top of everything, I was saying, I only go when she has to see a specialist, if it's just for a prescription, or to pick something up at the pharmacy, she'll go." IT - DB05

The decision to employ this kind of assistance is almost always the result of an urgent need, or at least the result of pressure to find a quick solution. It almost always coincides with, or immediately follows, a critical event, such as an accident in the home, or a sudden worsening of the elderly person's state of health that requires more constant care-taking.

"In these last years I always have cared for her myself living here next-door, but since two years I had to employ a person caring for her 'round the clock. ... she could be let alone before, now it is not possible any longer. She already fell twice... I had to search for a person living with her, a migrant woman staying in the same home... if a person cannot stay alone how should we do?"
IT - DB04

This solution is usually aimed at delaying, for as long as possible, the eventual placement of the elderly person in an institutionalised setting that, in countries such as Italy or Portugal, would be much more expensive (estimates for Italy suggest more than 30% more costly, but many Portuguese participants suggested even greater cost differences).

From the first estimates of how this particular solution has changed the local context of the supply and demand for elder care (for example, in the province of Reggio Emilia), we see that the average age of placement in protected settings is rising, and that the numbers of residential and semi-residential interventions and in-home assistance services have declined. Waiting lists have also shortened, while requests for placement in adult day care centres and for care allowances have increased. There are also signs of a real shift in preferences of families and elderly people for greater self-management of assistance, with more flexible solutions that are better 'governed' by families themselves growing in favour (Ferrari, Mazzoli Rebutti 2002). The phenomenon appears parallel to the de-institutionalisation of elderly followed in Northern European countries in recent years (Rostgaard and Fridberg 1998), though for different reasons. The presence of a person paid to stay in the home of the elderly person (which isn't always easy for the old person himself) seems to be a much more acceptable solution within a value system that in principle privileges informal caregiving by family members over institutionalisation. In addition, though family members are not completely freed from the obligations and burdens of care, this solution redistributes the work and lightens it significantly, permitting better management of the daily care arrangement.

For many of the immigrants who engage in this type of work, assisting an elderly person is often the first job they obtain upon their arrival in Italy. It is a 'transition' job, nearly obligatory, especially for women. Eastern European women, entering Italy on temporary residence permits, sometimes take turns in a couple with the same family, remaining for the duration of their visa, and then returning home to apply for the next one. In this case it is necessary that they earn as much as possible in the short time that they are here, for which they accept extremely heavy work loads. It is likely that the recent law calling for the regularisation of these immigrants will not do much to alleviate this type of situation.

In any case, as Gori points out (Gori et al.2002), it is a very fluid market, because the transitions from regular to irregular employment, and vice versa, are numerous, with frequent interruptions and changes in employment relations. It is difficult to quantify because it is mainly organised by the workers and families themselves. Employers offer many justifications for illegally hiring this type of assistance, ranging from economic reasons (hired help for only a few hours a week), to references to the discontinuous and occasional nature of the services, to the necessity of having a trial period.

Italians who engage in this kind of work are for the most part middle-aged, retired, or housewives or women who have always held these kinds of jobs, paid, but without being officially employed. For immigrant workers, other justifications are used for not offering them regular contracts, such as the lack of valid residence permits. It is significant that in the five

cases of this type included in the sample, there were only two families who had begun the regularisation process for their employees. From an immigrant woman's point of view, however, assisting the elderly is both a constraint (because they can't find other work) and an opportunity that presents some advantages, such as room and board, and sometimes even the chance to take professionalization courses in nursing or geriatric care. Cohabitation with the elderly, however, is not a permanent solution for women who have their own families in Italy.

4. 5. 1. The Caregiver's perspective

Based on the experiences of our participants, we can reconstruct the stages of a 'typical' pathway leading towards the externalisation of care, to the acquisition and request for non-professional care services. Each stage has its own points of internal differentiation.

A) Finding 'suitable and available' assistance

The first challenge families face is finding out where to look, or to whom they should turn to find a suitable person to care for their elderly family member. Our participants relied on informal channels, asking friends or neighbours, or on voluntary associations. In any case, the responsibility of selecting the right person, which is often quite difficult, remains that of the caregiver or family.

"I've only found these gathering places that are managed by Caritas, but also there... since I work during the day I try to take care of things by telephone, and maybe it would be easier if I went in person, I don't know, but I, not having time, I would have had to take some days off to look and so I did this long, very long search... Because you see everything! You find people who are here illegally, and then people that you don't know, they come to your house to give their interview, people that it's difficult to choose: well, you have to find someone to have in the house, you can't take just anyone, it's important, especially for an elderly woman, and so you see these people for five minutes and you have to judge if they're trustworthy or not and it's very difficult, it makes your heart ache, because you meet really desperate people, beyond everything else, because they are people who are desperate for work, who have terribly sad stories, so that you almost feel guilty because you can't help them out... we're kings, we are kings compared to them and so well it makes you feel bad...". IT-DB04

"Through my shop. I found her through my shop because in front of the shop there's a bar where I have coffee every day and the husband married a Polish woman. And she gave me the addresses of her cousins, her friends, the things everything that's out there that is external. At the beginning, when she first got there, we spoke, I used to eat with my parents, so we would all eat together, I would chat more with her, but I was talking less to my parents" IT-LP06 DB

"I was really lucky to find her through an association, I still have all the paperwork and I keep up with it 'religiously'. Everything worked out very well. I was really very fortunate, they found a young woman who was really good, who came to our house." F - DB03

It is just as challenging to find a babysitter, even though in this case the chain of informal information allows respondents with a double front of care to have extra information to evaluate their choice:

"I looked around a bit, at the people who live nearby, and I asked someone who was living next door to us, I had asked her mother and she, this lady had a family with a mother, a father, and three daughters, one of them was already married and I asked him about this mother that I had already seen, I knew how she was with her own children, I remember, she used to organise parties for them, but she didn't want to and instead suggested her nineteen year old daughter and she was more willing to do it, yes. Then she went away, and we had another nanny then she was a friend of the first one, then another, this because she was at home and so there was work for her every day." IT - DB05

In comparisons of experiences looking for child care and elder care, our participants sustain that it is actually more difficult to find elder care, given that they are less familiar with the channels necessary to find these kinds of workers:

“It’s complicated. It was very difficult. For the children I would say that it was easy enough, sometimes putting the word out among my friends, or with the lady I had before the girl I have now I found through the parish, I asked if they knew anyone and they sent me this girl. But for my mother finding someone was a nightmare, the biggest problem with finding elder care is the lack of information, that is, you don’t know where to look, who to turn to. Then we decided, let’s find an immigrant! But I had no idea, who can help me find an immigrant? I don’t know where to go, and I know that it isn’t just me, I know that lots of people other people have the same problem that I do, also at work I’ve met people who had trouble after I did, who needed to find someone but didn’t know where to start”. IT - DB04

4. 5. 2. The relationship between the family helper and the elderly person

The introduction of a family assistant to an elderly person is a delicate moment, even more so than in the case of professional services. Indeed, these helpers, often foreign, and in any case an ‘outsider’ to the family, are asked to substitute for the family member that pays them to do a series of jobs that are potentially intrusive and annoying, such as putting the house in order and actually handling the elderly person’s things, not to mention assistance with personal hygiene and the like.

The family helper must do as another family member would, in their place, but using family ways, codes, and cultures that he/she doesn’t know. They are quasi-relatives, isolated with respect to the emotional dynamics of the family-elderly person-aide triangle, who must negotiate a possible exchange of roles (Piva 2002). In addition, this individual does not have the protection of professional training to orient reciprocal behaviour and expectations. The encounter with the elderly person and his family is thick with unknowns for everyone, especially if the work arrangement also entails cohabitation.

Positive (or negative) outcomes seem the product of chance, or of the unforeseeable compatibility between the personal characteristics of the carer and the person being cared for:

“Grandfather, well, the other times that our grandmother was in the hospital he came to our house, always, because there were a number of times that one of the two of them has been hospitalised. This time, though, since there was already this girl there helping them, and she was there until four in the afternoon, we decided to see if he and the girl could stay together on their own, and it turned out well, he even started to improved, he didn’t have so many problems, when he’d get upset, he even ate all of the Peruvian dishes, while instead he had always been a very picky eater, yes, he improved a lot, more self-sufficient, and he was walking more. So it was a good thing, like before when he stayed at home with me.” IT - DB03

Sometimes explanations of why the relationship works with one person but not with another mix up ethnic-cultural stereotypes with personal characteristics.

As in this case, the attribution of a ‘sweet’ character to a Filipino woman, and an ‘exuberant’ character to an Ecuadorian woman is a strong explanatory factor, in absence of other criteria: the interviewee looks for such an “easy and natural” explanations without examining the actual dynamics of the relationship between the elderly person and the foreigner woman. For example, that fact elderly people usually need a long process of adaptation that penalises the first aide and favours the second gets lost in the analysis:

“It really wasn’t very easy before this girl we had hired another one but that didn’t work out, my mother didn’t take it very well and so, I don’t know; she stayed for some months and then we changed. It’s gone well with this one, also for his mother-in-law, I’ve heard other people say that Filipino women are very peaceful and sweet, very calm and this helped. The girl that we had before was from Ecuador, she was a good girl, very young, but maybe she was too energetic, exuberant, and maybe she was annoying to be around, I don’t know how old people would react to that, I don’t know. So it was also a long process for that reason, too”. IT - DB04

In other cases, the process can be very traumatic for the assistant herself if the caring needs are too heavy, even for experienced care givers. The foreign woman referred to below was overwhelmed despite having been recommended by an association for families with Alzheimer’s patients:

“Last year we took her to the mountains for the month of August, because there is this little house where she was born and we went there; we decided to hire a, a Romanian woman, who in fact had been recommended to us by AIMA (association for Alzheimer’s patients) because she had already had some experience; but it was a complete catastrophe.

Q:[The Romanian woman?]

R: Yes, the Romanian. I had two of them, not one, I had two, in fact, she left after 10 days. And I said, ‘if I must’, that is, ‘I’ll watch her myself, if I have to be there anyway it’s completely useless to spend money’. She cried all the time, because she couldn’t sleep at night, during the day she couldn’t rest, and so I said ‘decide what you want to do’. And she told me ‘I’m leaving’, ‘good girl, go, I can take care of things better myself’. Since I can’t go anywhere anyway, I might as well”. IT - DB08

4. 5. 3. A truly atypical work relationship

As the work cited above has frequently highlighted, the relationship between family assistant and an elderly person is truly atypical, because the codes of family care, of affective relations, and work relations are tightly interwoven. Many difficulties related to the risk of turn over and the precariousness of the working relationship emerge from this web, because it is not always possible to agree on the system of rights and duties, on how families can check the quality of assistance to their relative, and, in the case of immigrant workers, they must also face the complications of unravelling the laws on immigration:

“Then this having to put yourself on a list, based on income, obviously between us and my brother we have an income that it’s true we could afford private assistance, yes, but in fact I don’t want a free Filipino woman, that’s not it, I want someone who helps me, because I often don’t know what to do, how to behave, I don’t know if it’s right to say one thing or another..” IT - MC16bis DB

“She’s part of a nuclear family before there was a girl and this is her mother in law, well, the immigrants are like that, they get by this way, now this girl who stayed before had a study visa, and then her mother-in-law came, now, with the last immigration law, I got this girl a regular visa because now this lady will also go away and she came to help, because I let them stay with us, both the girl who is helping my mother and her husband, a couple of people from another country. Her husband works on his own and comes to sleep here, it’s a roof, he comes for dinner, and she stays with my mother. Now that I’ve done the paperwork for her visa I’m waiting for them to call me about the work contract. That way, as a home assistant, she can have a work permit”. IT - DB04

The work relationship is also complicated by the fact that in some cases, the person delegated to care for the elderly family member really has to take care of everything. In these cases the

person burdened with caregiving is overloaded with responsibilities ranging from the relationships with the health system, to the management of crises and emergencies, to having to confront the death of the person they are caring for:

Q:[referring to her grandmother] R: "Yes, but she's got someone, a Filipino woman who stays all week there. I'm ashamed to say it, but I don't even go to visit her anymore. You shouldn't wish death on anyone, but in this case it would be the best, she's a vegetable, laying there in bed, every once in a while it seems like she's going to die, but then she rebounds. She'll have moments when it seems like she's there, there to die, poor woman but she, it's been years since she's been able to see, she doesn't speak anymore, she doesn't hear, my mother does all the shopping, no no, my mother takes care of that but there is always this other woman there, she has one day off a week." IT-MC 11

Until just a few years ago, private home assistance was a 'luxury' that, in Italy, only the most well-to-do families could afford. The situation has so radically changed, however, that this type of service is ever more demanded by middle-class families, who have such complex and chronic problems of care that the public sector can no longer deal with them.

We now see a new form of self-organised private care in which the public sector, with health and home assistance, has a new role: it has changed from the primary service provider to become, in fact, a specialist consultant and case manager. The presence of family helpers opens up new possibilities to public services as well, which should consider more carefully how these figures fit in as fundamental nodes in the overall assistance networks. Progress is being made with initiatives started, for example in Piedmont, Liguria, Lombardy, and Emilia-Romagna, where training programs are offered to these workers (called 'family and individual home help, support, and accompaniment'). In this way, these workers gradually become not only more skilled, but also more visible as network actors in the market of personal services.

4. 6. The Volunteers

Volunteers seem more important sources of support for families with dependent and fragile elderly persons than for families who need help with child care. These associations intervene in different ways to put families in contact with the 'right' person, as we saw in the Italian and Finnish cases, cited above:

"Yes, at the point when, well, not really anything else but at the stage when I tried to arrange this mother had been hospitalised then, no, it was before that, mom might have been home at that stage still, when I tried to find someone who would take father out, he was already then, he could move around with crutches inside the house, but mostly in the wheel chair. And this person came through the Red, no, was it the companion service of the Red Cross or a deacon, I'm not sure anymore, but it was difficult to find one, you know, father is a big man so that it was no use having a small person to help him" FIN-DB08

In other cases they provide services that meet the specific needs of a family, such as companionship:

"My husband turned down the idea though when I suggested: how about it if someone came here to go out on walks, or a walk, with you, so he turned it down totally saying that no way. So, then I again, I reflected on the matter, and then I took care of it so that I went to this Association, you know, to see this, this guy and, well told him, since he had promised to go out for walks, so I told him that, that well, that this is really, that my husband has dementia and he therefore needs, would need someone so that he wouldn't get lost and then I asked if he could come to our place and see how it would go. I sort of spoke to him so that he wouldn't get scared because I didn't

know what would happen because you can never tell. So he, we agreed that I would be home, I had a day off to be at home. And well, he came to our place in the afternoon and I made some coffee and we drank the coffee and talked and, well, then I said that okay, it's time to put the jacket on and you two can go out for a short walk. And my husband didn't say anything, so they went out and it, it went really well then, so the boy came about twice a week and sometimes even three times. He came in the afternoon and, well, then they took a walk. Though my husband did laugh, brag, that the boy had a hard time keeping pace with him, that he was sort of left behind. So that my husband really was in a very good condition, so". FIN - MC20 DB

This same Finnish participant also confirmed the importance of associations in supporting caregivers of people with Alzheimer's disease, an illness that, as mentioned above, is particularly difficult for caregivers and the nuclear family to manage. These types of associations are organised along the lines of self-help groups, and they encourage the exchange of support and information with other people who have the same problem:

"Right. At the time I was working half a day, he was there for day care, so that we went together and left together. And then, that was really, at that time there was still, as the Finnish Slot Machine Association was, we were at that point trying out this Dementia Association day care at the Kuusela Home, so when I had days off work, it was almost always I really, I really tried every week if, and I did succeed too, so I took him there and got to go and run errands and, and do things, do, you know, do something else.

Well, we have, first we have this first-hand information day when we give, our neurologist gives then this information package, information package about this illness and, well, tells about. And you can ask questions, questions, it's such a small group, so it's very different from other places to ask and, and well. Then after it follows the peer support, so there these, we have several psychologists and others, they sort of concentrate on the mental side, on the energy reserves, that side sort of gets the emphasis then. And then I think it is a big deal that you can, you can talk with other people who have the same problems". FIN - MC20 DB

"Then we became members, my husband is a member of the association and since then we've read all of their handouts and everything...they have a newsletter that they send every month that describe different cases, with the doubts, all of that. There are always a lot of things that help you recognise the different phases of the illness, what things you need to do, how to treat them, all of that. Because we really didn't know anything" P - MC09 DB

Volunteers are also important sources of support in caring for dying family members:

"You see it costs a lot, an awful lot, to take care of the elderly. I would see what my grandfather had to spend on medication, a lot of money, so just getting some help paying for medicine is already a big help, and then there are many private agencies and volunteers that also we, for example, we were in touch with ANP that is an association of people who volunteer their time; we at least we never paid a cent and they come to volunteer in your home, they help people who are terminally ill with cancer. They are really beautiful people". IT - MC 9

"A few weeks before Mum died when she couldn't be left alone at all. It was a tiny little cottage so I was having to sit in the chair in the kitchen at night. The district nurse got Marie Curie nurses to come in at night as I was exhausted and needed to sleep. The hours they would come was 10:00pm to 6:00am. I would use that time to come home and see my husband. So in actual fact it was even more exhausting as I'd have to wait until they came, then get down home with S. Then be back by 6:00am in the morning before the nurse had to leave". UK - DB01

"[So you got them straight away then?]And then of course when the things were delivered from the system I returned all I had loaned from the Red Cross which were brilliant. I just wouldn't have been able to cope with the gap. I had thought of getting Mum onto a bowl but I thought if I get her in I'll never get her out again. You don't realise what it's like and since that time I have

brought a bedpan and I'll keep it forever. (laughter) No, you just don't know when you might need one." UK - DB02

"And that my brothers have taken good care of mom. It's in other words this thing that you can talk to someone, in the same way as I did back in '99 when I was about to break down. I called this, this, what is it now, this Cancer Association, they provide service help. I called them to get some concrete advice in mom's medication and other things that would be helpful to her. But at the same time, there was this wonderful person, so I could vent my own situation and my own anguish and my own worry and concern and lack of energy". FIN - DB02

Once more, in addition to concrete help, on short notice, caregivers really need information, emotional support, and someone who can listen and empathise with their exhaustion and frustrations. For these reasons, the presence and activity of volunteers and associations are truly precious, irreplaceable resources.

4. 7. Caregivers' perceptions of non-family helpers

The words of our caregivers provided us with much interesting information and many evaluations of how the family care arrangement network can be interwoven and combined with the activities of public and private services and volunteers.

In the preceding sections we analysed the organisation and the direction of care in these families, as well as the typical characteristics of responsibilities on two fronts.

We will now attempt to understand what the division of labour between families and different types of services means, and what constitutes real assistance and relief.

An issue that cuts across all of our interviews is the centrality of the family and the caregiver in the general organisation and control of the care arrangement, even if it is often indirect, in assuring the 'synergy' and co-ordination of the various activities, even in the richer and more co-operative networks. The caregiver keeps this central role even for small things:

"He has to, he has to, like when he uses a handicap taxi, he gets support for it, he gets these taxi tickets, so he always wants me to call it for him, he says it's so nice when I do it and then call him back and let him know when to be ready, could you please call it for me. So he has sort of, perhaps I've made the mistake that I haven't made him do things himself". FIN - DB04

As with child care, the main caregiver is still the guarantor that at least minimum standards are met in the care and the quality of services delivered. Sometimes, this seems to be an impossible task when many actors are involved, or when institutions are involved that seem impervious to the family's requests.

Perhaps this is the main responsibility of caregivers, and also the most burdensome one, even for caregivers who have been able to delegate many tasks to other people. The difficulty is that it requires organisational work, a capacity to negotiate, and the ability to see how everything fits together.

It is a continuous composition of words and reports that also requires the utmost attention to the needs and desires of the person being cared for. In the case of deeply disabling illnesses, these needs and desires can only be 'guessed' at.

Even with family members, the construction of a common meaning of care is framed in shared values. Interestingly, this framework of values is not so far from the world of services, in so much as they provide services that imply differentiated commitment and responsibility; not just a framework of rights and duties or the application of laws and regulations.

The theme of ethics and values is an underlying theme in the way caregivers talk about the division of caring tasks between service providers and families.

One, indeed, spoke very frankly of a sort of right to personal differences, a sort of right of the caregiver to excuse herself from caregiving tasks that might be ‘humiliating’ for either or both the care giver and the cared for, even if done for a loved one:

“ In addition I think that all of the elderly, we are all quite different from each other...while one old person might be able to completely detach himself from what is being done to him, it might be impossible for another, it depends on their personality, of course... I think that effectively the physical dependence and mainly the need to take care of personal hygiene and all of that... They are situations in which if the person doesn't have a certain attitude...It's always very humiliating, you're not prepared for it, even if the people who come to take care of it are wonderful, they still understand it as a humiliating moment either for themselves or for the other person, I think that's how people feel, you don't need....” P - MC07 DB

Some caregivers accept (or endure) the wishes of their elderly charges to only have other family members take care of their toilette.

"What I miss most is not having someone to do what I do (personal hygiene). Now she has begun to have sores [the mother-in law], and that for me is... it's just that I never thought it would be so hard, treating sores, because it's rotten skin, so it smells bad, but I have got used to it now, to it all.... My godmother always says 'this girl one of these days will be a professional home helper, she certainly needs no more training' ". P - MC01 DB

Others, instead, refuse to do it. Some professionals (caregiving professionals were quite common in our sample of caregivers) confront this theme highlighting the need to delegate certain chores to outsiders, so as to maintain a certain healthy ‘distant intimacy’ in the parent-child relationship, or between relatives. In fact, in other interviews it was taken for granted that people whose professional work involves care giving would automatically carry out the same work at home, or at least should be more open to listening:

“Since I am a health professional, when he (her father) feels bad he turns to me...; he doesn't talk to me very much about his psychological difficulties, he tells me about his physical aches and pains, and for me it's my chance to console him and let him know that I am there, but in reality these just mask his psychological suffering”. F - DB01

For some people, the overlap in personal and professional roles is unacceptable, because they prefer to protect their ties of affection than overload the relationship with their professional know-how:

“I told myself: I am not my mother's *aide soignante*, I am her daughter. So when things got worse I asked for a home assistant”. “I'm thinking about our relationship, and then there are people who need to work, that's their job” F - MC23 DB

“They couldn't find a nurse right away, and so I did it myself for some months, just until home services could take over her case”., F- MC23 FU

Q“ You never had to take care of things like personal hygiene? R: No, no, I really don't think I'm cut out for that. Q: It was never really necessary [out of modesty?]. R: No, I think that he wouldn't, that he wouldn't feel comfortable, he would prefer that it is someone else”. P - MC06 DB

“ My husband, when my father needs something related to what my husband does (social assistant), my husband tries to ask one of his colleagues, or he asks advice. He doesn't act like a son, but as a source of support, the mutual respect they have for each other isn't because of

his professional work, but from their own relationship, from what they have built together” F - DB01

Services respond not only to material needs and the concrete necessity for care, but also to the deep need to distinguish roles that some people find nearly irreconcilable—that of caregiver and that of service professional. In this way individuals are freed from overwhelming material and psychological obligations.

For some, being a social or health professional is a source of extra stress for caregivers, instead of a resource. Indeed, for the following, understanding the process and the likely trajectory is not perceived as a resource for handling the psychological weight of care:

“I think that it is harder because I notice all of the small details, you have a better idea of what will happen...at least if you don't have someone else in the family who you can also talk to like a professional...(...) Let's say that we know exactly what is going on, but that doesn't mean that...any way, the hard part is the psychological part, the feelings, because we understand all of the rest”. F- MC23 DB

Others instead see professional knowledge about the mechanisms and traps of caregiving responsibilities as a resource for greater awareness and ‘self-help’, not to mention a compass for orienting their choices about how to care for the elderly person::

“But I have been a home helper too once upon a time, so I know that you can't be there all the time, and he can fall the moment I walk out of the door. So that I don't have any of that how would I put it it's pretty, I don't feel guilty at all really ever because of not going there more often or otherwise, so that that's.. ” FIN - DB10

"It has in the sense that, for example, when it comes to mom, because you knew her temperamental nature and stuff she had this confidence in her own abilities, although she had lost them, or the conception of them, so it influenced things so that you considered carefully what you said to her or what kind of words you used and stuff, and which affairs you took care of and which you didn't, or what you didn't do, and what you said and what you chose not to say, so. But maybe my profession, what I've done professionally has also had an impact in the sense that which things I've regarded as relevant and which of secondary importance, so that I haven't blanched at things and worried about every single thing". FIN - DB08

As we have seen many times over in both sections on family, neighbour, and service assistance networks, confronting care on two fronts is certainly facilitated by the presence of informal networks and services, even if every network needs organisation and continuous maintenance of the relationships and communication between the various nodes.

Sharing among several subjects facilitates the management of the many chores, and attenuates feelings of being overloaded with responsibility. We would also like to add that sharing constitutes and added value in two other ways: time for oneself and respect for the habits of the elderly person.

“But...the advantages are that the person gets to stay in his own house...in my father's case it will always be better if he is able to get around, to go out for a walk, to go drink coffee with his friends, play cards. My father always has to be on the ground floor, because even without legs he must weigh between eighty and ninety kilograms, and every time that I take him to lower him out I know how much that is”. P-DB06

“the domestic helper is here for two hours, for two and a half hours every time she comes. This is a big relief for me, and it's important that they don't take her away from me, otherwise I don't know what I'd do. There are people who tell me: you shouldn't have a right to a domestic aide, with your mother at home you could take care of her yourself. It's true, I could do it, but with the

helper that frees up two hours for me, I can do other things, I can do something for myself, I don't have much time either, with two daughters". F - MC22 DB

Analogously, having a domestic helper also eases the reconciliation between work and care:

"most of the things that could worry me during the day are delegated, as my domestic employee stays until five. Today, for example, it's a privileged day, because exceptionally my employee is staying until eight, so all is well and I'm relaxed". P - MC06 DB

In conclusion, the need to think in terms of a *system* of care compatible with paid employment emerges ever more clearly from the words of our participants on the functioning of the diverse networks that permit reconciliation between two fronts of care and paid employment; from their strategies to do so; and from their evaluations of the opportunities that already exist.

By thinking about the networks between families and services as a system of care, we are able to depart from a logic that envisages either total delegation of care, in which the asymmetry of the relations is in favour of services (who have the power to 'govern' the network), or the myth of specialisation, such that services, according to the health services model, deal with only small components of user's needs without examining how they interact with and affect the bigger picture. In both cases families, as nodes in the network, and the *system* of care are only considered as passive agents and consumers of services, or else as the executors of the prescriptions decided by whoever governs the system of care (Scortegagna 2002).

Indeed, the growing recourse to non-professional services in every country, whether paid or voluntary, can be interpreted not only as a strategy to meet an unsatisfied need, but also as an effort to find more flexible and personalised solutions that, most important of all, leave to the family the 'government' of the care for their own dependent members.

5. Balancing the two fronts of care: children and the elderly as mutual resources (and their possible relationships)

In all five of the countries included in the research, parents of small children did not find the need to provide care on two fronts to be an excessively demanding burden, provided that the physical and emotional needs of their elderly family members remained within certain objective and subjective limits. In these cases, it was taken for granted that families would direct most of their attention to caring for children, and it was not surprising to us that this type of care takes priority over, and is guaranteed independently of any other caregiving activities, such as visits or guardianship, that have been promised to aged family members. It is only when the care demands of the elderly become more frequent and time-consuming, such as the need for daily visits or even around-the-clock care, that parents with small children begin to feel unhappy with the arrangements, often experiencing feelings of guilt for the time lost with their own children. It is here, however, that differences among the five countries emerge. Parents in Southern Europe, and sometimes France, seem much more likely to express feelings of regret and sadness about not being able to guarantee as much time to their children as they would like.

"Well, the fact that I have to take care of my mother is the main thing that gets in the way of my spending time with my little girls". F - M22 FU

"Sometimes I had the impression that I was neglecting the boys a lot more [...] even afterwards, especially when we had other things to worry about (of other elderly relatives) I always felt the need to see if I could somehow combine things, and there were definitely times that what the boys needed got postponed or lost by the wayside" IT - SP01 DB

"Usually it's our littlest one who loses out the most, because the time when we pay the most attention to him is usually at bedtime, and he needs more than that from us. There are days in which...lately my mother-in-law has been worse, and we don't give him the attention that we'd like to. He wants us to play with him, to take him to the playground or to go out with him for a walk...small things" P - MC09 DB

"Well, there was a period in which I was very busy taking care of my mother, and I really wasn't there for them, and they saw her as an enemy: 'You're always at her house, you're always with Grandma!' They didn't handle it very well, and then they don't see her how children usually see their grandparents. [...] They don't feel a lot of affection for her; she's just a very needy person to them, someone who takes me away from them, and that's all. [...] my children...they practically see my mother as their enemy, it's something that comes between us." IT - DB04

"What do I miss the most? Time. Time to stay with them without having to nag, without having to say 'put your sweater on, take your sweater off, go wash up, hurry up, go get your backpack ready, make sure you have your swimsuit, make sure you have your gym clothes...' To have time to relax with them, to watch a movie or go out for ice cream, or talk about a book with them" P - MC01 DB

In other words, what really leads to feelings of being over-burdened is when the time necessary for caring for elderly family members interferes with that needed to manage the daily lives of children. In these cases, children are often asked to take too much responsibility for themselves in a way that is unnaturally forced by the circumstances, and not appropriate for the timing of the development of the child. A minority of interviewees emphasize the limits imposed on their own families by the need to stay close to a dependent parent or grandparent: they can't go away for vacation or take a day off. Paradoxically, however, this problem is one of those most easily recognised, and solutions are often found via social services or the broader kinship network. In

contrast, the damage done to everyday family life is more insidious, and there don't appear to be good and "practical" solutions to face the psychological burden and the lack of time.

While families in Southern Europe appear to sacrifice time with their children to care for elderly relatives, despite their associated feelings of guilt and regret, families in the UK and Finland (or France) with small children instead are more likely to use their own family responsibilities as a justification for *not* becoming the principle caregiver. Indeed, in these countries, having childbearing responsibilities is accepted as a reasonable excuse in family negotiations on care, which we know often take place in 4-generation families, that in any case are richer in caring resources. On the one hand, while children in these countries achieve autonomy at an earlier age, on the other hand, families that do assume a double front of care (responsibilities for both young and elderly family members) are relatively unusual given the general cultural norms on intergenerational solidarity. Those who bravely do take on the double front probably do so out of rather uncommon ideas about family obligations and relations:

"We've returned to *this kind old-fashioned thing* [...] I think that this thinking of money has gone in a totally wrong direction... If we speak of doing this for money, then the whole motivation is wrong. I've got help, so now it's my turn to give help. That's is how it goes in this chain of generations". FIN - SP12A DB

"So that I must say that when it comes to me, thank god, I've been raised, should I say, *in an old-fashioned way*, which I am thankful for. I think it is a good thing. But it also includes this aspect of being nice and good. Children must be good." FIN - DB01

At the other extreme, still in Finland, the most 'secularised' country from this point of view, we have in contrast a case in which becoming a grandmother furnished one participant with what she considered to be a good reason to suspend an unusually strong and burdensome commitment she had made to her own parents. This even though the use of childcare in Finland is very common:

"... I experience it so that this grandchild in a way gives me an excuse, so I don't have to go and see them when I'm with the grandchild. [...] It helps to soothe my conscience, why I'm not going to see them. Until E. was born I used to go twice a week to see mom and dad. Then when she was born, or last winter or fall when the university started and she went to day care, I then made it clear to myself that I wouldn't go to see them more than once a week". FIN - DB06

"Q: [did you consider having her - the grand mother - move in with you?] R: oh no, no, we said no...because family life is already stressful, and then there are the children, well, no" F - MC01 DB

The same discomfort with competing caring needs that we saw among Southern European interviewees also emerges among some of the Finnish participants, and it is often expressed in nearly identical terms, especially when there is little choice in how the caregiving is managed. In the following case, for example, the woman who accepted the double burden fits the demographic pattern found in Southern Europe: both she and her mother bore their children relatively late in life:

"...even now I think that she's [the child] being taken care of elsewhere much too much. I have a guilty conscience about it, like many others do I'm sure. A child is small only once and you should find the time to live the day-to-day life with your child, it doesn't have to be anything special, you know, just the regular daily life. And when it comes to mother, I don't want to, it's because I've promised her, like I said, I've promised to take care of her until the end". FIN - DB10

A corollary to the difference between Mediterranean countries and those where children tend to become independent at an earlier age also consists in the fact that, often, the conflict between the two fronts of care in the former countries is felt most strongly when the children reach school age, and even beyond. Missing out on these 'formative years', when problems become more complicated, seems to produce more guilty feelings than losing time with very small children and babies:

" So that also influenced my decision to put my father in a home, because, when he was here at home it was so complicated for A., even his relationship with his grandfather; even though he loved his grandfather - he visits him in the home, we all go there - but it was difficult. I couldn't give him enough attention *at a time when he needed it, just when he was starting school* and everything" P - DB02

"...The oldest one needed some special attention, he had problems at school, it wasn't going well and I really felt badly that things were hard for him, because I could see how much he was struggling. [...] you make me remember that was the year [the year the participant's in-laws had moved into their house] my oldest son failed his exams. I couldn't really say it was because of his grandparents, though, I have my doubts about that." IT - DB03.

"I think that there were moments, yes [...] there were inevitably times when both my husband and my children suffered for it, that's obvious [...] For example, when my father had his heart attack, [my son] P., we know him, we know what kind of personality he has. When at the end of the first trimester [...] we knew that it was important not to let him down [...] we hadn't been there enough to support him during that trimester...[...] when they're at that age you have to be there for them" F - DB03

"I think you have to spend even more time with them, when they're 15, 19 years old. Of course they're home less, but when they are there I feel like I should be there, of course I had to relent a bit with my father, I'm on vacation and I stay home; [it is important] to be at home when they need to talk to you, or even when they don't want to talk, but they just need to have you around, they need to see that you're there for them if they need you. And since there were a lot of problems this winter, and I was never home, I thought that I had spent enough time with my parents" IT - MC16bis DB

"I wasn't able to give enough to my children... If you buy them new shoes, but you don't pay attention to them; for example yesterday my daughter went to practice an oral presentation with a friend, if I had had time I really would have liked to help her, to share in what she is studying, these are the important things that you miss. When she was small I would stay with her until she fell asleep, I would spend the whole evening with her, now I can't do it anymore: if you only see your child for 20 minutes a day it's not enough for him to tell you his problems..." IT - MC14 DB

Though it seems counter-intuitive, we found that in all countries, caring for an elderly person and a very small child was less difficult than caring for an elderly person and a bigger child, at least when the level of dependency of the elderly person was not at a pathological level. Indeed, oftentimes the caregivers were able to see similarities between the needs of the very old and the very young. Furthermore, many expressed the potential the old and the young have as resources for each other.

"then, watching the children play, their smiles, they give her hugs, these are things that an old person [...] She is coming to the end of her life, and so it is important to give her these things. [...], children are like medicine for the elderly, and vice versa, grandparents have an incredible wealth of affection to give" IT - DB07

"I have small Nami-Nami Puddings from the store for both of them, or small bags of candy, [...] *because elderly people are like children*, they get most delighted when you take some candy to them [...] I can in other words take grandma exactly the same thing I'd buy for Anni. And that's what makes it special in a way..." FIN - DB10

"she [the 22 month old baby] goes right to her, she calls her 'granny' and she'll take her hand, it's like she's saying 'you come, too!' Yesterday morning she took her great-grandma out to walk on the terrace, she was so cute, so careful, I could have died laughing! She's very careful, you know, she worries about things in the way, it's really adorable. When they would get ready to turn we would tell her 'go slowly, don't go too fast, you know grandma has a hard time walking" F - MC08 FU

"Mum and dad loved to see the little boy, it made it easier if anything, because my mother had been a child-minder herself before in her life. So it was really helpful to have the little one around because it took Mum's mind off of being so ill. She was always saying 'does he want this, does he want that' and really it made it easier". UK - DB02

"And her ability to speak suffered somewhat but not very much.[...] I'm sure it was a big help to her recovery then that she stayed more at our place again. The children made her read books aloud to them. Since she was sitting there on the couch anyway and had nothing better to do Grandma read books to them. And it was of course a priceless help to me that... amidst all that hassle. And I noticed very clearly that reading aloud was probably very good for her". FIN - DB11

"Mauri [the grand-grand-child] is so very important to her, in other words if you think of people her age, many of them are in an old people's home and pretty demented. But she doesn't have time to get demented, or sick, in the middle of all this. I've noticed about her that, you see, earlier she lived alone in Kissanmaa. A home helper came in a couple of times a week and did the grocery shopping. The bags were too heavy for Vaula to carry. Mauri was born and when he weighed ten kilograms, she was carrying him around like he wouldn't weigh much anything. Even I've told her that there's no need to carry him" FIN - SP12A DB

In addition, the dependence of the elderly is more easily accepted by grandchildren, who, having always seen their grandparents in such a condition, see it as natural. For the adult children, however, it is often more difficult to construct a different image of their own parents, who they remember as being omnipotent:

"In fact I realized that it isn't so bad, because both my daughter and my granddaughter...they've always known their grandma this way, they've always seen her a bit infirm, and sick. They can accept it. For them it is less of a problem than it is for us". F - MC04 DB

[looking at the photos] "...and the very young son is there. He's probably aware that Granddad's not well, but doesn't seem bothered by it. He hasn't got the insight probably to understand how ill his Grandfather is. [...] The differences are that the child, which I assume to be the Grandson, is much younger and in some ways it's easier, others more difficult. It's easier in that this 3-4 year old doesn't have any real insight into what's really going on whereas teenagers do". UK - SP02 FU

"Well, children don't question things very much. If you have a good relationship, I think that they pick up on things pretty quickly [...] I talked about my mother a little bit with Laura, every once in a while, but not so often any more. But I don't think that it bothers her very much, deep down, I think that she believes that my mother has always been ill'. F- MC23 FU

Some of our participants even mentioned that the grandparent/grandchild relationship seems particularly able to withstand the deep disorientation and disability that accompanies ageing and that often erodes other relationships, being the one which "passes through" even in cases of

Alzheimer's disease. This bond appears to remain a durable and important reference point for the elderly person's own sense of self-identity:

"I usually take the child because mother remembers her and she clearly gets delighted by the fact that she is with me. So, even though she can't produce much speech, she does often ask when I am there alone, that where's the child, why didn't she come along?". FIN - DB10

"Well, it's that she doesn't recognise; except for the youngest one, she always recognises him when he visits her...'the little one, where is he?' She always remembers him as the little one, but she recognises him, maybe he's *the only one who she really recognises*" IT - DB08

Among parents who are constrained to keep very small children together with dependent elderly relatives, even those with significant needs, we witnessed some truly notable similarities across very different national contexts and civic cultures. Often, adult children appear to universally 'rediscover' something that has been lost in our society, but that still remains in some lesser developed countries, as we saw in our research on immigrant families. It is as if, constrained by circumstances to try an arrangement that has become taboo in our society, they find a resource of olden times that has been obliterated, today, by the concealment of suffering and death. Even those who feel ambivalent draw strength, however, from this more traditional image of the family, and by the unexpected factors that ease the situation:

"I think the best example about this was, and I'm sure it had a healing effect on grandma, that the children were there all the time. [...] Even though it required a lot of adjusting and stuff, I nevertheless think that *it was morally and ethically terribly right* in that situation. In a way it was the same way things were taken care of *in the old days*. You didn't put children and the elderly etceteras in different compartments then, you know. Also the illness ought to be let be present, so that children can see illness and it doesn't need to mean anything frightening that one can't talk about. Being ill is sometimes like that". FIN - DB11

"She is still alive, she hasn't reached the end yet, so I, well, you bear with it, because she, when she laughs with the children, the mornings when I change her sometimes she laughs, sometimes she cries, sometimes she remembers something sad and she cries. Sometimes I think she remembers happy times, for her, for her children; for this I don't want to send her to a nursing home for good; she would suffer without the children, he is always there with her, he plays with her in bed, he goes to visit her, to talk. That makes me happy; also when they ask me 'but why is grandma still in the nursing home? When will she come home?'. IT - MF31 dB

"...for the kids it all seems normal, my children grew up having their grandma in a wheelchair, and for them it seems normal, so it also means when they see other handicapped people it doesn't upset them, it's not a problem for them to go to the hospital and see all that, it's normal to spend time with old people, I see the oldest one, when he was smaller he had no trouble spending time with old people, because he was used to that kind of relationship [...]" IT - DB06

"Anyway I think *we are going back in time*, because years ago...we didn't take children into the rest homes, you didn't want to expose them to that". F - MC08 FU

Frequently, parents recognise that by exposing their children to their elderly and infirm grandparents, the children learn to accept illness and death as a normal part of existence. Indeed, sheltering children from these facts of life in the end leaves them more vulnerable and less equipped to deal with them:

"But really! Children have to learn that anything can happen, because if they only learn what they see on television, we'll make misfits out of them! In other words...this 'don't talk about it! Don't talk about it in front of them!' But when you live all together, the children understand, they also have a sense of death, nowadays many children don't have a sense of death, but at my

house we've always spoken about it,...it's normal, so we've always been able to talk about it, we've always joked about it... but please, it's not that we're making light of it, for heaven's sake, because we've really felt some terrible losses, but we joke about death itself, we laugh about it, we tell jokes about it, but we also talk seriously about it. Children need to understand these things, if not how will they get through life? Instead no, that's wrong, you can't take children to funerals. But please. And when the grandparents are sick, it's 'out, out of the room, out, it's not good air for children', but why? Why do this? It really upsets me, because children need to understand this,...] well I would never let a child see someone in terrible pain, this, no... one who is moaning, or crying in pain, this no, but the suffering of a person who is in bed anyway...whether because they've broken a leg, or had an operation, or because they can't walk anymore...why not let them see this?" IT - DB02

"... for example little children are not guarded against seeing things that are natural things in life, things like elderly people in a poor condition, or that you wouldn't take a child to the hospital to see misery, but you do because it's part of life. I think, I feel that Tauno is pretty mature in the respect he is not scared of it. [...] I have instead thought that he's in a way learning for his future life." FIN - DB01

"Interestingly it is only my middle son who is interested in his Granddad. To the point that he visited him in hospital which he found extremely distressing. But he wanted to see him. Where as the other two really avoid the fact that he's so ill, deny the fact that he is and don't really want to be involved". UK - SP02 FU

In fact, as emerges in the above citation, the grandparent-grandchild relationship, usually forged in the grandchild's early childhood, when the former cared for the latter, sometimes retains its significance even after the grandchild grown up, if they haven't been too 'sheltered' or 'distanced' from the ageing process of their grandparents. This relationship is an absolutely under-valued resource in the catastrophic and completely depersonalised prediction about the future of ageing. It is true that the next generation of elderly will have far fewer daughters and daughters-in-law to care for them, but it is also true that they are the first generation to have enjoyed such a long and active period of their lives as grandparents in good health (Attias Donfut et al. 2002). Indeed, on a personal level, the relationship is equally rich for the grandchildren. We see traces of this in our sample as well, when, for example, the grandchildren are used to paying spontaneous visits or else (even in this case, where the relationship hadn't been particularly warm) are capable of helping their elderly relatives accepting the changes of the modern world. Grandchildren also appear to be a more natural bridge than their parents (the middle generation) between their elderly grandparents and technological innovations:

"... Juha wasn't married yet and had another girlfriend... and grandma and grandpa had been over for a visit and the grandpa said that, well, Risto has a good microwave, if I could have the same kind, I might learn to use it. Well, then I said to Risto to go and buy exactly the same kind of microwave oven that he had". FIN - DB06

The most aware parents respect and appreciate the differences and complementarities the grandparent-grandchild relationship has with respect to their own relationships with their elderly parents. In these cases, it sometimes becomes possible to embrace the openness and solidarity of many generations in time, even when the elderly person is infirm or difficult in character. Those families who manage to intelligently focus on what resources the elderly person retains, can take advantage of what the dependent family member adds to the relationship between children and the elderly, even if he or she is generally difficult to get along with.

"sometimes even the older one goes [the granddaughter to her grandmother's]. And if I hear them arguing, I tell myself, 'oh, I can't interfere in this', because well, her grandmother talks about the past. And it's also important that the children learn things that we haven't thought

about teaching them [...] It's a positive thing to put different generations together, because they learn from each other. My daughter gives something to her grandmother, and my grandmother gives something to her...if only she weren't so set in her ways, it would be perfect". F - MC22
FU

"if the father works, and the mother works, and this poor kid has to get shuttled here and there, enough of that! It would be better to have the whole family together, if they get along, where the child could stay with the grandma, any quiet grandma. [...] you have everything you need, everything is in place to manage an extended family and so there aren't these problems; in my opinion that would be much better, our way of life is insane, in my opinion it is inhumane. I've always thought extended families were a good thing...[the daughters] they have the most fun with my father, not with me, or my husband, but with my dad". IT - DB02

6. Conclusions: Implications for Care Support

The most unexpected conclusion that we can draw from our data concerns the age/generation of women who are most burdened by care responsibilities on two fronts. While academic literature on the issue has mainly concentrated on the generation of women between the ages of 50 and 60 years who find themselves with responsibilities both towards their elderly family members and their very young grandchildren, our study instead brings to light the challenges faced by a slightly younger cohort of women who up to now have been invisible in debates on family care. These women, having delayed childbearing by several years, and often being the last born of their own mothers, must sometimes meet the caring needs of their own parents or elderly dependent family members (or sometimes a seriously ill husband) while they still have quite young children or young children and teenagers of their own to raise. In these situations, the customary timing of the life course is confused and caregivers must deal with an ‘unnatural’ coincidence of needs that would normally occupy different stages of their life. The overload experienced by such caregivers was emphasised by some of our participants:

“...there were some periods in which I was trying to compensate for everything, and my husband and I...we were so incredibly tired. [...] For several years, when the children were smaller, we were completely exhausted because we had to take care of everything at the same time: we had two small children to care for, and an elderly woman who couldn’t take care of herself anymore, and this combination of things was very difficult to manage [...] it was a sufferance, a huge crisis.

No, if we had had our children earlier...because it’s *the people who have their children late* who find themselves in this situation who find themselves with older parents and young children. That’s what the problem was. [...] You are more likely to have an elderly parent to care for, unless they pass away quickly, as my father did, you are more likely to find yourself taking care of both your parents and your small children”. IT - DB 04

These situations arise not from a diminishing age gap between generations, as was originally supposed, but rather by its widening. It is thus most frequently found in those countries where population ageing is accompanied by trends in which young people delay marriage and stable cohabitation. The Nordic countries, with their new-found demographic vivacity, are instead the countries in our sample where we did find four-generation families to be more commonplace, and where the ‘sandwich’ generation of slightly older women with care on two fronts has begun to obtain a certain level of social visibility:

“So our poor mother is running around caring for two children and one old silly man. One can’t stretch her endlessly, either [...] ...these old women are really working hard. Between two generations they care. My mother is not the only one. She has three sisters, they are four siblings and almost all of them have similar situations”. FIN - SP13DB

This last example also occurs in three-generation families in which one partner of an elderly couple becomes ill, thus triggering a double burden for his/her spouse. These situations, though, can be understood as a normal part of the life cycle. What we would like to emphasise here is that in the end, with the exception of some of the little-considered psychological aspects of caregivers’ attitudes, which have already been addressed, these are only differences by degree. In this report, rather, it seems most worthwhile to organise and present the many suggestions that our families provided us with over the course of our study. Their ideas, grounded in their own profound experiences with elderly family members and the sensitive management of inter-generation relationships, are rich in practical solutions and provide many lessons for social policy. We have already documented, on many levels, a notable convergence of strategies that seem valid for all countries facing population ageing, despite the different national contexts. We will attempt to lay these out systematically below.

6.1 *Social support services should consider **all** fronts of care families face.*

There is no doubt that not a single of our five countries can be said to be generally capable of offering care services that encompass the extraordinary burdens associated with caring for both dependent elderly relatives and children and/or grandchildren, or even, in addition, a disabled or dependent relative or foster children, which occurred even in our very small sample. In general, the services and forms of assistance found in our sample countries are instead always aimed at one problem at a time, and are incapable of comprehending double (or triple) directions of need, the various commitments they demand, and the consequences of such burdens on family life. What these policies amount to is a mix of various forms of formal care—which apparently are made accessible and delivered according to very strict rules—with a completely arbitrary blend of whatever forms of informal care happen to be available.

In practice, only a few of our participants managed to compile relatively advantageous packages of support from the publicly available resources at hand, and only then because of unusually fortuitous circumstances. For example, the shortened work day offered to mothers of school-aged children in Finland allows one mother to manage better in caring for her parents:

"... it might have been last fall or was it in the spring when this older one said to me that why aren't you ever at home. So I must have made exceptionally many visits and things at that point. In a way they haven't really been able to interpret this, you know. And then, wait a minute, nine, when was it that the other one started school, '99, so at that point I had shorter working hours, but it was because my child started school". FIN - DB08

In some Regions of Italy, like Tuscany, mothers can conversely spend more time with their children in summer, when a respite break of one month is guaranteed from their caregiving obligation to elderly: but, even if in a sense children and elderly needs are considered by the social workers, they aren't really connected.

6.1.2 *An evaluation of personal resources should be part of the access criteria*

An evaluation of the total personal resources that make a family 'care-rich' or 'care-poor' should be systematically and objectively formulated so that it can be inserted into the access criteria of various support programs and services. At present, family caring resources are 'counted' only in so much as social protection systems use them punitively, as 'demerits' against an individual's right to assistance. We often saw this phenomenon in Southern Europe, where family resources are measured so that help may be accordingly taken away. This accounting should instead support the allocation of services whereby decisions about assistance are based on the informal resources available, their specific qualities, and how they might be combined with other services. The objective should be both to activate these resources, and to provide them with a protective frame of reference. In fact, this is the most general recommendation that we can derive from our research, not least because formal social recognition and consistent support of family caregivers, many of whom demonstrate a tremendous capacity to spontaneously mobilise on many fronts of care, could prevent the exhaustion and burn-out of such an important resource.

In suggesting potential access criteria for social assistance that takes family caring resources into account, we find the objective, transparent criteria used in France for access to the *Prestation Dépendance* especially useful. This program allocates a certain number of hours of assistance, of one kind or another, based on demonstrated need. A family's *need*, however, is calculated by taking into consideration each front of care on which they are occupied, including childcare, elder care, or care for other disabled or dependent family members. Furthermore, while the

nuclear family is the first unit of analysis, the extended kinship network also enters into the equation. This system is also important for those who lack relational resources, or do not have family members to help with small daily chores. The recognition, compilation, and valorisation of small and even occasional forms of assistance or companionship from the family network and community should become part of the shared culture, and aimed at preventing the exhaustion of any one relationship or source of support. . On the contrary, the practice of paying for care seems very different in its practical outcomes: by putting the main responsibility on one person, it usually does not preserve or try to enhance the richness of the network, which constitutes such an important resource. Suffice it to remark that, behind all the considerations of our respondents, it has been recently proved important even in preventing dementia (Fratiglioni 2000).

A more network-sensitive approach could, instead, accommodate the range of generosity found across the different welfare regimes (each country could continue to distribute a level services and assistance that is proportional to its past), while at the same time providing a new foundation for the genuine convergence of the criteria used to evaluate need. Finally, the functioning of services could also become more similar, because, though embedded in different institutional structures and offering differing levels and types of coverage, to reach the objective of high quality service, the means are often very similar (Eliasson-Lappalainen and Szebehely 1999).

6.2. *Assistance and services should be timely and global*

As we saw from the interviews, when families first encounter a care crisis for an elderly relative and are pressed to quickly develop new care arrangements, they above all require assistance in ‘constructing’ the new setting and orienting themselves in these radically changed circumstances. What they find most lacking are clear points of reference capable of providing comprehensive, updated information and of understanding the complexity of the situation, and not just certain clinical or sectorised dimensions of it. These families want to know to whom they can turn to get a full and straight answer not only on the forms of assistance available to them, but also on the meaning and potential duration of the crisis. Unfortunately, this high level of integration is sometimes even lacking in relatively generous countries and in those where the arrangement of services is particularly efficacious. On the local level, even in France and the UK, the moment in which an elderly person is dismissed from the hospital into the care of his/her family is extremely critical:

“There should be something at the hospital, a service that puts you in contact with the right agencies, because it’s a nightmare. I went to check out the elderly services at St. B., I went to see the social worker, I went to learn about everything they have a right to. The *aides-ménagères*, that’s very good, but first of all you have to wait a ridiculously long time to get one, for a few hours a day, that’s fine...by chance there is an association at St. B.’s that recruits workers so that you only can have the caregiving... well, from a financial point of view, I found this solution, but financially it wasn’t possible for my parents. So back I went for more information, they can get help from the *Conseil Général*, so I did all of the paperwork, all of the forms, and now here we are”. F - DB03

“This kind of flexibility is lacking entirely. I think it’s the big problem that the flexibility between different kinds of care solutions for the elderly... not to mention the fact that the Cupertino between the different actors in the social and health care sectors isn’t always the best possible, there are lots of examples. I think that out in the field... it doesn’t work yet”. FIN - MC 21 DB

One potential solution could be different forms of ‘first aid’ services available for the organisation of care. These could include easily accessible services--perhaps furnished with toll-free hotlines—that furnish, on short notice, the equipment families need to care for an elderly person at home or that could make caring for an old person much easier. In other countries, the

provision of this type of equipment is already part of home care services. Importantly, these ‘first aid’ services should not be thought of only in terms of emergency case management; what are really needed are assistants with multi-disciplinary expertise, capable of assisting families even with long-term chronic illnesses that might arise later. At the very least, adequate and correct information on the time needed to procure some form of social assistance on all fronts would be better than none at all. Families could thus manage these transition periods, either with their own or privately paid resources, knowing that the period would eventually come to an end and that the disruption they experience is only temporary. The tendency to ‘not see’ the overall configuration of the double front of care in fact limits the capacity of services to understand the necessity of guaranteeing regular, decent, everyday family life to caregivers, which is precisely what our respondents care about most. Indeed, sensations that one’s life is being uncontrollably consumed by the double front of care are most acute when aspects of ‘normal’ family life is disrupted.

Some of our participants, for example, clearly emphasise the heavy strain that assuming the care for one or more elderly relatives places on the personal relationships of couples and young families. It is not simply a matter of sacrificing time with one’s own children; couples, too, feel the stress—even to the point of separation. Perversely, such circumstances destroy, in the most obvious way, the most spontaneous care resources available.

"...it's true that these days, if you think about the life of those children, well, working life is so tough. And then you have the kids to take care of, so I don't know, I think it's too much to ask,, nobody has that much extra resources and interest. I know a few people, a few people who right now have to look after and take care of their demented mother, and it's absolutely, I said that it's a wonder if that won't end up in a divorce. Your family doesn't understand that you have to, that you have to go there every day and do those certain things, like she has to do to her mother, so it can happen that it will finally end in a divorce". FIN - MC20 DB

"it got to be where I couldn't go out anymore, I couldn't have a weekend off to pay some attention to the baby; I started to have problems with my husband, because the atmosphere had become strange and unfamiliar and after three years he told my father 'dad, we need to find another solution' [...] And then we start to argue and things get complicated, very complicated. But I don't even let my parents see this, because in the end they would be the ones who would suffer most. if I start telling my father that I'm having problems with my husband he'll get even worse" P - MC08 DB

In fact, a common thread among all of the different types of families we interviewed with double fronts of care is that of having to demand a division of labour that is spread out over a much wider area than that of a ‘normal’ nuclear family. Members of the extended kinship network are involved, especially siblings, and spouses are as well. Wives more frequently dedicate themselves to the care of the elderly, sometimes in a conscious effort to spare their spouses the worst. They do so, however, only in as much as their partner agrees to take more responsibility, at least for the children and the house. The undeniable evidence of the *weight* of caregiving that women must bear sometimes even induces more traditionally-inclined men to accept a part of the burden

Q:[And does your husband help you care for your parents?]

R: "Well, he does what he can but I try not to bother him very much, I'd rather take care of things myself, I'd rather just sacrifice myself and do it on my own [...] He'll vacuum, or bathe the children, but he finds it annoying, I have to ask him again and again, really nag him, but there are men who don't like to work very much". P - MC08 DB

Q:[And your husband, let's say what is his contribution in taking care of your mother?]

R: "Well! A lot, because when I'm at her house he has to take care of the children, so he's an important part of the arrangement, even if it is just while I do the shopping. I do it once a week, I

also do my mother's shopping, but someone has to stay with the children [...] usually I do the cooking, but we take turns setting the table or putting the dirty dishes in the dishwasher". IT - DB04

In this sense the technical capacity of 'first aid' care services⁹ could resolve certain fundamental problems precisely because they [the services] would be generally configured according to a comprehensive overview of the resources available and the expected course of care, and not simply on the hurried delegation to whichever unlucky relative happens to be closest to the events—the usual method taken by services, especially health services. Services should clearly provide the most support to principle caregivers, publicly recognising their role and their difficulties within the framework of the variable geometry of the 'new family spirit' (Attias Donfut et al. 2002) that they should try to mobilise.

6.3. *Services should bring to light intra-familial negotiations*

Support services should facilitate the clarification of both the intra-familial solidarity pacts and the gender contract on which future care arrangements will hinge. We have seen the tacit and taken-for-granted ways in which principle caregivers are designated, but if public assistance were conditional on a sort of explicit, contractual stipulation of *who*, among siblings or within couples, is responsible for what caring labour, an enlarged sense of collaboration could take root. The idea that other people are also involved in the caregiving relieves a complaint expressed by some main caregivers who receive no assistance. For them, the feelings of isolation are more overwhelming than the actual care they must provide. Of course such 'contracts' would need to be accompanied by extremely sensitive negotiations in which the principle of reciprocity cannot be strictly measured. We have learned from our families that unequal contributions can also be, in the bigger picture, counted as equivalent. Rotating responsibility, even if not in perfectly equal ways, is also a viable solution. Finally, the nature of the prior relationship between the dependent family member and the potential caregiver also must be considered so that each can define her/his role according to what feels mutually most comfortable. The outcome to be avoided is that caregivers are left alone with the responsibility because no one else is willing to help. By no means should the laying out of explicit terms of caregiving be considered simply as a means of coercion or a tool for sanctioning non-participating family members. Instead, the value of such contracts resides in the transparency they give to the nature of each family member's contribution. They also highlight the value of the shared agreement in point of fact in the social construction of a world of more acceptable and solidaristic relations—relations that have a certain amount of stability and that will thus endure.

The development of explicit shared agreements could also prevent situations in which the designated caregiver suffers extreme social exclusion as a result of her caregiving burdens. As has been well-documented, individuals who were designated in their role at a very young age are especially at risk for this, having had to sacrifice important elements of their own self-realisation to meet the needs of the person they care for. We were not surprised, even within such a small sample, to learn of at least two, and possibly three instances of this. The following respondent is only now trying to finish her studies in the evening, while working:

"When I was born my mother was 46... she had severe health problems.... The first two years of my life I always went with her to her job, she was an homemaker... Our day was divided between the private homes she worked in and the hospitals... we visited my brother every day. I entered primary school when she was already retired... my education was mostly an education

⁹ Or else of follow-up services aimed at meeting needs that arise with the passing of time; in any case, it would be better to avoid overly-bureaucratic passages, and the competencies are not fundamentally different if states in fact manage to integrate the social and health dimensions of the service.

at home... I began to work when I was 12, not out of necessity, my parents always obliged me to learn... to have an education.. It was me who didn't want". P - DB02

From this point of view it is obvious that these 'first aid' points, while fighting worst social exclusion, would be adjusted and made compatible with the scope of family obligations that are understood and accepted within the specific cultural framework of each country (Miller and Warman, 1996), as the previous workpackages often explained. However, the awareness of the greater disadvantage suffered by southern European caregivers facing care on two fronts should discourage the 'first aid services' from making misguided normative evaluations about the complex balancing between needs and resources. Such interpretations already count against families, as described by our participants in the punitive attitude assumed by social services when calculating the family share of expenses for institutionalised care (cf. par. 1.2). In any case, a comprehensive evaluation of the care resources of each family should be sufficient for confirming the relatively heavier care burdens that one is more likely to find in these countries: they are at the intersection of demographic decline, which diminishes personal resources; and they are likely to encounter the double burden as a result of delayed childbearing (see par. 1.1), residential proximity, and daily contact with elderly family members.

Finally, an imposition of caregiving obligations that is foreign to one's own culture is found to be unacceptable even to the most generous Finnish, British, and French caregivers, who, as we have seen, often describe their own contributions as traces of a solidarity of times past. At the same time, it is true that Italian and Portuguese participants' recognition of extended family obligations appears deeply marked by a sense of duty:

"Well, in my opinion, if you can no longer handle the person: like those who open the gas valve and leave the house, or those who undress themselves in the middle of the street, and whatever else, well, that kind of situation obviously needs a different solution; if not, well, I think that taking care of your entire family, and not just your father and mother, is an absolutely sacred duty: siblings, cousins, whoever, whoever, in my opinion the family is sacred and I am absolutely against this idea of just the nuclear family, of just having a mother, father, and child in the house, but why? It's so much nicer... IT - DB02

Q: [Do you think that it is the duty of a daughter-in-law to take care of her husband's parents?]

R: "I think so [...why?] Because she is married to their son, isn't she? I think so" P - DB01

And to the same question:

"I think so. If one day it ever should happen...fortunately my parents are still in very good health, but in the future, if they should need, I would appreciate it if he would do it, I would like it if he felt the same way I do". P - MC09 DB

On the other hand, Italians and Portuguese (though not just them) are also most likely to sharply refute the notion that they provide caregiving solely out of a sense of obligation. Indeed, denying the idea that they give their time and resources freely would make their own condition much more burdensome, depressing, and unacceptable.

The most sincere motivation to care for an elderly relative remains that of free, humane choice. This was reiterated by our participants, again in very similar ways across the five countries:

"It's never happened that no one was there to care for her. You find time, you go by trial and error. It's a matter of priorities, to see who is the least needy, who has fewer demands, the person with the least, they step up...every little bit of extra suffering we can avoid is a duty"

"It's not that, I don't like to think of this as having been imposed on me, as a duty, I think that people know what they should or shouldn't do, what they want or don't want [...] It's not an obligation. It bothers me to put things in those terms of obligation, of burden, to say that it's an

obligation to do it, it stresses the idea of a burden and I do not think that people should do things when it's a burden. If it's a heavy burden, rather don't do it" P - MC01DB

"...in sum, I would say that I don't believe in 'moral' obligations. But I do think that people shape their own lives according to the choices they make, and these can also be political, to challenge this process of atomisation of the society, of people, all of these mechanisms associated with economic calculation...that's how I see it. I think that you recognise other duties, beyond those to your children, there are those of being a citizen. On the other hand, the family, [...] it's one of the few points of resistance to this process of social atomisation; well, I don't think that the liberty of a child, of a member of the family can be discovered in simply following your own selfish interests". IT - DB03

"What's all this about obligation? Obligation is doing what we want and that which is within our possibilities...and doing it out of our own free will, isn't it? Because that's how I see it: it's preferable to be with them for one hour of our own free will than to be there all day, frustrated. So with regard to obligation, our obligation is to help within our possibilities" P - MC06 dB

"No, no sacrifices, to me the word sacrifice gives the wrong connotation. I would rather say that I'm putting my life on hold for a while, but it's a choice, I wanted it, I chose it. Even if sometimes..., pff!". F - DB02

"I don't think it should feel like an obligation, if that's how it feels than it's better not to do it, if you have to force yourself it turns out badly [...] the others you shouldn't feel obligated because they need you, if they need me, if I can help them I do, it, it's not something you have to impose on me, you shouldn't be chained to it, and it isn't even because it makes me feel good about myself; it has to be given sincerely, without strings". IT-MC25 DB

For all of these reasons it seems crucial that public services attain a deep understanding of the complicated ethical motivations behind caregivers' willingness to care for their elders. Service operators need to learn to act within a framework of altruism; in a certain sense, services need to learn to speak the same language of families. Caregivers do not want to be complained but sustained to keep the 'high level' meaning of care which is so important to them.

6.4. *'First aid' points for caregiving should be able to mobilise the necessary expert knowledge*

The counselling capacity of the 'first aid' points for caregiving should be able to mobilise any expert knowledge regarding both the present and future needs of each case. The systems of social protection of the countries in our study seem to be, if it is possible, even *less* capable of introducing a range of relatively 'light' and less costly measures that, when used well, and at the right time, could serve as preventive mechanisms and reinforce families' capacities to help themselves and to sustain the caregiving burden over time. Once more, however, in order to be able to think about these services within such a complex world of meaning, it is necessary to start from a more well-defined idea of what providing care means for our families.

"Maybe taking care of people means, but I wouldn't say it means having succeeded, to stay close to their problems, as well as to their needs". IT - DB03

"It means trying to anticipate...trying to understand...trying to put their needs in perspective, into the right light. To try and understand and decode language that isn't necessarily easy to decode: To try to get them involved, to try to make them accept, to accept being the bad girl...all things that you don't think about when you're under stress [...] to adapt to the situation...things change very quickly. But it also means to *not mourn for someone who is still alive*". F - DB01

“Taking care of the children like your own parents did, I would say with love, and above all, with an open heart, to listen. That, and then, listening doesn't have to mean you agree [...] and so what happens later is that you end up learning from each other To build [...] And then parents, too. It means listening not just to their physical ailments, but also to the things that worry them, that distress them, what they wish, what they are unhappy about...” F - DB02

“Because I care about her and wouldn't be able to live with myself if I didn't. I wanted to do everything I possibly could to make her as comfortable as possible. You know, clean sheets every day, nice talcum, fresh flowers, obviously it made me feel better, too”. UK - DB01.

One speaks, then, of services designed to support caregiving that is not simply a matter of meeting the basic needs of an elderly person, but rather an activity rich in meaning that can be shared by family caregivers. The priority is to help these caregivers preserve the meaning of their personal relationships with their family members, often expressed with small ritual gestures and respect, and not to waste it or burn it as a resource. In some countries, institutionalisation marks a moment when the health or status of the elderly person becomes irretrievably worse; in others, it marks the moment when the caregiver, whose life has already been ruined by the caring burden, throws in the towel. The meaning for all, however, is that of a defeat in the relationship.

6.4.1. Help in accepting decline and death

There is no doubt that the greatest difficulty for which caregivers find themselves most unprepared is the daily sight of the deterioration of their loved ones. A counselling service could usefully ease such a difficulty, even if only providing human contact and a listening ear:

“The emotional conflict, more than anything. I can cope with the hours and doing jobs around the house, time with people, I can cope with the hours, but it's the emotion I can't”. UK-MC08FU

“...and then the children become parents to their own parents, because that's really what happens. [...] for me the most difficult thing was caring for my mother, of handling this situation, it was also a psychological challenge: seeing the decline and the loss of a someone that you remember in a different way, the memory of a person who was independent, autonomous; then to see her like this was really depressing, it weights on your feelings, it weighs on you psychologically, yes, yes. It is difficult to accept and even now, at least for me it is difficult to accept that such a strong person is brought to this [...] The fact is that her mind is no longer present, she can't reason anymore, and it is difficult to accept that you can't explain anything to them anymore. [...] this is what is difficult to accept, it weighs on you, it really weighs on you. Because then you start thinking about it, you reflect on it: 'Is this how we will all end up?' and you also project your own ageing. I did, to be honest, I had these thoughts. I don't know if it is normal or not, but I did think about it like that. In fact, that was the most difficult thing, not being able to accept this, most of it is psychological”. IT - DB04

“It makes you feel extremely guilty, extremely guilty when you see the pain, the discomfort of your own parents...you don't want to see them suffer...and above all, whether or not they exaggerate, you can't deny that they cannot take care of certain things any more [...] but you can't always be available to them...”. F - DB03

“This isn't what I want to say. It's not having to do her laundry for her. What is hard is that 'my mother is getting old, I can't stand to see her get old, it means that I'm getting old too, and that's impossible' [...] [The difficult thing] is what it does to you, emotionally. It's the psychological effect. [...] When they shout and are aggressive towards their old parents, that's what I think the problem is. It's their way of saying 'he's getting old, he's getting old, and I'm getting old with him'. And this is...Accepting that they're not who they used to be, to accept having them age with difficulty, this is the really terrible thing”. F - MC23 DB

As the experience of self-help groups for caregivers illustrates, it is not necessary that these operators providing counselling services have specialist training in formal psychology. Being able to listen to feelings that are hard to express is enough. Oftentimes, caregivers even lose their ability to distinguish their own real physical problems from the distress caused by their impatience and, often times, feelings of guilt:

“And then there is this thing with the family carers that when you’re really tired, you just explode with rage, and then you feel so bad, ‘cause you know that he’s not being mean when he does it, he’s just ill. The hardest one must be this fatigue, this mental fatigue, when you have to live, have to live, well, with that ill person, you have to live with that ill person and see how he or she all the time gets worse and you can’t do anything else but watch. (...)

Then there is this senseless bad feeling that burdens the caregiver so horribly”. FIN - MC20 DB

One likely reason why caregivers tend to hide these feelings—even from themselves—is that taking care of an elderly person also means confronting the experience of death, of having to overcome, with very little assistance, an extremely powerful social taboo. Some of our participants discussed these feelings, offering wisdom and courage from which much can be learned:

“If people could live with complete control over their lives and that when one begins to decline...that they have enough...but no, this isn’t what is missing in our society, maybe we all have too much, anyway. Rather, you have to face up to the fact that we don’t accept the idea of death, that we don’t accept the idea of ageing... we doesn’t accept these things, and we don’t know how to come to terms with them. And I think that this is something that maybe we need to learn how to come to terms with”. F-MC04 DB

“Oh, yes, I imagine that the death of my father will be even more traumatic for me than that of my mother, even though I adore my mother equally. But I know how he feels about dying, I can’t just let him go in any way, that would be impossible [...] I won’t let him go that way, alone, that’s for sure. He has to be surrounded by us, anything else is unthinkable. Anyway, it is all very hard to think about”. F - DB03

From this point of view, it is easier to understand how important it is that caregivers be supported as they construct and ‘furnish’ a perspective of the future that embraces this taboo. Services that share technical knowledge aimed at preparing families for the worsening of certain illnesses, and that help families anticipate the stages of illness, and the appropriate remedies for each phase, would be a tremendous help in reducing the existential anxiety that arises from these situations. One would imagine that these types of services could effectively lower the chances that some siblings completely withdraw from the care of their declining parents because, as even abandoned caregivers clearly understand, they are incapable of managing the emotional difficulties associated with seeing their parents in decline.

“I think that he [a brother] did what we all did, he, it isn’t that he’s denying the situation, but maybe he refused to see it, because of course it would make him suffer. And then, once he realised how things were maybe he didn’t want to get too involved, or maybe he wanted to get involved but he didn’t know what to do, how to keep going...” F - DB1

A further advantage of this arrangement for caring for an elderly person, shared, as much as possible among siblings and other family members, also consists in the enhanced opportunity families have to honour the wishes of the elderly person him/herself. When a greater number of potential caregivers are available to assist with a range of activities, even if only very minimal, families can avoid the development of a too-exclusive relationship between a single caregiver and the cared-for. These relationships, whereby the elderly person is constrained to live a life of complete dependence on one person, often become filled with rancour and detrimental to both.

A corollary to this caveat regards elderly couples. Sometimes, if only one of the partners appears fragile, the couple seems to be able to maintain autonomy for as long as the marriage lasts, without having to request very much outside support from the family network. In reality, however, the strain on the healthier partner is substantial, and she/he also weakens. When the other partner finally dies, it becomes apparent that the couple had actually already ‘collapsed from within’. Weakened by the care burden and the loss of the loved one, the surviving spouse quickly runs out of internal resources and becomes extremely dependent.

6.4.2 Preparing families for subsequent stages

Services that structure the future, prepare families for subsequent stages, and offer potential solutions, could prevent caregiver’s anxiety associated with the approaching death of their loved ones. Even without addressing the theme in-depth, a certain amount of information about decline and death, and how to prepare for it, could be developed and incorporated into service programs. It would be very useful if such a resource, grounded in the wisdom that caregivers themselves accumulate with experience, was widely circulated and accessible. As we have seen from our participants’ accounts, the capacity to interpret the situation from the point of view of the elderly person, to perceive their small needs and to maximise whatever resources of self-sufficiency they retain, greatly helps. One example of this--perhaps the most extreme among our interviewees--is a daughter whose father is diagnosed with Alzheimer’s disease. ‘Heroically’ refusing to accept the diagnosis, she has managed to honour his wish to stay in his own independent household, while taking all the precautions necessary to keep him safe. As a caregiving professional, this respondent by no means underestimates the gravity of the diagnosis. Nevertheless, her capacity to keep the final scenario of her father’s illness and dependence ‘dormant’ for as long as it is appropriate, is a great lesson in how a gradual, day-by-day approach to determining the extent of an ill person’s needs can prolong their enjoyment of ‘normal’ life. Furthermore, this attitude can be a source of psychological support in so much as the deterioration of a loved one does not completely overwhelm his/her relationships with others, and family members still have the opportunity to respect and cherish the signs and traces of the ‘old self’ that remain. This gradual approach, though, completely contradicts the ‘threshold’ logic behind service provision for the elderly.

The history of the personal relationship with the elderly person remains the crucial starting point in the willingness to provide assistance with intimate tasks such as personal hygiene. The final decision on providing this care was sometimes counter to expectations, though, because deciding not to provide this care, or, on the contrary, to refuse the help of outsiders, is understood as a way to protect the relationship as it was before the crisis. It is thus absolutely essential that services are designed to follow the lead of the fundamental needs expressed by the caregiver. It is not surprising that the more generous and developed welfare state regimes are clearly more capable of taking these kinds of needs into account.

In contrast, welfare states in Southern Europe appear to exhibit a particularly brutal incomprehension of the meaning embedded in requests for assistance with such extremely intimate tasks. Such services are taken-for-granted as part of the family’s obligation, which can be extremely challenging, even violent, for some family care-givers to accept:

“...I, I really can’t believe what I can handle now, ever since I was a little girl these things have turned my stomach, I never would have imagined that I would have to do those kinds of things, I was never cut out for it, for me I never ever would have considered nursing as a job I would take. [...] Most of the time when I had to change my mother I would calmly go right into the bathroom afterwards to vomit. [*it was hard.*] I was a [...] squeamish about everything, really, if

someone else touched my fork I wouldn't be able to eat with it. Q: *[And how did you get used to it?]* R: I don't know, I changed from being like that to this [...] It was hard in the sense that, to do things I hadn't been able to do before, my father knew how I was and he told me 'don't worry about it, I'll take care of it'. [...] now I realise that nothing bothers me like that [...] back then it was exhausting to care for her, even the small things were a challenge. Probably...since I never had grandparents in the house, at least not sick grandparents with these kinds of needs, obviously when they needed something, it's natural with your own children, and with my mother, it just took time but then it seemed natural" IT - DB 06

There is probably another reason why the presumed and commonly discussed numerical diminution of potential caregivers for the elderly is based not on an understanding of the real rules of family reciprocity (Godbout 1998), but on imaginary hypotheses. For example, the very special relationship between grandparents and grandchildren is still relatively unexplored (for an exception that confirms this impression, see Attias-Donfut Segalen 1998). This relationship potentially provides a wealth of security for children: it is their chance to skip over a generation and spend time with calm and self-assured adults who, free of the strains and responsibilities of parenting, can afford to always be 'on their side'.

"The motivation is purely love ... you love your grandchild sort of on a different level than your own children. It's perhaps because all the extra is gone You look at things sort from above. Small things don't bother you any more, you can see the whole in a way" FIN - SP12A DB

One would think that such a relationship would not be without its own reciprocities; these might emerge when the relationship is transformed and the dependencies are reversed. Once more, skipping a generation, the grandchild is situated in a symmetrical role where, though not being directly responsible for caregiving, he/she is permitted to provide care gratuitously.

Of course, the general history and quality of grandparent-grandchild relationships also shape the involvement of the child when the elderly person becomes dependent. Some of our interviewees clearly noted how these relationships could constitute an unexpected resource for their children.

"...look, Granddad had a stroke, but in all of Angela's (her daughter) 19 years of life, he never once dropped by, not a single Sunday morning to say, "I'll take her (A) out for the day". Now A. is incapable of stopping by her grandfather's to say, "Come on, Granddad, let's take a walk", as she should; you can imagine how much time my mother and I spend taking him out to walk in the neighbourhood, or to the park...it's a big waste of time and money, but besides that it's cultural idiocy because A. has a lot to learn from her Grandfather, she should spend a few hours listening to him, he could help her figure out some important concepts..." IT - MC16 DB

Among our five countries, only Finland has attempted to compensate family members for this type of caring, instituting a care allowance that can be claimed by caregivers over the age of 18, even if they are a relative of the person being cared for. Though admirable, we should ask ourselves whether or not placing a monetary value on the relationship might undermine the altruistic ethic that in these cases characterises the grandparent-grandchild relationship. Even if it has many times been demonstrated that money does not generally ruin existing relationships, this very special relationship seems, at the same time, open to a certain degree of ambivalence and we should try to preserve it on the basis of a better research-based knowledge. A better solution might be the awarding of a longer-than-average parental leave, when the grandchild has need of it, or else the accumulation of credits in a time bank that could be used for the care of his/her own children. These types of retribution seem more harmonious with the long-term balance of inter-generation give and take that actually characterise the grandchild-grandparent relationship. Anyway, even if it probably only involves a scant minority, the Finnish Law granted to open a symbolically very important path.

There is definitely a visible connection between the compulsive and punitive subsidiary forms of old-age assistance made available in Southern Europe, and the fact that Southern European families are the most likely (along with Estonians) to try to shelter the youngest generation from relationships with grandparents who are seen as being too ill or frail.

“Me and my sister, we haven’t wanted to bother the next generation too much they have their own children and their own activities, you can’t recruit everyone to this thing, so we’ve decided that the matter’s clearly between the two of us. (...)” FIN - MC21DB

One could argue that the cultural changes seen in France or in Finland, where caregivers have more rights to choose, based on their own relationship with the person being cared for, to take responsibility or not for the most intimate caregiving tasks, can be seen as a necessary condition for the mobilisation of an enormous patrimony of intergenerational solidarity. Family relations can thus be seen as richer, and not poorer, than they were in times when the mechanisms of duty and exchange were the defining factors. From this perspective, the greatest potential contribution of a ‘family history database’ such as ours is undoubtedly that it allows us to test certain aspects of the gradualness of ageing, as well as the processes of relationship building with the elderly. Importantly, it is on this level that the mechanisms of social integration in opposition to the ‘self-destructive spiral of solidarity’ can be tried out (Castel 1995).

We can also ask ourselves if types of services such as occasional companionship, which are sometimes proposed to ease the burden of families who care for elderly relatives, can be thought of not just as “band-aids” for already desperate situations, but rather as strategies capable of compensating for demographic imbalances that threaten to dry up intra-familial caregiving resources, especially in southern Europe. (Laslett et al 1993). In conclusion, we cite here a participant whose words demonstrate that the worst fears of demographers are not unfounded. This respondent admitted that the heavy caring needs of her elderly parents and in-laws had forced her to compromise her own childbearing plans and give up the idea of having a second child:

[Wife]” Sincerely, I would have liked to have had another child, but...[Husband] We thought about it several times, but, then...[Wife] We thought about it a lot, then [...] having these elderly in-laws, what could we do, leave it in a crèche? You couldn’t even enjoy a baby, but let’s see if we will even be able to enjoy the one we have. Well, and then we’d also like to have some time for each other, from this point of view we’re a little selfish, if you want to call it selfishness”. IT - DB01

We can thus definitively conclude that the efforts to define a more sustainable social justice must first address a new social contract that articulates more evolved forms of the gender contract and inter- and intra-generation solidarity (Esping-Andersen 2002). Importantly, this last point cannot be adequately resolved within the restricted debate on pension reform, and it discourages an over-sensationalistic reading of breaks in the inter-generation social pact (Laslett and Fiskin, 1992; Bengtson, 1993). Inter- and intra-generation solidarity must be based on a joint consideration of what forms of informal and formal assistance can be mobilized in light of the public and private social costs of an ageing society (Myles 2002; Attias Donfut et al. 2002).

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Appendix 1

Table 1 Interview numbers of the varieties of double front

	France	Finland	Italy	Portugal	United Kingdom	Total
Light double front of care	FDB1 FDB2 FMC3	FINMF14 FINMF23 FINDB3 FINDB5	ITMC1 ITMC12 ITMC24 ITSP6 ITSP23	MC6DB PMF11	UKSP1 UKSP8 UKSP9 UKSP12 UKSP13 UKSP15 UKSP18 UKMC5 UKMC12 UKMC16 UKMC23	25
Sandwich generation	FMC5, FMC7 FMC4 FMC8FU	FINSP13 FINMC14 FINMC16 FINMC21 FINDB2 FINDB4	ITMC7 ITMC14 ITMC20	-	UKSP7 UKMC6 UKMC18 UKMC22	17
Medium to important	-	FINDB6 FINDB7 FINDB8 FINDB10	ITDB1 ITDB2 ITMC26 ITMF12 ITMF24 ITMF26	PDB2 PMC7	UKSP2 UKSP3 UKMF2	15
More Important or Periodical burden	FMC11 FDB3	FINDB11 FINMF16 FINMF24 FINMF25 FINMF26	ITSP1 ITMC25 ITDB3 ITDB5	PDB1	UKSP5 UKMC24 UKMF1 UKMF5 UKMF8 UKMF11	19
Very heavy double burden of care	FMC22 FMC1 FMC23F	FINSP12 FINDB12 FINMF13 FINDB1	ITDB4 ITDB6 ITDB7 ITDB8 ITMC2FU ITMC16 ITMF27 ITMF31 ITMF32	PMC1 PMC8 PMC9	UKMC16 UKSP2FU UKMC9 UKMF12F UKMF14F UKDB2	24
Total	12	24	27	8	29	100

Table 2a. Interview numbers of the different work arrangements

Type of Work	Regular working hours		Irregular working hours		Weekly working hours not known / impossible to define	Total	
	Full time	Part time	Full time	Part time		Men	Women
Employees / Subordinate Workers	FDB2, FDB3, FMC3, FMC5, FMC7, FMC11, FMC22, FINDB8, FINDB10, FINMC14, FINMC16, FINMC21, FINMF16, FINMF23, FINMF24, FINMF25, FINMF26, ITDB1, ITDB4, ITDB5, ITMC2, ITMC1, ITMC7, ITMC14, ITMC16, PDB1, PDB2, PMC9, PDB11, UKSP13, UKSP15, UKMC16, UKMF14 (man)	FMC1, FMC4, FMC23, FINDB4, FINMF1, ITDB2, ITDB3, ITSP1, ITMC12, ITMC20, ITMC24, ITMC25, ITMF24, ITMF26, PMC6, UKMC12, UKMC18, UKMC23, UKMC24, UKMF2, UKMF5, UKMF8, UKMF11	PMC8, UKMC6	FDB1, FINDB7, PMC1,	FINSP12, UKSP3, UKSP5, UKSP12, UKSP18	1	65
Semiautonomous collaborations / Freelancers, term jobs			ITSP23DB (man)	FINDB3, FINDB11, FINSP13, UKMC9D, UKMC22, UKMF12	FINDB1, FINDB2	1	8
Professional Workers	ITSP6DB (man), FINDB12, UKSP2FU, UKSP9	UKMC5	FMC8FU, PMC7		UKDB2, UKSP1, UKSP7, UKSP8, UKMF1	1	11
Seasonal / Occasional Workers		ITDB7	ITMF12			0	2
Sub total	37	25	6	9	12	3	86
Not working at the moment of the interview		FINDB5, FINDB6, FINDB9, FINMC20, UKDB1, ITDB6, ITDB8, ITMC26, ITMF27, ITMF31, ITMF32				0	11
						100	

FRANCE: 12
FINLAND: 24
ITALY: 27
PORTUGAL: 8
UNITED KINGDOM: 30

Table 3a. Interview numbers of the different network organisations

	ONLY FAMILY	INFORMAL+ Family	SERVICES+ Family	Family INFORMAL & SERVICES
RICH	FIN-SP12 DB / UK-MF01 DB / IT-MC16DB / ITMF26 DB / IT-MF32	UK-SP08 DB / UK-SP09 DB / UK-MF05 DB / FIN-MF24 / ITSP23 / IT-MC12	UK-MC06 FU / P-MC7 DB / P-DB 01 / F-DB1 / F-DB03 / F-MC05 DB / IT-SP6 DB / IT-MC26	FIN-DB1 / FIN-DB3 / FIN-MC21 DB / UK-DB01 / UK-DB02 / UK-SP07 DB / UK-MC22 DB / P-MC8 DB / P-MC9 DB / F-MC4 DB / F-MC11 DB / F-MC22 FU / IT-SP1DB
Total rich 32	Total 5	Total 6	Total 8	Total 13
SPECIALIZED	UK-MC24 DB / IT-MF24	UK-MC5 DB / IT-MC 7 / ITMC14 /	FIN-DB12 / ITDB3	UK-MC12 DB / P-MC01 DB/ ITDB1 (RSA) ITDB8 / IT-MC02FU
Total specialized 12	Total 2	Total 3	Total 2	Total 5
MINIMUM	UK-SP02 FU / UK-SP03 DB / UK-SP13 DB / UK-SP15 DB / UK-MF08 DB / FIN-MF16 DB / FIN-MF23 DB / FIN-MF25 DB / FIN-MF26 DB / F-MC1 FU / UK-MC18 DB / IT-MC1 / ITMC 20DB / IT-MF27 / IT-MF31	UK-SP01 DB / UK-SP12 DB / UK-SP18 DB / UK-MC9 DB / UK-MF11 DB / UK-MF14 DB / F-MC23 FU / PMF11 DB/ ITDB2 / IT- MC25	FIN-DB2 / FIN-DB5 / FIN-DB7 / FIN-DB8 / FIN-DB9 / FIN-SP13 DB / FIN-MC16 DB / FIN-MF13 DB / FIN-MF14 DB / UK-MC16 DB / P-DB 02 / F-MC03 DB / F-MC07 DB / ITDB4 / ITDB5 / ITMC24 DB / IT-MF12 DB	FIN-DB4 / FIN-DB6 / FIN-DB10 / FIN-DB11 / FIN-MC20 DB / UK-SP05 DB / UK-MC23 DB / UK-MF12 FU / UK-MF02 DB / P-MC6 DB / F-DB2 / F-MC08 FU / ITDB6 / ITDB7
Total minimum 56	Total 15	Total 10	Total 17	Total 14
TOTAL 100	TOTAL 22	TOTAL 19	TOTAL 27	TOTAL 32