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S.IN.CA.L.A.

IO1 - “Tell me about you”: users’ experiences of families with caring role

Data Reporting

Developed by CASO50+

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INTRODUCTION

Background

In Europe, 80% of care, in case of chronic illnesses and disability, is provided by informal caregivers – i.e. people providing unpaid care to someone with a chronic disease, disability or other long-lasting health or care need, on an unpaid basis.

While caring for a loved one can be a source of personal rewarding, it can also entail its own set of challenges. These challenges are broad and go from physical and mental health problems, social exclusion, to difficulties in balancing paid work with care responsibilities and financial problems.

Generally, in households, when a member has a chronic illness or disability one of the relatives is designated his/her “primary care” (i.e. the person having the main care responsibilities). However, it is known that when there is a change that affects one family member, it affects all family as a whole (Wright & Leahey, 2000). Families caring for an older person in physical and/or cognitive decline are faced with increased caretaking demands over a long period of time with limited community resources to support them. Members of a family – spouse, adult children, grandchildren -, will take on diverse roles leading to different experiences and perspectives on the burden of care. While the caregiving experience for each family member is different, all will encounter a change in the social relations between their spouse, parent or grandparent. A functional relationship among family members is key to successful change of roles and adaptation of the family. Establishing a new balance is influenced by the meanings families attribute to their situation.

The stress of a chronic health condition or disability in a family member therefore can cause problems in a family, particularly if the different caregivers within the family attempt to deal with his or her feelings alone and without support. The ability to communicate effectively is a critical aspect of healthy functioning families. Communication is even more important where chronic illness is present as there are more problems to be solved and caregiving tasks to be undertaken. One of the primary threats to communication is the repression of affect, when family members suppress negative feelings like, guilt, uncertainty, conflict, confusion and being overwhelmed with their situation. Being able to openly express these feelings and share emotions can build caregivers' resilience. Sharing the complex realities faced by persons who have experienced comparable situations and the feeling that they are not alone in their experiences or emotions has been found in previous research to be beneficial to dementia caregivers (Greenwood et al. 2013). Hence providing informal carers with an opportunity to share their personal experiences within a supportive empathetic community can help to resolve complex deep root emotions such as guilt, fear and conflict.

The S.IN.C.A.L.A. project

The S.IN.CA.L.A project will meet common need of all EU countries: to address the challenge of providing care and support to an ageing population, particular among the older old (80+). In all countries, there will be a need for an increasing number of families to provide care. To achieve this, policy and supports for family carers will be imperative. Indeed, the EU has taken steps to address informal carers needs. The Europe 2020 strategy on employment and the European gender empowerment strategy (two-thirds of Europe's carers are women) are examples of this, as is the recent European pillar of social rights and 2016 Parliament report on carers in the EU.

The S.IN.CA.L.A project aims to develop a carer support programme based on a narrative approach. The goal of this intervention is to support different family members – spouses, adult children and grandchildren- providing care and support to an older person to express their inner thoughts and feelings in a safe non-judgemental space; thus making families resilient in how they cope with the challenges caring brings.

The educational tools developed will be based on experiences carried out in Greece, by partner Alzheimer Hellas, and will be adapted and transferred to all other country contexts.

Purpose and scope of the report

The 'Tell Me About You' Report will outline the experiences and needs of families with a caring role in six countries – Estonia, Greece, Ireland, Italy, Portugal and Slovenia. It will explore with informal carers in the different countries the impact of caring on them and on family relations; their coping strategies and unmet needs. In particular, this report explores how caring can have different impact on carers of different age groups, how family relationships have been positively or negatively impacted by caring, what kind of adjustments and coping strategies families have adopted to be more resilient and adaptive to the changing situations.

The report, while providing new qualitative inputs to the research on family relationships coping strategies and educational needs in families with caring role, will also define to which extent the existing training materials can be transferred and how, on the other hand, they need to be integrated and adapted.

The report, once delivered, will be presented to a round table of social and health care professionals in each country who will act as peer-reviewers, commenting on the outcomes in relation to the educational resources that the partnership intends to implement. The findings from the research report will inform the development of the narrative based workshops and the MOOC (Massive Open On- line Course).

Tell me About You – Methodology

The first task of IO1 was to conduct a literature review about the experiences and needs of family informal caregivers (hereinafter referred to as IC, as an abbreviation for informal caregivers), in order to understand the state of art of several aspects, namely:

- what are the needs of IC;
- what is the impact of caregiving in the lives of IC;
- how IC manage and adapt to the challenges raised by caregiving;
- what contributes to their resilience;
- are there differences in the experience of caregiving when looking at IC with different kinship relationships to the care recipient;
- what is the impact of informal caregiving in family dynamics; which methodology and instruments/topics to assess IC.

Besides allowing analyzing the previously mentioned aspects of caregiving within families, the literature review also aimed to inform on the methodology that should be adopted in order to collect data. In this sense, a ‘Methodology Script’ was developed with the main aspects to be followed when collecting data, such as: techniques for data collection; ethical considerations; inclusion and exclusion criteria; tips on focus group facilitation; structure of the session. Meanwhile, a ‘Data Collection Kit’ was also developed. This kit contemplates the schedule for the focus groups, as well as all the other documents needed to start the focus group, namely: Registration form; Informed Consent (also a Parental Informed Consent); Questionnaire; Data collection checklist; and Reporting framework. This would guarantee some coherence and homogenization among the partners.

Desk Research

The demographic pyramid is changing, with an exponential increase in the average life expectancy and, therefore, on the number of elderly, which raises a number of questions. People live longer, but with lower quality of life. The increase in the number of people suffering from chronic and disabling diseases and the lack of long-term care has created new needs (Sakakibara, Kabayama & Ito, 2015). Given that health care and formal care do not proliferate at the same pace as the needs of the elderly, informal caregivers are responsible for providing care and support at home, and at several levels (Silva, Teixeira, Teixeira & Freitas, 2013; Zwaanswijk, Peeters, Beek, Meerveld, & Francke, 2013).

According to different authors, the definition of informal caregiver - although with some distinctions - presents some common aspects regarding the type of support that is provided. In this sense, an informal caregiver is someone who is a member of the family, friend, or neighbor who, in an unpaid way, provides support to a physically, emotionally, financially and informally ill or physically disabled person (Bove, Zakrisson, Midtgaard, Lomborg & Overgaard, 2016, Horrel, Stephens & Breheny, 2015, Vaigankar et al., 2013).

Culturally, the family is seen as the first line of response regarding care (Vaigankar et al., 2013). Across Europe, most care is provided by relatives (Gonçalves-Pereira & Sampaio, 2011; Jayana & Hurria, 2012; Bruggen et al., 2016; McCabe, You & Tatangelo, 2016). According to Thompson and Roger (2014) the percentage is between 60 and 80%, while for Hawranik and Strain (2007) the numbers are even more significant: between 75 and 90%. However, globalization has also brought about changes in the availability and motivation to care for, with geographically dispersed relatives and women working outside the home having an impact on this matter (Horrel et al., 2015).

Regarding the socio-demographic characteristics of family caregivers, studies are not unanimous. In terms of age, research shows a predominance of middle-aged people as caregivers (Jayania & Hurria, 2012; Silva, Teixeira, Teixeira & Freitas, 2013). However, there are other authors that refer an increase of younger caregivers (Blanton, 2013). In what concerns the kinship with the person cared for, spouses occupy the first place, immediately followed by the children (Buscemi et al., 2010; Zwaanswijk et al., 2013). For other authors, the ratio is the inverse, with children being the main caregivers, followed by the spouses (Bruggen et al., 2016; Horrell et al., 2015).In terms of gender, studies shows a predominance of women as main caregivers (Buscemi et al., 2010; Roberto & Jarrott, 2008; Silva et al., 2013; Zwaanswijk et al., 2013). For Campbell (2010), daughters are more likely to take care of their parents than their brothers, and those, when married, rely on their wives. Although, for a long period of time, caring was considered primarily "women's work," (Anderson, 1987) some authors have mentioned the growing role of men as family caregivers (Blanton, 2013; Campbell, 2010; Hawranik & Strain, 2007; Roberto & Jarrott, 2008). In fact, carers are a heterogeneous group and their response to caring has been related to their age, sex, as well as to the relationship to the dependent person.

In general, the literature shows that the impact of caring on the caregiver is quite negative, since the informal carer’s tasks are uninterrupted and, unlike a transient event, demand responsibility and transform the individual’s life in the sense that they may constitute significant stressful events, creating a burden of care which requires the carer to redimension their life so as to try to adapt to the implications caused by the continuous provision of care (Cedano, Bettencourt, Traldi, Machado & Belasco, 2013). The pressure, stress or load endured by a person who cares for a chronically ill, disabled, or elderly family member can be defined as caregiver burden (Stucki & Mulvey, 2000). The burden is felt especially in more advanced phases, or when the level of dependence increases. (Buscemi et al., 2010).

Burden is especially felt in 4 main areas, namely: physical; social; financial; and psychological/emotional, the latter being the most studied.

At a physical level of, there are reports of increased blood pressure, musculoskeletal problems and sleep disorders (Hawranik & Strain, 2007, Horrell et al., 2015, McCabe et al., 2016, Mthembu, Brown, Cupido, Razack, & Wassung, 2016; Roberto & Jarrott, 2008; Sakakibara et al., 2015; Thompson & Roger 2014, Vaigankar et al., 2013). The deterioration of the health conditions of informal caregiver appears as one of the main causes for the institutionalization of the person cared for (Horrell et al., 2015, McCabe et al., 2016).

Depression, anger and anxiety (Bruggen et al., 2016; Buscemi et al., 2010; Giosa et al., 2014; Hawranik & Strain, 2007; Horrell et al., 2015; Jayana & Hurria, 2012; McCabe et al., 2016; Mthembu et al., 2016; Roberto & Jarrott, 2008; Silva et al., 2013; Thompson & Roger, 2014; Vaigankar et al., 2013) appears as the most prevalent negative psychological effects, followed by feelings of impotence, fear of death, a sense of injustice, exhaustion (Buscemi et al., 2010), guilt (Campbell, 2010), and loneliness (Silva et al., 2013).

Loss of social ties and/or relational deprivation, limitation or cessation of leisure activities, alteration of work rhythms, or even loss of a professional role appear as negative social consequences for family caregivers (Neufeld et al., 2007). According to Zwaanswijk et al. (2013) in moderate phases of the disease the negative effect of caring impacts mostly on a social level, due to loneliness and a decreased contact with friends and family; in more advanced stages the burden is transferred to the caregiver's health, since care is experienced as physically more demanding.

Although the majority of studies shows a negative impact of the caring process, this is a complex task that may be seen by caregivers as an ambivalent experience (Horrel et al., 2015). More recent studies has shown the existence of a positive dimension related to care and that refers to a sense of personal growth, the development of competences , feelings of satisfaction and gratitude, more patience and tolerance, and a better relation with the relative taken care of (Bruggen et al., 2016; Campbell, 2010; Horrell et al., 2015; Sakakibara et al., 2015; Mthembu et al., 2016 Buscemi et al., 2010).

The kinship may have an influence on the type of impact of caring – positive or negative. In Roberto and Jarrott (2008) study, wives appear as showing higher levels of depression and worse quality in social interactions. For Jayana and Hurria (2012), daughters seem to be the ones suffering the most. On a study with 2701 carers, Bruggen et al. (2016) conclude that children have more (and more difficult) problems to manage.

There are some aspects that help predict a greater or lesser impact of caregiving on the caregiver, such as: the characteristics of the person to be cared for, namely the degree of dependency (Roberto & Jarrott, 2008); the type of disease – in cases where there is a cognitive behavioral deterioration (e.g. dementia), the negative impact is higher and the positive effects are felt to a lesser extent (Bruggen et al., 2016; Thompson & Roger, 2014; McCabe et al. Jarrott, 2008); the duration of care and the unpredictability of their course (Thompson & Roger, 2014; Zwaanswijk et al., 2013) and the previous relationship with the carer - the caring process seemed to exacerbate the preexisting connections and difficulties in family relationships (Blanton, 2013; Campbell, 2010).

Research on the needs of caregivers shows a higher incidence of those related to information and psychological support (Gonçalves-Pereira & Sampaio, 2011, Washington et al., 2011). Other authors also refer the need for professional help (McCabe et al., 2016) and financial and legal support (Silva et al., 2013, Vaaiankar et al. 2013). Kim, Kashy, Spilers and Evans (2010) further add medical and spiritual needs.

A systematic literature review (Silva et al., 2013) showed that all articles referred to informative and practical needs. The topics in which caregivers most wanted to have help on were regarding diagnosis, risk factors, disease evolution, symptoms, treatment, prognosis and management of symptoms. They also felt the need to develop more technical skills in certain tasks, such as bathing or feeding (Horrell et al., 2015; Kim et al., 2010; McCabe et al., 2016; Silva et al., 2013; Thompson & Roger, 2014; Tsai et al., 2015; Vaigankar et al., 2013). As far as psychosocial support is concerned, caregivers mention the importance of support from other relatives, the need to reduce social isolation, the need for support and sharing groups, and the need of a greater recognition of their role (Kim et al., 2010, Tsai et al., 2015, Vaigankar et al., 2013).

Data Collection

This part of IO1 constitutes mix methods (qualitative/quantitative) research, consisting of carrying out 3 focus groups and a survey in six European Member States (Estonia, Greece, Ireland, Italy, Portugal and Slovenia) to understand the experience of caregiving among family informal caregivers in general, and particularly regarding the type of kinship with care recipient and the cultural background of the different countries. Building also on the outcomes of the literature review, the findings from these focus groups are intended to inform the adaptation of the workshops to be held in IO2.

The aim of this data collection is: To explore the informal caregivers' caregiving experience, to understand and identify the caregivers' needs related to this, and what variables contribute to resilience; To gain a better understanding of the caregiving experience of informal caregivers; To understand and identify caregiver's needs; To explore how caregivers adapt to the caregiving role and what factors contribute to resilience.

As already stated, the design of this study was a cross-sectional mixed methods study (qualitative and quantitative data collection) comprising focus groups and questionnaire. Focus groups formed the main technique of data collection, while questionnaire is a supporting method which will allow to collect data in a more systematically way. The option to use a qualitative methodology allowed to establish a more close relationship with the participants - which is in accordance with the objectives of the project regarding the importance of giving voice to the subjects - and to get more detailed data.

Data collection was developed on the bases of ethical considerations, which included: Informed consent; Voluntary participation; Confidentiality; Anonymity; Principle of the relevance of the information.

Focus Group/ Interviews

As already mentioned, all partners had access to the same materials to collect the data as well as a report framework, which objective was to facilitate the reporting of the information gathered.

Each partner was able to collect data from all target group previously defined – grandchildren, children, and spouses. However, due to some constraints related to informal caregivers' availability (whether to move from their house or because there wasn't a schedule suitable for everyone), some of the partners had to develop individual interviews.

In total, 11 focus group discussions (EE-GR-IE-IT-PT-SI) and 14 interviews (EE-IT-PT) were developed. The total number of participants involved was 86. For more detailed information see Table 1.

Country	Focus Group			Interviews			Total of Participants
	Spouses	Children	Grandchildren	Spouses	Children	Grandchildren	
ESTONIA (EE)		2	-	1		1	12
SLOVENIA (SI)	1	1	1	-	-	-	14
GREECE (GR)	1	1	-			1 group interview	12
ITALY (IT)	1	1	-	-	-	2 (+ 1 group interview	18
PORTUGAL (PT)	-	1	-	2 (+1 group	-	5	13

				interview)			
IRELAND (IE)	1	1	1	-	-	-	17
							86

Table 1. Number of focus group/interviews per partner

From the 14 interviews, 3 were group interviews. Since the first goal was to develop focus group discussions, partners tried to gather a minimum of 4 caregivers per target group available at the same time. However, as previously explained, in some cases this was not possible. In three cases (GR, IT and PT) there was a possibility to have some caregivers available at the same schedule, so the partners from those countries chose to do a group interview (PT with 2 caregivers; IT with 2 caregivers and GR with 3 caregivers).

Each session, whether focus group or interviews, followed the same structure, namely: i) Opening: the moderator(s) briefly introduced and explained the objectives, what was expected from the participants and presented the ethical aspects; ii) Warm-Up: each participant introduced themselves with some personal information, namely, who was the person who they care for; iii) Discussion: the moderator(s) began to present the topics for discussion, making sure that everyone participated; and iv) Closure: the moderator(s) summarized the main ideas and guaranteed if anyone would like to add something. At the end of each session, the participants were asked to fill a small questionnaire.

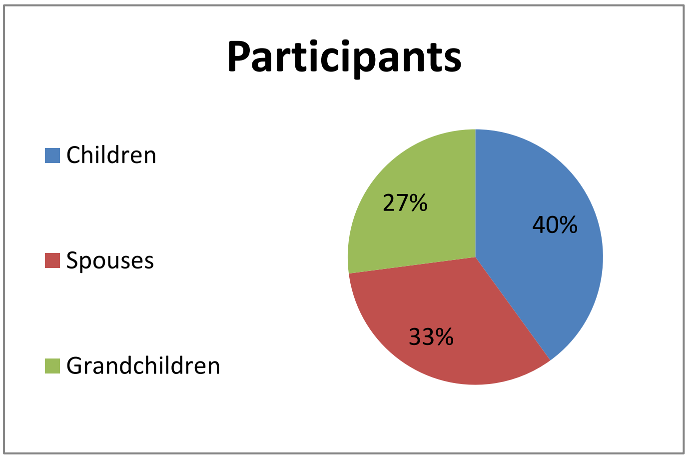
The same script was used both for focus group as for the interviews, and it cover topics such as: Overall experience as a caregiver; Resilience; Intergenerational relationships; Overall needs (Physical, emotional and social needs; Information, communication and instrumental support needs).

Each partner was responsible for the audio transcription of the FG or interviews sessions and for anonymizing the data (so each participant was given a fictional name). These transcriptions were crucial for further analysis. After that, all partners were responsible for reporting the data on the report created for that purpose.

Participants' socio-demographic information

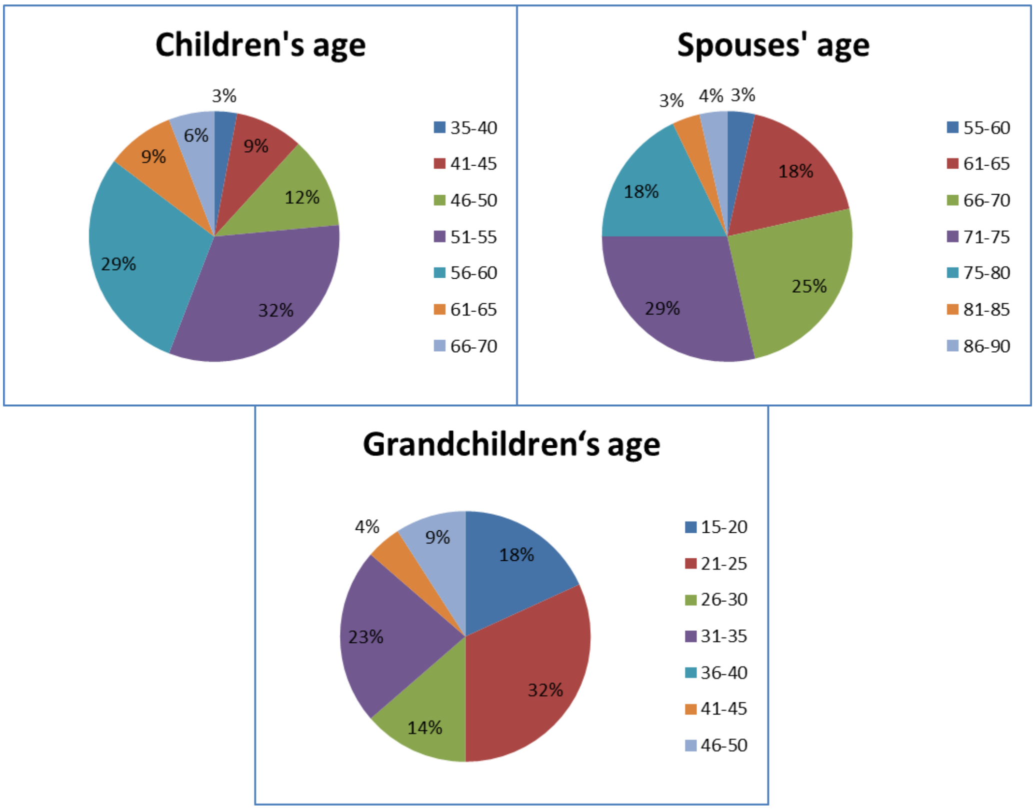
Despite of the efforts from all partners to gather the same number of participants (at least a minimum of 4 participants per kinship) this was not possible in all cases. In this sense, and from the total of participants in the FG and interviews, 40% were children, 33% were spouses and 27% were grandchildren (see table 2). This might be result of the culture of care in each country, where children are usually those who become responsible for taking care of their parents.

Table 2. Total of participants



Regarding the participants' gender, overall the majority of the participants were female which is in accordance with what is stated in the literature (please see Buscemi et al., 2010; Roberto & Jarrott, 2008; Silva et al., 2013; Zwaanswijk et al., 2013). Considering age, the range, considering all the participants, went from 16 years old to 88 years old (see Table 3).

Table 3. Participants' age



Children range from 38 to 70, with a mean age of 54 years old. Spouses' age were between 59 and 88 years old and the mean age was 71 years old. Grandchildren's age range between 16 and 49 years old, with a mean age of 28 years old.

Data Analysis Reporting

Regarding data analysis, it followed an established method of content analysis. Qualitative data analysis involves organizing, accounting for and explaining the data; in short, making sense of data noting patterns, themes, categories and regularities (Cohen, Manion & Morrison, 2007). To proceed with the analysis we worked with a predetermined analytical frame of themes, namely those used in the FG and interviews script. This frame of themes came from the literature review and, as previously mentioned, allowed to develop a 'Data Collection Kit' that contemplates a reporting framework on which the partners should report their findings with illustrative quotes. In this sense, data is analysed and presented according to the following themes: i) Overall experience as a Caregiver; ii) Intergenerational relationships; iii) Resilience; and iv) Overall needs.

For each theme, data will be presented by kinship and illustrated with quotes from the participants.

It is important to state that the data analysis aimed to identify the similarities among partners in order to present a broader picture of the caregiving and caregivers reality across 6 European countries. In some cases, however, some particularities may be explored.

I. Overall experience as a Caregiver

Children

In general, all adult children perceived their role as carers of their parents as a way to reciprocate what they have done for them during their lives. The blood-tie is at the center of the experience of being a carer for their parents: in the core, is the love for the parent, and the sense of 'repaying the favor'. However, in cases where the relationships between parents and children were difficult, the perception and feelings about the caregiving activity can be primarily negative, since they are greatly influenced by the pre-existing relationship with parents:

> **"I realized I do not love my mother and I did not receive love from my parents … The sense of duty is very strong and I cannot relax and think about myself"**
>
> (Giulia, Italy)

In most cases, participants pointed to lack of support from other members of the family. In the case of the parent moving in with one of their adult children (the carer), other siblings take on more of a visiting role. Visits are not always frequent (sometimes once a week for only 1hour) and in some cases, siblings only contact their parents by phone-call, to check if they are okay.

> ***"my brother tries to come down once a week and he thinks he is great, he stays for an hour"***
>
> (Erin, Ireland)

This can, in some cases, be justified by the fact that other siblings are emigrated which makes it difficult to be present to assist in the caregiving process.

Nonetheless, there is one case (Estonia) where the families of the caregiver are usually involved in the care process. Usually, the primary caregiver emerges amongst the children of the care receiver and it comes down to the primary caregiver's capability to lead the care process and willingness to involve other members of the family or relatives into the care. Of course this depends on the care burden, family composition and the status of family members. In some cases, the caregiver can also rely on support received outside the family, but most frequently the help comes from spouses, brothers and sisters of caregivers (other children of care receiver). This, of course, is usually case-sensitive and depends on the current needs of care receivers and caregivers.

Where a parent has dementia and they no longer have capacity, decision-making about their care becomes a family matter and this can cause difficulties between siblings where there are different understandings of the parent's illness and their needs. For example in Ireland the child who has been given power of attorney has control over decisions and this can cause conflict within families where relationships are not good.

"They have control over what mother eats, what she wears and who visits her... if we don't go with the flow, that access to our mother could be pulled away from us"

(Bridget, Ireland)

Adult children mentioned some issues with adapting to the caregiving situation, since it implies organizing and agreeing with other relatives how will they organize the care and also, how to organize their job. In this sense it proved to be easier for those who were unemployed.

" I took it on really because my brother said it to me, that I was the only free one and they said they would come much more often than they are actually coming 'oh we will call"

(Erin, Ireland)

Regarding the interaction between care receiver and caregiver, in some cases, it proved to be difficult for the parents to accept they are being taken care of by their children. In the Slovenian case, children mentioned that their relationship with their parent got better and deeper, but only after their parents accepted their disease. This interaction between carer and care receiver can also be influenced by the type of care provided to their parents: if the caregiving is mainly visiting the parents at their home and helping them with some daily activities or if it is providing 24/7 care.

“My dad was pushing me away at first. He could bare the fact that he needs help and that I’m the one to do it. But with time he realized this is the only way”

(Slovenia

Spouses

In general, becoming a caregiver of a spouse seems the natural step that happens to the onset of a disease or condition that makes the spouse dependent or in need of care, motivated either by love/emotional bond, or by a sense of duty/marital responsibility.

“With my wife there is now a kind of "fraternal" love, our relationship is changed, but it is not less intense and what I do for her I do it with satisfaction”

(Alessandro, Italy)

Additionally, in Portugal, one of the spouses implicitly referred gratitude as the major motivation for care. Keeping the spouse at home seems to be the ‘natural’ solution which also corroborates this idea. Yet, spouses will consider institutional measures when they are no longer able to take care of their family member.

The relationship between spouses has become better and deepen in some cases (e.g. SI, IT)

“I verified the depth of the emotional relationship and of the solidarity with my wife”

(Diego, Italy)

while in other countries it seems to be affected by the difficulty of the care receiver to accept his/her condition, by the severity and characteristics of the disease, or by the attitude/collaboration of the care recipient.

"I don't mind looking after him if he would only cooperate, anything any of us is doing including the kids is for his benefit"

(Breanna, Ireland)

"There is so long history that it is difficult to separate care and daily living. Sometimes the good memories are shadowed by the care responsibilities. There has been a lot of it. Diagnose came, what it is, yes, almost 40 years ago"

(Eliise, Estonia)

Spouses from all countries pointed out difficulties and challenges regarding caregiving. Taking care of a spouse is financially and emotionally demanding. The constant feeling of fear and impotence for the safety and well-being of the spouse seems to be common in most of these caregivers. Burden, constant tiredness, the feeling of losing the partner and to become a caregiver and no longer a spouse, sense of being a prisoner, are some of the negative and difficult aspects mentioned.

"I wouldn't abandon him but if someone came and said they would look after him I would say in all honesty take him on"

(Breanna, Ireland)

"Since he came home it's a prison"

(Catarina, Portugal)

Adapting to the new role seems to be automatically in Slovenia, but more drastic changes have been discussed by others. For instance, spouses in Portugal mention that they had to do dramatic changes in their lives, like selling their house and abdicate of their social life.

Positive aspects of being a caregiver seem to be related with the sense of duty fulfilled and with the feeling of doing everything to provide the best care to the spouse.

In general, spouses receive only very occasional support from other family members, sometimes because they try to keep some distance themselves, especially regarding their children.

"Sometimes I feel sorry about our children, this means that all the things happening at home and problems, I just do not want to tell them. I do not want to bother them."

(Roosi, Estonia)

Some spouses mention that family and friends "disappeared" after the onset of the disease/care condition. Professional/external help is or was present at some point, it seems not to fit the needs, are scarce and/or expensive.

Grandchildren

The relationships between grandchildren and their grandparents are different from country to country. On one hand, there are cases where grandchildren revealed that their grandparents had difficulty accepting care from them. This situation, however, changes at later stages of the disease when they begin to accept the help since they realize they couldn't do it on their own anymore.

"It was hard for my granddad to accept my help. But it got better after sometime"

(Slovenia)

On the other hand, in some cases such as in Portugal and Italy, grandchildren do not mentioned any difficulties on this matter, by contrary they stated that their grandparents develop a closer relationship with them.

"Since I begin taking care of my grandmother she only has eyes for me. It's funny, it's not that that we weren't close (…) but now there is a type of closeness and involvement that are amazing"

(Ana, Portugal)

A sense of valuing the support given by the grandparent in childhood is also mentioned, which makes the caring process a way of repaying it (EE; IT IE; PT)

"I do it (taking care) because it is right that I do it … I do it because my grandmother took care of me when I was a baby, so I must reciprocate"

(Roberto, Italy)

In this sense, the love between grandchildren and their grandparent overcomes the frustration and demands that the situation brings and helps to sustain them.

Most of the participants play a role of secondary caregiver – in fact only two of the caregivers within this target group lives with their grandparents - being their parents (especially their mothers) the primary carer. In this sense, sometimes the support they give is not only to their grandparents – eg. running errands - but also to their parents.

"Now my mom is very stressed because my uncle's family has never been too present, primary she takes care of my

grandmother and my uncle gives her a little financial support, but in practice he is almost never present”

(Filippo, Italy)

Given the time spent on care provision or supervision, the social limitations that are imposed on the caregiver’s life have a negative impact on their well-being and also on their family time.

II. Intergenerational relationships

Children

The relationship between parents and children may appear, in some cases (e.g. Italy), very complex and often conflictual.

“the little I do, I don’t do it willingly. I am still waiting for a positive development in the relationship with my mother… getting hurt was common, was part of everyday life. That’s something that leaves a mark! However we must love parents”

(Marco, Italy)

Conflicts are linked with the changing of roles: now is the parent who receives care form their child. In some cases the attachment to care recipient might alter the rationale of caregiver and might lead to difficulties in relationships. For example, with their parents failing health, adult children experience the loss of their parent in the role they know them as a mother or a father.

“I would say about three years ago I came to realize I had lost my mother. The woman in front of me is not the same woman that I could sit down and talk to”

(Cassidy, Ireland)

Caregiver sets down extra boundaries and focus solely on the care receiver needs and forgets to address their own. Added pressure comes from financial aspects and the distrust of the specialists that they have met and experienced during the care process – health and social services included.

“Even if I could spend 3.000 euros per month (as I had to do with my father) the places in the care facility are limited and there is the risk of having a place far away from home”

(Martina, Italy)

“If we talk about finances, there could really be such financial support that a caregiver would receive (...) All right, I may not need it right now, but I think maybe in 10 years. For example, if there are still 2 people needing full care and you can't go to work, you should have support (...) Or financial assistance for access to care services”

(Margareete, Estonia)

Generally, the most difficult part of caring was emotional part of accepting the disease of their loved one and the constant fear for their loved one safety and well-being. In the cases where children do not live with their parents, they reported experiencing constant fear of what might happen while they’re not with them.

Conflicts within family members are mentioned by some of the participants, especially conflict between siblings.

> ***“My brother does not go to visit my mother, he does not accept to see her like that because she does not do things like she would have done (before the illness)”***

(Martina, Italy)

Spouses

Family relationships appear to be complex and sometimes ambiguous. Although spouses say that children are concerned and help in what they can, it is possible to realize that this "closeness" does not materialize in effective help behaviours. Indeed, and in generally, spouses can only occasionally rely on children’s support, either because they live far, don’t have emotional attachment or don’t have time.

> ***“they make a special effort to come from Clare or Leitrim or Kildare and Dublin, like they all have full time jobs and marriage”***

(Kailyn, Ireland)

Mostly this support is emotional and not tangible, with phone calls and occasional visits. Also, parents do not want to overload their children and don’t ask or refuse their support, giving the impression that they don’t need it.

> ***“Sometimes I feel sorry about our children, this means that all the things happening at home and problems, I just do not want to tell them. I do not want to bother them”***

(Roosi, Estonia)

> ***“My daughters help a bit. But they have their own families you know. I can’t burden them with my problems”***

(Slovenia)

Some families accept better the disease, condition and caregiving condition, and adapt to the new needs, while other families move away. In some families, not only children as also grandchildren demonstrate concern about their grandparents.

The caregiving dyads are connected by different means: love, gratitude, marital responsibility. In either case, this closeness seems to happen naturally. Although some of the spouses refer that they no longer feel like husbands/wives, but almost exclusively as caregivers, positive feelings seem to follow this process.

"What I do gives me satisfaction"

(Alessandro, Italy)

Grandchildren

Regarding the relationship between grandparents and grandchildren, the majority of the participants claimed that the relationship with their grandparents did not suffered major changes, in fact, in some cases the relationship improved and deepened (PT, SI). However, some participants highlighted the fact that although they constantly try to maintain a good relationship with their grandparents, this is not always possible since they do not always remember them, which makes it harder for them.

"Perhaps the saddest thing is that my grandmother started not recognizing me before my marriage. This is too sad, I say sad because grandparents should share (this kind of experiences) with their grandchildren, so it has been a little bit difficult for me but let's say that my grandmother is my idol, she has not changed"

(Sara, Italy)

In Ireland, for example, there was a sense of loss of the special relationship based on being listened to and able to share anything with grandparents, when a grandparent developed dementia. However the love remained and overcame the frustration.

"I still love being with her... the frustration is there quite a lot... but we still do have good chats and we can still talk for hours ...that kind of makes up for it"

(Darcy, Ireland)

Also, taking care of one's grandparent may involve challenges related to generational relationships and to the understanding of the world, since different generations may have different expectations and perspectives about life.

"The understanding of the real situation came to me later. It is difficult to make decisions for 34 year old and 92 year old simultaneously"

(Mia, Estonia)

Caregiving for an older member of the family also have an impact on the relationships and dynamics between family members. Two main changes were reported: the family members either became closer or they grew apart. In the first case, families prove to be more understanding, supportive and willing to learn about the condition and adjust to the new role of caregiving (e.g. GR, SI). In the second case, families seem to rely on the person responsible for taking care of the grandparent and do not have a proactive role or concern with the caregiving process; or different opinions regarding the caregiving process (e.g. PT).

"It is not an easy process. My grandmother being like that drove her family away, far away. It is often said «when there are too

many people wanting to be in charge, there are problems» (…) and then I'm the one to blame because I'm the one who is there"

(Ana, Portugal)

It is important to refer that in the Portuguese case, as well as in Estonia, the grandchildren were the primary caregiver, so they are more involved with the caregiving process.

Being third generation, grandchildren take more of an outsider view on the situation, the past history and relationships that exist between parents and their children. This allows them to see the situation from different perspectives, considering their grandparent's perspectives and being tolerant towards them, but also their parents' point of view:

"they [grandparents] can't see that it is having a toll on her [mother] because she hides that when she is with them"

(Rachel, Ireland)

III. Resilience

Children

Regarding resilience and well-being, they depend and are linked to personal aspects as well as to the care provision history and family relationships. However, in general, it appears as a result of balancing the capacity of adaptation and ability to overcome care difficulties, with i) the necessity to resist, and ii) the recognition and acceptance of the situation and of the care role.

"I had to accept what cannot be changed and now I can no longer be hurt"

(Elena, Italy)

There are some negative feelings related with the caregiving activity, such as: anger, frustration, resentfulness. Some Italian participants mentioned that they will be able to recover well-being only after the death of their care receiver.

> ***"To feel better I would need to go away, far away. I feel bad to think this, but only in this way I feel that "the cage" could open up"***
>
> (Giulia, Italy)

Having someone to talk to or some activity to escape and have a break (e.g. Yoga, gardening, peer support groups, etc.), are pointed as important aspects helping them coping with the situation and contributing to their well-being.

> ***"Also humor. All kinds of music, everything that is creative, this is where I charge my batteries. For this I just cut time for myself. Leaving home for just a moment charges batteries"***
>
> (Liisa, Estonia)

Spouses

Caregivers spouses clearly feel overload with all the tasks and dedication that care requires. They feel that professional help does not correspond to their needs and most of the time is scarce and expensive.

> ***"The informal caregivers' problem is the lack of support from formal caregivers, because it is needed. And I'm aware that it exists, if you pay for it, and I can't"***
>
> (Catarina, Portugal)

They feel alone and isolated in their role, but manage to find strategies to overcome adversities. Caregivers “give up” several spheres of their lives, especially the social one, express that loss and the lack it makes in their lives, but still resign themselves as this is the necessary sacrifice to be able to provide the due care. Most of the spouses feel like prisoners of the caregiving situation and lack the time to take care of themselves.

"My house now feels more like a prison than a home"

(Sofia, Greece)

Even though, these difficulties seem to be overcome by recognizing the value and gratification with caring (e.g. Italy).

“I feel the value of helping”

(Alessandro, Italy)

Anyways, spouses had to adapt to new situation and found strategies for each challenge related to the progression of their spouse’s condition/disease or to their own problems. Having some kind of support that allows them to have time to dedicate to themselves, help spouse caregivers to better deal with their caregiver role.

“And evenings out, where you can still go to the cinema or go to the theater, or go somewhere in the spa and be in nature is the best, which will alleviate it all”

(Roosi, Estonia)

However, in some cases caregivers feel unable to take advantage of the free time they occasionally have, because they are constantly preoccupied with the person they take care of, or because they feel alone and awkward, therefore demotivated for any activity, such as having lunch or walking. They recognize the need to engage in activities in their own benefit like vacations, time with their friends, physical activities.

“I have been able to articulate with my sons and to take a day off (…) in the beginning I had a lot of guilt, but not anymore. Now I really need to have one day for my own”

(Catarina, Portugal)

Responsibility weighs heavy on spouses, as they carry the care of their partner often alone and constantly asking themselves “how long I will be able to keep going and doing this”. Each day can be a struggle.

“When you wake up in the morning, they (care recipient) are the first thing on your mind and I said if I could get my breakfast, I would live for the day”

(Keira, Ireland)

Grandchildren

Those who live with their grandparents and have the main responsibility of the caregiving process, experience, evidently, more burden. For those who have a secondary role, the biggest concern is with the wellbeing of their parents. In this sense, the focus is to help their parents, stepping into their shoes, in order to provide support.

Some of the factors that contribute to the well-being of participants are: having quiet moments for staying with the family (children and parents) and have the support of other people that take care of the care recipient.

“Other relatives are supportive. We talk and discuss different matters. It gives energy and understanding that I am not alone in this. In some cases I can ask for respite.”

(Mia, Estonia)

One of the participants mentioned that she felt guilty for not spending so much time with her own child; because she was busy taking care of her grandmother

"I miss many things with my son because I'm taking care of my grandmother, and that is something that kills me"

(Ana, Portugal)

Also, one of the participants with higher care responsibility described the importance of isolate himself during difficult moments.

"My strategy is that, when she (the grandmother) starts to get uglier, I increase the volume of the television or I wear headphones, then she calms down"

(Robert, Italy)

Some of the participants referred the difficulties that other relatives have in understanding the nature (and consequences) of their grandparents condition. One participant in particular, that has a degree in Gerontology, claimed that her relatives somehow discredit her, thinking she exaggerates.

Separating the diseases from the person helps grandchildren cope; also, what sustains the relationship and care provision is the love grandchildren have for their grandparent.

"This is not the worst, it's better than them being dead, it is a fraction of what they have done for us over the years"

(Rachel, Ireland)

IV. Overall needs

Children

Regarding challenges and needs of the caregivers one of the most challenging aspects is not knowing what comes next. Caring is a demanding role that leads to burden and tiredness that, consequently, might lead to health problems; that may have a negative impact on personal relationships; and that may originate the need of care for themselves.

> ***"At the same time I understand that I have to look at myself, that I can't handle it, I can't work, I don't have money. It is a difficult situation. Roles have changed. I feel responsible for my mother"***
>
> (Liisa, Estonia)

Children that have a role of caregiver and their own family (with children) experience feelings of guilt (feel they are neglecting their own family). Also the lack of support from other members of the family is mentioned. In Italy, some of the participants referred economic help as something important for them to endure as well as to be able to keep their job. Caregiving for children can also have an impact on their professional life: for instance, in Portugal one of the children needed to change to a part-time job in order to be able to take care of their parent. Another challenge identified by the participants is the refusal of the parent to acknowledge their situation and the need of care and support from their children.

Having spaces for sharing their experience, to unburden and to be trained (in order to be able to provide a better care) are identified as key aspects to help them deal with the situation.

Spouses

When looking at overall challenges and needs in caregiving, making sense of what is happening and try to handle the situation appear as one of the main challenges (Italy).

“What happened, happened, but the challenge is to understand how to feel better, not only those we love but we too. What remains in the end is the love that you have given. We save ourselves in this way”

(Francesco, Italy)

Emotionally accepting the disease/condition is one of the first tasks that caregivers must overcome. Adapting to all the demands, in terms of time organization, financial pressure, tasks to perform, social participation, family life, just to name a few, needs to be integrated into a narrative that brings sense to the situation in which the spouses are involved in.

“I miss a lot of things. It´s very complicated to have a cup of coffee with a friend. Now, my circle of friends is basically informal caregivers (…) and I have two or three friends that are informal caregivers that give me advice (…) the others disappeared”

(Catarina, Portugal)

Caregiving is physically and emotionally demanding, with caregivers suffering from physical consequences and having to deal with situations with high emotional load such as the change of the person as they knew (the loss of the partner), "no retribution" and negativism. Having family and professional help to help overcome these difficulties is a need that seems to cross-cut all countries in the partnership.

"My main demand from professionals is to help me with my wife's behavioral problems. She is so different now, sometimes I think I have a devil in my house"

(Nikos, Greece)

Spouses feel the need to have time to take care for themselves. Additionally, spouses also mentioned the need to have support from professionals and from the health and social systems, to help them understand what is happening with their spouses and to help them financially (Portugal). Over time, the more experienced caregivers find creative ways to deal with awkward and sometimes dangerous behaviours performed by care receivers, and manage to give a sense of what is happening.

Grandchildren

In Italy, participants highlighted the lack of time for themselves, in the case where they are the primary carer, or for their parents, when the responsibility to care is theirs. This is also shared by the Portuguese participants that cohabit with their grandparents.

> ***“Let's say, the quality of the time you can have all together [family] changes and maybe the most difficult part is to know that your parents are facing a more difficult period”***
>
> (Roberto, Italy)

In Estonia, participants referred that the most challenging aspect of caregiving is not knowing what comes next or how to deal with the challenges. In Greece, the participants agreed that after becoming a caregiver, they had to redefine their daily routines, needs and relationships. They also highlighted that they would like to know and understand the disease and its impact on their grandparent (idea that is also shared by Irish participants), as well as to have some psychological support. In this sense, one of the participants in Portugal referred the need to attend a psychotherapist to help her cope with the situation.

- Physical, emotional and social needs

Children

Caregiving experience have different impacts and created mixed emotions. On one side, caregivers feel that they could return the love that their parents gave them, feeling accomplished with managing the care process and providing parents with the support they deserve and with the fact that there are ageing at home. On the other hand, feelings of guilt towards their own families (spouses and children) and about leaving the care receiver for some time to live their own lives are mentioned. In general, the caregiver role had an impact on participants' family and social life, since even if they not live 24/7 with the care receiver, they never really forget about their role as carers and they are in constant fear of what might happen to their parents while their absent.

Participants' needs are mainly associated with necessity to share, to tell one's own difficulties, to feel understood.

"Even it helps when someone listens to you. I'm going to a psychiatrist. I can honestly say. Sometimes it is helpful to go somewhere to complain. You don't always have to get something back, the main thing is that you can let out some steam and then it's good again."

(Margareete, Estonia)

Spouses

Taking care of a spouse can bring a set of mixed feelings. Love, obligation, anger, frustration, are only a few feelings that can coexist in the caregiving relationship. Having to accept and adapt to the spouse condition/disease is difficult and caregivers feel sorrow in seeing the other person suffering. Caregivers have constant fear of what may happen to their spouses when they are not around, and also when thinking about the future, considering that they might get sick and not be able to continue helping. Frequently, caregivers put their own health to second plan, and when they get sick and need treatment, another strain comes into the caregiving equation.

"What will happen to her if I will dead before? Would she put in a place for elderly?"

(Francesco, Italy)

Being involved with associations helps gaining better understanding and skills to overcome these difficulties and to find some free time for them, but in some cases, family and friends disappear and professional help doesn't fit the needs. Caregivers often feel isolated and lonely because of the loss of their friends and social life. Respite care seems essential to help caregivers to continue capable of taking care, as also as use technical aids and find new interests for the spouse being taking care of.

Grandchildren

In general, grandchildren referred that social and physical aspects of caregiving may be challenging. As social aspects they pointed out lack of people's knowledge on how to react in a specific situation regarding the care receiver situation; and also social isolation, especially in the Portuguese and Estonian cases where caregivers are the primary carers of their grandparents.

> **"Going out for dinner, it's impossible!"**
>
> (Amélia, Portugal)

Some of the participants seem to consider very important the emotional support by professionals such as psychologists or social workers, especially for the members of the family that spend the most time with the patient and have the main responsibilities (GR). There are also some statements referring the need to have external support from groups of caregivers, such as mutual support groups.

Participants also mentioned some physical constraints associated with the caregiving process, namely with lifting their grandparents (SLO; PT).

- Information, communication and instrumental needs

Children

Participants referred the need of having more services available, and that these services should be accessible to anyone (especially financially), should give response to each individual needs and provide personalized care and support.

> **"That I could have some type of information package. Everything might be good for now, but if something should change, here is the right information how to move forward. Easily understandable and timely."**
>
> (Liisa, Estonia)

Other aspects that were mentioned were: the need to have more information about support and legal issues; home support; training courses; awareness raising about dementia and other problems related with ageing.

> ***"More assistance services should be set up and affordable for people with dementia"***
>
> (Slovenia)

<u>Spouses</u>

Spouses referred the need for better understanding from the social and health systems/services regarding old people, and particularly people with dementia, since in a disease like this, informal caregivers do most of the job, with little or no support (formal or informal) and with no clear and robust information about the disease and evolution. Collaboration between social and health services and coherence between professionals could help caregivers cope with the situation and with the different demands they face as the situation worsens. Caregivers find themselves in a limbo on the diagnosis and along the way, with lack of information and afraid of what may happen. They not only know nothing about the disease, and don't know where to find it, as also as where to find help. Spouses refer to walk alone in this process until they reach, sometimes fortunately, someone or some service that can help them.

"Dementia is the hardest thing I found because I didn't know what dementia was. I didn't know where to go for help, there was information (…) I'm years just travelling blind"

(Keira, Ireland)

So, information, training and more support services, more affordable and well prepared are few of the needs mentioned by spouses who are taking care of their partners. Services and professionals need to communicate better, and the needs of the caregivers and the person receiving care need to be met timely and adapted to the full needs. Peer support is also seen as a valuable resource to help overcome burden and the prementioned difficulties. However, the lack of support prevents caregivers from attending.

At the opposite end, spouses in Slovenia don't feel need from professionals for emotional and psychological support, since they believe that talking with someone close to them about the situation is enough to help them cope with the situation. Even though they lack accessible and more personalized social and health services, information on dementia and more volunteers in this area.

Grandchildren

In general, all the participants would like to have more professional help from formal services. However, there are complaints regarding its costs, and also regarding lack of offers – for example, on participants was able to pay but did not found a solution for leaving her grandmother during the summer holidays.

"The problem is the fact that I want to have holidays, just for a week, and I can't (…) because I can't find a place to leave her. This year I didn't even try"

(Amélia, Portugal)

In the Estonian case, the obstacle is also related with the unwillingness by the care recipient to use formal services.

> ***"Official care services are more on the table and we openly discuss the options with grandmother. Sometimes we can reach common understanding but still it is difficult to make the next steps"***
>
> (Mia, Estonia)

As already mentioned before, grandchildren in general also highlight the need and importance to have more information on how to manage the situation; to have the help and support from mutual support groups; to have more assistance and support by other relatives: to have training and reliable information.

Recommendations for IO2

Purpose of Intellectual Output 2

In general, carers seem to have difficulty in expressing their feelings regarding caregiving to their social network or even a classic support group due to personal limitations or the environment itself, but being able to openly express these feelings and share emotions can build their resilience.

As shown by recent studies, art can be an easier way for caregivers to externalize their variety of feelings concerning their role (Murrant et al., 2000; Caldwell et al., 2005; Mackenzie et al., 2007; Kidd et al, 2011; Swinnen, 2014).

Having this in mind, the Caregivers Unit of Greek Association of Alzheimer's Disease and Related Disorders (Alzheimer Hellas) in Thessaloniki (Greece) developed a support group – Listen to my story intervention - using poetry and literature as motivation and narration and expressive writing as creative tools to help families of people with dementia to express their thoughts, feelings and experiences and make sense of their situation. Caregivers use literature and poetry to exchange thoughts and experiences, to answer some of their questions about dementia and caregiving and in the end have a new point of view concerning their role.

Within the S.IN.CA.L.A. project, the partnership aims to adapt the original "Listen to my story" intervention of Alzheimer Hellas, in order to respond to specific needs of different generations of informal caregivers adopting a whole family approach, and to extend its usability not only to carers of people with dementia, but also to carers of older people in general.

Recommendations

Based on IO1 report, the partnership will develop a programme based on narration and expressive techniques in order: i) to help caregivers to express their feelings, ii) to render their experiences meaningful and iii) to familiarise themselves with their situation.

In this sense, and considering the results from IO1, the development of the "Listen to my story" intervention should follow the subsequent recommendations:

- The intervention should **consider the three groups of family informal caregivers** previously identified within the S.IN.CA.L.A project, namely spouses (S), children (C), and grandchildren (G). In this sense, each group will have its own intervention group.
- Besides taking into consideration the specificities of each group (S, C and G), the intervention should also take into account the caregiving culture of each country, so the **content of the sessions may need to be adapted for each partner’s country.**
- IO1 revealed some main themes that emerged from the interviews and focus groups with informal caregivers, namely: i) Overall experience as a Caregiver; ii) Intergenerational relationships; iii) Resilience; and iv) Overall needs. Within each theme there are **topics related with the caregiving experience that can be used as guidelines** for the “Listen to my story” intervention.
- However, and since the S.IN.CA.L.A. project involves caregivers with different kinships, their experience can also vary (which is also identified in IO1 report). In this sense, and although IO1 highlighted some topics that could be taken into consideration, **the first session of this intervention should explore participants’ caregiving experiences** in order to identify the main concerns/ constraints/ obstacles and articulate those with the material used during the intervention following sessions.

- The participation in this intervention needs to take into account some criteria. The **inclusion criteria** can be the same as used during the data collection phase for IO1, namely: Being 16+; being an informal carer of an older person for at least 6 months; Provide actual care at least in one ADL (basics or instrumental) or in supervision; Being able to and willing to share their experiences about informal caregiver role with the other participants. However, since the "Listen to my story" intervention implies writing, the partnership will guarantee the resources/help in order for everyone – even those with less writing skills/competencies – to be able to express themselves.

Note: there are many cases in which Informal caregivers experience social isolation (which was something that was stated during the IO1 data collection phase), so this intervention should be able to promote an environment where the participants feel safe and comfortable to share their experience through art but also to talk to each other – this will not only benefit the intervention *per se*, but will also create a more positive impact on the caregivers experience.

References

Anderson, R. (1987). The unremitting burden on carers. *British Medical Journal*, 294(6564), 73-74.

Blanton, P. W. (2013). Family caregiving to frail elders: Experiences of young adult grandchildren as auxiliary caregivers. *Journal of Intergenerational Relationships*, 11(1), 18–31.

Bove, D. G., Zakrisson, A-B., Midtgaard, J., Lomborg, K. & Overgaard, D. (2016). Undefined and unpredictable responsibility: a focus group study of the experiences of informal caregiver spouses of patients with severe COPD. *Journal of Clinical Nursing*, 25, 483 – 493.

Bruggen, S. V., Gussekloo, J., Bode, C., Touwen, D. P., Engberts, D. P. & Blom, J. W. (2016). Problems experienced by informal caregivers with older care recipients with and without cognitive impairment. *Home Health Care Services Quarterly*, 35(1), 11 – 24.

Buscemi, V., Font, A. & Viladricht, C. (2010). Focus on relationship between the caregivers unmet needs and other caregiving outcomes in cancer palliative care. *Psicooncología*, 7(1), 109 – 125.

Campbell, L. D. (2010). Sons who care: Examining the experience and meaning of filial caregiving for married and never-married sons. *Canadian Journal on Aging*, 29(1), 73 – 84.

Cedano, S., Bettencourt, A.R.C., Traldi, F., Machado, M.C.L.O., & Belasco, A.G.S. (2013). Quality of life and burden in carers for persons with Chronic Obstructive Pulmonary Disease receiving oxygen therapy. *Rev. Latino-Am. Enfermagem*, 21(4), 860-867.

Giosa, J. L., Stolee, P., Dupuis, S. L., Mock, S. E. & Santi, S. M. (2014). An examination of family caregiver experiences during care transitions of older adults. *Canadian Journal of Aging,* 33(2), 137 – 153.

Gonçalves-Pereira, M. & Sampaio, D. (2011). Psicoeducação familiar na demência: da clínica à saúde pública. *Revista Portuguesa de Saúde Pública*, 29(1), 3 – 10.

Hawranik, P. G. & Strain, L. A. (2007). Giving voice to informal caregivers of older adults. *GJNR,* 39(1), 156 – 172.

Horrel, B., Stephens, C. & Breheny, M. (2015). Capability to care: Supporting the health of informal caregivers of older people. *Health Psychology*, 34(4), 339 – 348.

Jayani, R. & Hurria, A. (2012). Caregivers of older adults with cancer. *Seminars in Oncology Nursing,* 28(4), 221 – 225.

Kim, Y., Kashy, D. A., Spillers, R. L. & Evans, T. V. (2010). Needs assessment of family caregivrs of cancer survivors: Three cohorts comparison. *Psycho-Oncology,* 19, 573 – 582.

McCabe, M., You, E. & Tatangelo, G. (2016). Hearing their voice: A systematic review of dementia family caregivers´needs. *The Gerontologist,* 56(5), 70 – 88.

Mthembu, T. G., Brown, Z., Cupido, A., Razack, G. & Wassung, D. (2016). Family caregivers´perceptions and experiences regarding caring for older adults with chronic diseases. *South African Journal of Occupational Therapy*, 46(1), 83 – 88.

Neufeld, A., Harrison, M.J., Hughes, K. & Stewart, M. (2007). Non-supportive interactions in the experience of women family caregivers. *Health and Social Care in the Community*, 15(6), 530-541.

Roberto, K. A. & Jarrott, S. E. (2008). Family caregivers of older adults: A life span perspective. *Family Relations,* 57, 100 – 111.

Sakakibara, K., Kabayama, M. & Ito, M. (2015). Experiences of “endless” caregiving of impaired elderly at home by family caregivers: a qualitative study. *BMC Research Notes*, 8, 1 – 11.

Silva, A. L., Teixeira, H. J., Teixeira, J. C. & Freitas, S. (2013). The needs of informal caregivers of elderly people living at home: an integrative review. *Scandinavian Journal of Caring Sciences,* 27, 792 – 803.

Stucki, B. R., & Mulvey, J. (2000). Can Aging Baby Boomers Avoid the Nursing Home: Long-term Care Insurance for" aging in Place". American Council of Life Insurers.

Thompson, G. N. & Roger, K. (2014). Understanding the needs of family caregivers of older adults dying with dementia. *Palliative and Supportive care,* 12, 223 – 231.

Tsai, P.-C., Yip, P.-K., Tai, J. J. & Lou, M.-F. (2015). Need of family caregivers of stroke patients: a longitudinal study of caregivers´ perspectives. *Patient preference and adherenc*e, 9, 449 – 457.

Vaingankar, J. A., Subramaniam, M., Picco, L, Eng, G. K., Shafie, S., Sambasivam, R., Zhang, Y. J. … Chong, S. A. (2013). Perceived unmet needs of informal caregivers of people with dementia in Singapore. *International Psychogeriatrics*, 25(10), 1605 – 1619.

Washington, K. T., Meadows, S. E., Elliott, S. G. & Koopman, R. J. (2011). Information needs of informal caregivers of older adults with chronic health conditions. *Patient Education and Counseling*, 83, 37 – 44.

Zwaanswijk, M., Peeters, J. M., van Beek, A. P., Meerveld, J. & Francke, A. L. (2013). Informal caregivers of people with dementia: Problems, needs and support in the initial stage and in subsequent stages of dementia: A questionnaire survey. *The Open Nursing Journal,* 7, 6-13.