TELL ME ABOUT YOU

family members' experiences of caring role

RESEARCH REPORT (IO1)

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1. INTRODUCTION

1.1. 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, as observed 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 with physical and/or cognitive impairment 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.

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

The S.IN.CA.L.A project meets a 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-judgmental 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.

1.3. 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 from different kinship groups; how family relationships are positively or negatively impacted by caring; what kind of adjustments and coping strategies families have adopted to be more resilient and adaptive to their changing situations.

The report, contributes to research on family care of an older person by providing new insights into family relationships from perspective of different kinship groups and the coping strategies and educational needs associated with their caring role. The research also informs the extent the existing training materials can be transposed to the different country contexts and where it needs adaptation.

The draft report was presented to a round table of social and health care professionals in each country who acted 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).

2. Tell me About You – Methodology

The first task in undertaking this study was to conduct a literature review about the experiences and needs of family informal caregivers (IC)[1] to build knowledge and an understanding of different aspects associated with caregiving, including:

- what are the needs of IC;
- what is the impact of caregiving on the lives of IC;
- how do IC manage and adapt to the challenges encountered in providing care;
- 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 on family dynamics.

The literature review also aimed to identify a suitable methodology that would enable the collection of the relevant data. From this review, a 'Methodology Script' was developed outlining the process for collection of data, such as: techniques to be used; ethical considerations; inclusion and exclusion criteria; tips on focus group facilitation; structure of the session. A 'Data Collection Kit' was also developed to ensure a unified and integrated approach to data collection and analysis by all partners. This kit contained the focus groups schedule, along with other documents required such as: Registration form; Consent form (parental informed consent form for any participant 16 or under); Questionnaire; Data collection checklist; and Reporting framework.

2.1. Desk Research

The population pyramid is changing, with a widening at the top in the older age groups representing increases in the average life expectancy and, therefore, on the number of

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[1] IC will be used as an abbreviation for informal caregivers

elderly, which raises a number of questions. People are living longer, but often with lower quality of life. The increase in the number of people living with chronic and disabling diseases and the lack of long-term care has created new needs (Sakakibara, Kabayama & Ito, 2015). State provision of health and social care has not kept pace with the growing number of older people who require this care resulting in responsibility for meeting the care and support needs of older people falling to informal caregivers (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 provides some type of unpaid, ongoing assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to a person with a chronic illness or disability (Roth, Fredman & Haley, 2015; 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, with geographically dispersed relatives and women working outside the home, has brought about changes and impact on the availability and motivation to care (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 relation to kinship with the person being cared for, spouses are most likely to provide care, followed adult children (Buscemi et al., 2010; Zwaanswijk et al., 2013). For other authors, the positions are reversed, with adult 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, when married, brothers 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 and involvement with caregiving has been influenced by their age, sex, as well as by the relationship to the dependent person.

In general, the literature shows that the impact of caring on the caregiver is quite negative. Providing care for a person with a chronic illness is ongoing and demanding. Unlike a transient acute care event, care provision is not a temporary state but transforms the individual’s life requiring 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 four main areas, namely: physical; social; financial; and psychological/emotional, the latter being the most studied.

At a physical level, 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 of the informal caregiver is cited as one of the main reasons for the admission of a person with care needs to long-term care facilities (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 routines, 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 the moderate phases of the disease the negative effect of caring impacts mostly at a social level, due to loneliness and a decreased contact with friends and family; in more advanced stages the impact is on the caregiver's health, as care provision at this stage can be experienced as physically more demanding.

Although the majority of studies show informal care provision as having a negative impact; the situation is more complex and caregiving can be experienced in a more ambivalent way (Horrel et al., 2015). More recent studies have highlighted positive dimensions to caregiving including a sense of personal growth, the development of competences, feelings of satisfaction and gratitude, more patience and tolerance, and a better relationship with the person being cared for (Bruggen et al., 2016; Campbell, 2010; Horrell et al., 2015; Sakakibara et al., 2015; Mthembu et al., 2016 Buscemi et al., 2010).

The type of kinship may have an influence on the impact of caregiving – positive or negative. In Roberto and Jarrott (2008) study, wives appear to show higher levels of depression and poor quality in social interactions. For Jayana and Hurria (2012), daughters were found to be impacted most by the caregiving role. A study by Bruggen et al. (2016)

involving 2701 carers, concluded that adult children encounter more problems, which are also more difficult to manage.

A number of aspects can help predict the extent caregiving will have on carers. They include the characteristics of the person to be cared for, and their level of dependency (Roberto & Jarrott, 2008); the type of disease – in cases of cognitive disease such as 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 its 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 requirement for information and psychological support (Gonçalves-Pereira & Sampaio, 2011, Washington et al., 2011). Other authors also refer to 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) identify the meeting of medical and spiritual needs.

A systematic literature review by Silva et al. (2013) found that all articles reviewed referred to informative and practical needs. The topics in which caregivers most wanted help related to diagnosis, risk factors, disease progression, symptoms, treatment, prognosis and management of symptoms. They also wanted to develop more practical skills in relation to certain tasks, such as bathing and/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 mentioned the importance of support from other relatives, the need to reduce social isolation, the need for support groups, and the need of a greater recognition of their role (Kim et al., 2010, Tsai et al., 2015, Vaigankar et al., 2013).

2.2. Data Collection

A mixed-methods research design, using both qualitative and quantitative methodologies, was used to meet the aims of this research to learn about the experiences of family members providing care to an older person. Focus groups, interviews and a sociodemographic survey were undertaken in each of the in six European Member States (Estonia, Greece, Ireland, Italy, Portugal and Slovenia). To explore the experience of caregiving from the perspectives of the different kinship groups, separate focus groups were carried out with each kinship group – spouses, adult children and grandchildren. Building also on the outcomes of the literature review, the findings from these focus groups would inform the adaptation of the narrative workshops at the next stage of the project (IO2).

The aim of the data collection was: to explore the informal caregivers' caregiving experience, to understand and identify the caregivers' needs related to this, to examine how caregivers adapt and what variables/factors contribute to resilience. Focus groups were the main tool used for data collection, while questionnaire was a supporting method which allowed data to be collected in a more systematically way. Using a qualitative methodology facilitated the establishment of a closer relationship with the participants - which is in accordance with the objectives of the project to give voice to the subjects - and to get a deeper understanding of their lives.

Data collection was guided by ethical considerations, which included: informed consent; voluntary participation; confidentiality; anonymity; principle of the relevance of the information.

2.3. Focus Group/ Interviews

As already mentioned, all partners had access to the same materials to collect the data as well as a reporting framework, with the objective of facilitating the reporting of the information gathered in a consistent way.

Each partner collected data from all target groups: grandchildren, children, and spouses. However, due to some constraints related to informal caregivers' availability (inability to attend due to caring demands or timing did not suit) some of the partners undertook individual interviews using the same questions as those contained in the focus group topic guide. In total, 11 focus groups (EE-GR-IE-IT-PT-SI) and 14 interviews (EE-IT-PT) were undertaken. The total number of participants involved was 86. For more detailed information see Table 1.

Table 1. Number of focus group/interviews per partner

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 interview)	-	5	13
IRELAND (IE)	1	1	1	-	-	-	17
							86

For the focus groups, partners were required to recruit at least four caregivers per target group. However, as previously explained, in some cases this was not possible. In three cases (GR, IT and PT) it was only possible to organize for a couple of caregivers to attend at the same time, 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). In other instances, it was only possible to do one-to-one interviews due to education/work commitments, hence 11 individuals interviews were carried out mainly with grandchildren.

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 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 provided an opportunity for participants to add to the summary. At the end of each session, the participants were asked to complete a short questionnaire.

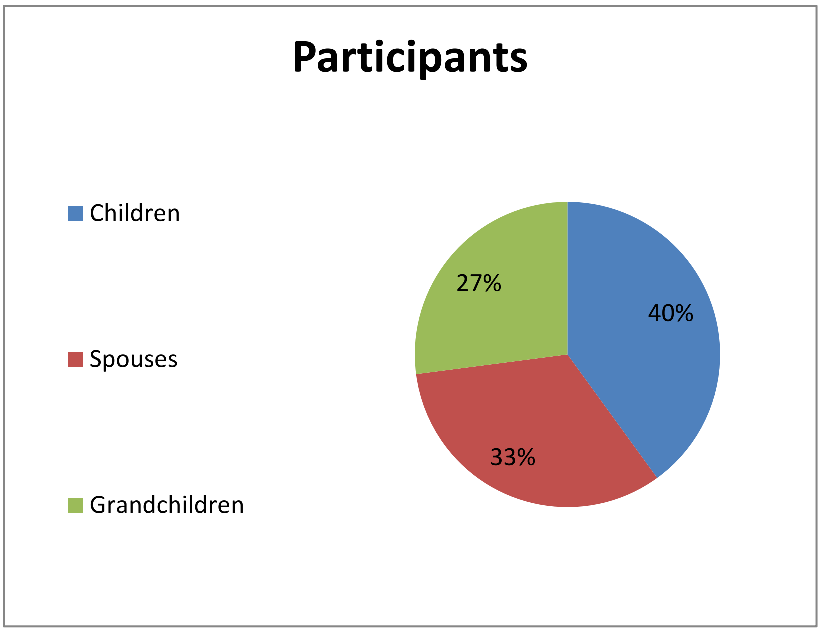
The same script was used both for focus group and for the interviews. It covered topics such as: overall experience as a caregiver; resilience; intergenerational relationships; overall needs (physical, emotional and social needs; information, communication and instrumental support needs).

Each partner was responsible for the audio transcription of the focus groups or interviews sessions and for anonymizing the data (each participant was given a fictional name). These transcriptions were crucial for further analysis. All partners were responsible for reporting the data using the reporting framework supplied.

2.4. Participants' socio-demographic information

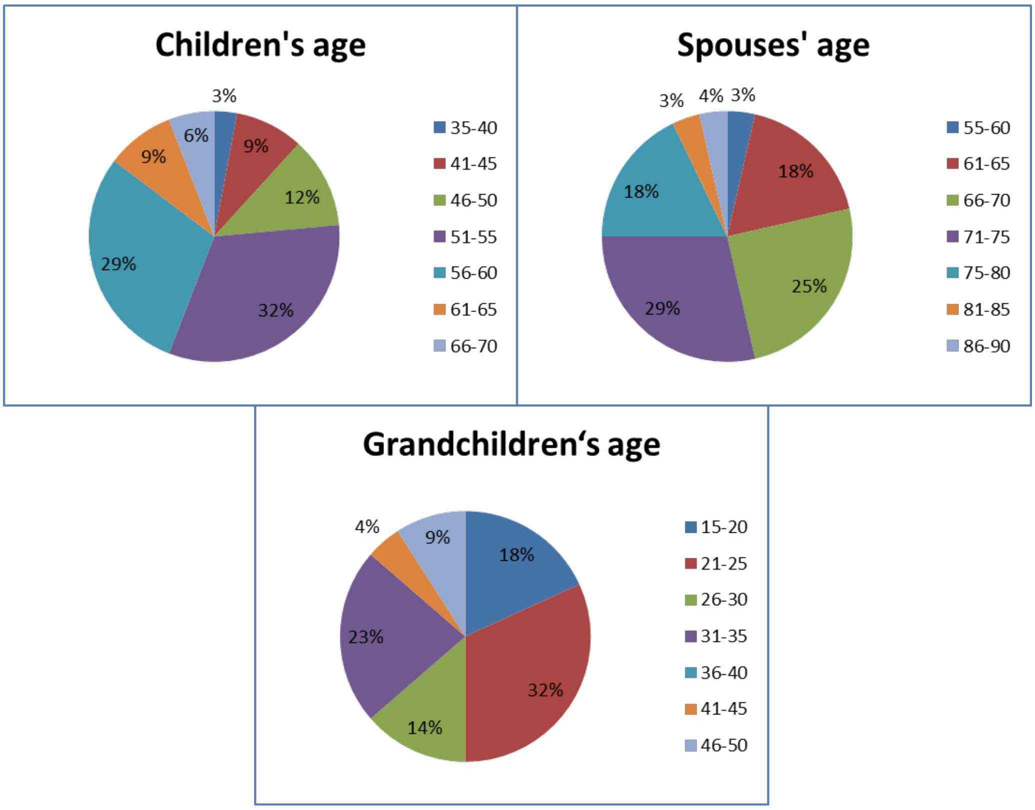
From the total of participants in the focus groups and interviews, 40% were adult children, 33% were spouses and 27% were grandchildren (see Table 2). This may reflect the culture of care in each country, where adult children are more likely to become responsible for taking care of their parents.

Table 2. Total of participants



Regarding the participants' gender, overall the majority of the participants were female which correlates with that reported in the literature (Buscemi et al., 2010; Roberto & Jarrott, 2008; Silva et al., 2013; Zwaanswijk et al., 2013). Table 3 outlines the age range of each target group. Overall, participants were aged from 16 years old to 88 years old.

Table 3. Participants’ age



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

3. Data Analysis and Reporting

Data analysis 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 undertake the analysis we worked with a predetermined analytical frame of themes, namely those used in the focus group and interviews script. This framework of themes emerged from the literature review and, was developed into a reporting framework and included in the 'Data Collection Kit'. Partners were asked to report their findings under the different themes and using illustrative quotes for each of the target groups. The data was analysed and presented according to the following themes: 3.1) Overall experience as a Caregiver; 3.2) Intergenerational relationships; 3.3) Resilience; and 3.4) Overall needs.

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 six European countries. In some cases, however, differences were also explored.

3.1. Overall experience as a Caregiver

Adult Children

In general, all adult children perceived their role as carers of their parents as a way to reciprocate what they had done for them during their lives. The blood-tie is at the center of the experience of being a carer for their parents: at the core, is the love for the parent, and the sense of 'repaying the favour'. However, in cases where the relationship between parents and children was difficult, the perception and feelings about the caregiving role was mainly reported in negative terms, 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. When the parent requiring care moves in with one of their adult children, 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, 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 have emigrated which makes it difficult to provide on the ground assistance to their parent.

In some cases (e.g. Estonia), 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, if he/she has the capacity to lead the care arrangments, he/she can involve and bring the other family members with them. This capacity depends on the care burden, family composition and the status and relationship between 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).

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. Agreeing and making decisions with other relatives as to how care will be provided and organized was often delegated within families to the adult child who was available, not working, with the promise of support dorm the other siblings who have jobs.

" 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 illness and need for assistance. This interaction between carer and care receiver can also be influenced by the type of care provided to their parents: visiting the parents at their home and helping them with some daily activities or 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"

(Alina, Slovenia)

Spouses

In general, becoming a caregiver of a spouse seems the natural step and occurs at 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)

In Portugal, a spouse providing care implicitly referred to gratitude as the major motivation for care. Keeping the spouse at home seems to be the 'natural' solution. However, spouses will consider institutional care when they are no longer able to take care of their family member.

The relationship between spouses can 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/cooperation 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"

(Maura, 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 to the 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 to most of the caregivers. Burden, constant tiredness, the feeling of losing their partner and becoming a caregiver and no longer a spouse, the 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"

(Maura, Ireland)

"Since he came home it's a prison"

(Catarina, Portugal)

Adapting to the new role seems to be spontaneous in Slovenia, but more drastic changes have been discussed by others. For instance, spouses in Portugal mentioned how they had to make dramatic changes in their lives, like selling their house and abdicating 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 protect their children by keep information from them.

"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, but it seems not to fit the needs, to be 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"

(Zala, Slovenia)

On the other hand, in some cases such as in Portugal and Italy, grandchildren do not mention 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. Therefore, sometimes the support they give is not only to their grandparents – eg. running errands - but also to their parents.

“I kind of noticed that my mom has been struggling… because my granny has needed like pretty much full time care”

(Sheila, Ireland)

For grandchildren in the role of primary caregivers (e.g. Portugal and Italy), the time spent on care provision or supervision, imposes social limitations on the caregiver's life and has a negative impact on their well-being and also on their family time.

3.2. Intergenerational relationships

Adult 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 resurface with the changing of roles: where the parent is now dependent on their child for care. In some cases, the change in role results in a sense of loss of what the parent represented/ meant to the adult child. 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"***
>
> (Roisin, Ireland)

There is a tendency for caregivers to focus solely on the care receiver's needs, forgetting to address their own needs. Added pressure comes from financial aspects and the distrust of professionals, health and social care, they have encountered and care processes they have experienced.

> **“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 the emotional element related to accepting the disease of their parent’s illness and the constant fear for their 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 were 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 thir children are concerned and help in any way they can, it could be postulated that this "closeness" does not materialize into effective helping behaviours. In general, it seemed spouses can only occasionally rely on children’s support, either because they live some distance away or they don’t have the time as they work and have their own families.

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

Some families are more accepting of their relative’s illness or condition and the caregiving it requires. They adapt to the new situation, while other families move away. In some families, not only children but 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 reported that they no longer feel like husbands/wives, but almost exclusively as caregivers, positive feelings can arise from this situation.

"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 their grandparent does 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 has 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 take a proactive role or concern themselves with the caregiving process. There may be differences of 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 note that in a Portuguese case, as well as an Estonian case, the grandchildren were the primary caregiver, so they were more involved with the caregiving process.

Being third generation, grandchildren take more of an outsider view on the situation, they are not part of 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)

3.3. Resilience

Adult Children

Regarding resilience and well-being, these 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 overcome the burden involved in the caregiving process, 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 were some negative feelings expressed in relation to caregiving activity, such as: anger, frustration, resentfulness. Some Italian participants mentioned that they will only be able to recover well-being 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.), were identified as important aspects in helping adult children cope with their situation and contribute 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 the tasks and dedication that care provision requires. They feel that professional help does not correspond to their needs and most of the time it 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; which is a huge loss to their lives. They resign themselves and see as a necessary sacrifice if they are to provide the due care. Most of the spouses reported feeling like prisoners of the caregiving situation and they lacked 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 of caring (e.g. Italy).

“I feel the value of helping”

(Alessandro, Italy)

Spouses had to adapt to new situation finding strategies to address each challenge such as those related to the progression of their spouse’s condition/illness or to their own problems. Having some kind of support that allows them to have time to dedicate to themselves, helps spousal 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 felt unable to take advantage of the free time they occasionally had, because they are constantly preoccupied with the person they take care of, or because they feel alone and guilty, therefore demotivated to participate in activities, such as having lunch or walking. However, they do recognize the need to engage in activities for their own benefit like go on vacations, spend time with their friends, participate in 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 will I 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 for caregiving, will experience, 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 to engage with the family (children and parents) and have the support of other people who provide care to 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 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 disconnecting from the situation 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 to the difficulties that other relatives have in understanding the nature (and consequences) of their grandparents condition. One participant in particular, who 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)

3.4. Overall needs

Adult 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 with the potential to result in health problems for the caregiver; it can have a negative impact on personal relationships; self-care is essential in maintaining the role of caregiver.

> ***"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)

Adult children providing care to a parent often experience feelings of guilt in relation to their partners and children; they feel they are neglecting their own families. The lack of support from other members of the family compounds the situation. In Italy, some of the participants referred to economic help as something important for them to sustain the caring role and to keep their job. Caregiving for adult children can also have an impact on their professional life: for instance, in Portugal one of the adult children had 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 adult 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 emerged 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 steps caregivers must overcome. Adapting to all the demands, in terms of time management, 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 not alone physical consequences but also having to deal with highly charged emotional issues associated with their situation such as the changes to the person they love (e.g. behavioural changes; the loss of physical intimacy). Having family and professional assistance 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 need to have time to take care for themselves but 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 of care receivers.

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 to the most challenging aspect of caregiving as 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 diseases like dementia and its impact on their grandparent (this need was also shared by Irish participants), as well as to having some psychological support. For example, one of the participants in Portugal referred to the need to attend a psychotherapist to help her cope with the situation.

3.4.1. Physical, emotional and social needs

Adult Children

Caregiving experience had different impacts and created mixed emotions. On one side, caregivers feel that they should return the love that their parents gave them; they have a sense of accomplishment with managing the care process and providing parents with the support they deserve and with the opportunity to age at home as is their wish. On the other hand, caregivers expressed feelings of guilt in relation to their engagement with their own families (spouses and children) but also in relation to leaving their parent when they take time away to live their own lives. In general, the caregiver role had an impact on participants' family and social life, even if they did not live 24/7 with the care receiver, they were always on their mind, which make it difficult for them to relax and be present as they are in constant fear of what might happen to their parents in their absence.

Participants' emotional and psychological needs are mainly associated with their need to share, to tell one's own story, 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, what will become of their spouse if they get sick or unable or to continue to provide care. Frequently, caregivers put their spouses' health and needs above their own health. Dwelling on the future can be another stress and worry for caregivers.

> **"What will happen to her if I die before? Would she put in a place for elderly?"**
>
> (Francesco, Italy)

Involvement with associations and support groups provides an opportunity to learn more about their spouse's illness and to gain better understanding and skills to overcome the challenges associated with the disease or condition. It also provides time away from the caring situation. 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 is essential to help caregivers to continue in their caregiving role, as do technical aids and providing the spouse who is unwell with new interests.

Grandchildren

In general, grandchildren referred finding some of the social and physical aspects of caregiving challenging. In particular, they pointed to their lack and the lack of other people's knowledge on how to react in a specific situation regarding the care receiver situation (particularly where the grandparent had dementia); 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 considered the emotional support provided by professionals such as psychologists or social workers very important, especially for the members of the family spending the most time with the patient and having the main responsibilities (GR). There are also some statements referring to 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).

3.4.2. Information, communication and instrumental needs

Adult Children

Participants mentioned the need for having more services available, and that these services should be accessible to anyone (in particular financially) and should respond to individual needs and provide person-centred 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”***
>
> (Brina, Slovenia)

Spouses

Spouses referred to the need for better understanding from the social and health systems/services regarding older people, and particularly people with dementia. Informal caregivers looking after someone with dementia fulfill the role of caregiver with little or no support (formal or informal) and with no clear and robust information about the disease and its progression. Collaboration between social and health services and multi-disciplinary approach between professionals could help caregivers cope with their situation and with the different demands they face when the situation deteriorates. Caregivers find themselves in a limbo, sometimes without a proper diagnosis, lack of information on how to cope with various symptoms and afraid of what may happen. Not alone, do caregivers not know about the disease, they also do not know where to get help. Spouses described how they have 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 that are more affordable, and being 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 should be met in a timely way and adapted to meet the person's full needs. Peer support is also seen as a valuable resource to help overcome burden. However, the lack of care support prevents caregivers from attending groups.

At the opposite end, spouses in Slovenia reported that they did not feel the need for emotional and psychological support from professionals, as they find that talking with someone close to them about the situation is enough to help them cope with the situation. They did report the lack of accessible and more personalized social and health services, and information on dementia and the need for 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, a Portuguese participant who is the primary caregiver to her grandmother could afford to pay for care for her grandmother but could not find a suitable respite place for 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 to the unwillingness of 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.

4. Recommendations for Listen to My Story – narrative based workshops for informal carers

4.1. Purpose of the Listen to My Story

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 and creative arts-based interventions for caregivers are well known for their therapeutic effects (Murrant et al., 2000; Caldwell et al., 2005; Mackenzie et al., 2007; Kidd et al, 2011; Swinnen, 2014; Butcher et al., 2016).

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. Expressive writing is a method where writing has the purpose of putting people’s deepest feelings and thoughts into words. 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.

In particular, a group of caregivers meet with two expert weekly - in the same room and at the same schedule every week - building a safe environment for them. On each session, that lasts about 90 minutes, the group first reads a text literature or poem selected by the experts. Then, each participant talks about the thoughts and feelings that arise from reading spontaneously, with encouragement not to focus on a literature analysis. There is a big variety of feelings that can arise (for example sadness, anger, happiness, stress, satisfaction), depending on the stimulus, on previous life experiences or on the present psychological state of each participant. After spontaneous sharing, the experts ask caregivers to try to associate arising feelings with something they have felt or experienced in their everyday life with the care receiver. The next step is for caregivers to write down their own stories, giving voice to their thoughts and emotions and using expressive and spontaneous writing techniques. At the end of each session, caregivers read their stories to the group (Karagiozi et al., 2017).

Although many caregivers report being upset during writing (and often crying), they also find it meaningful and valuable, leaving the sessions feeling deliberated. In conclusion, this intervention based on literature and expressive writing proved to be efficient for caregivers of people with dementia, as it provided them with a different form of expressing and sharing their deepest thoughts and feelings. Not only that, but it helped them change the way they feel towards dementia, caregiving, people with dementia and themselves (Karagiozi et al., 2017).

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. Three dedicated programmes of workshops will be developed: one for spouses, one for adult children and one for grand-children/young carers. Each workshop will take into account the specific issues and needs of the targeted group in terms of age and type of kinship with the person they care for, as highlighted by this report.

4.2. Recommendations

Based on IO1 report, the partnership will develop a programme based on narration and expressive techniques (IO2) in order: i) to help caregivers to express their feelings, ii) to help them make meaning of their experiences and iii) to become more aware of their situation as carers.

Taking into consideration the **findings of the research report "Tell me about you: family members' experiences of caring role" and the feedback from the round tables with experts**, the "Listen to my story" narrative workshops intervention should take cognizance of these aspects:

- Although there was a general understanding of what narrative workshops are, a more detailed explanation on how they will operate in practice would be appreciated. In this sense, when writing "Listen to my story" intervention the objectives and methodology should be clearly explained;

- 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.**
- The research report 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 to the caregiving**

experience that can be used as guidelines for the “Listen to my story” intervention.

- However, the S.IN.CA.L.A. project involves caregivers with different kinships, their experience can also vary (which is also identified in the research report). Although the research report 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 encompass and relate those with the material to be used as part of the follow up sessions of the intervention.
- This intervention should give family members the opportunity to say what they feel in order to help them feel better and heal. In general there is much emphasis on what is appropriate and how caregivers should behave, this intervention should provide a nonjudgmental space for doubts.
- In order to guarantee a safe place where participants can share their personal experiences, the group must first get to know each other, connect and create a trusting relationship.
- Near unanimous agreement that it will be difficult for spouses and adult children in the role of primary carers to attend 90 minute sessions for more than one or two sessions as they just won’t have anyone to take care of their relative;
- Due to the emotional component of these workshops, **additional support should be available.**
- I**nclusion criteria** for participation could be similar to that used for participation in the research study: being 16+; being an informal carer of an older person for at least 6 months; providing care at least in one ADL (basics or instrumental) or in supervision; being able and willing to share their experiences about informal caregiver role with the other participants. Since the “Listen to my story”

intervention involves writing, the partnership will guarantee the resources/help for everyone – even those with limited writing skills/competencies – to be able to express themselves. However, the educational level of the participants is a consideration as it is very different to write and express their own feelings compared to having to dictate to someone else.

- To use expressive writing as a medium might be challenging since it may scare people away or intimidate them. For those who do not have a culture of expressing themselves through writing the intervention may add another stress to their lives.

Note: there are many cases in which Informal caregivers experience social isolation (which was something that was stated during the data collection phase of the research report), 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.

5. Round tables

A round table event took place in each partner country, with the goal to present the draft results of the research report 'Tell me about you: family members family members' experience of caring role, to (at least five) professionals (representatives of carers associations, decision makers, social and health care professionals). The aim of these round tables was to have the research report peer-reviewed before its final release and, at the same time, to collect inputs from professionals in relation to the educational resources that the partnership intends to implement the narrative workshops 'Listen to My Story' intervention.

The structure of the event (Table 4) was the same for each partner and correspond to the following:

Table 4. Round Table Structure

Session 1: - Presentation of the methodology and results of the research report (project partner) - Round table discussion among all participants following the explorative questions in the script and asked by the facilitator of the meeting
Session 2: - Presentation of the outline of the 'Listen to My Story' narrative workshop intervention (project partner) - Round table discussion among all participants following explorative questions in the script and asked by the facilitator of the meeting
Session 3: - Collection of additional information through a questionnaire - Conclusions

The event was facilitated by staff members of the partner organization. In order to guarantee some coherence and homogenization among all partners, a kit containing all of the materials required to deliver the round tables was developed. This includes: draft of research report; the executive summary (see annex 1); power point presentation; consent form; attendance list; evaluation questionnaire; round table structure; and checklist.

In total, 41 participants from different professional backgrounds were involved in the round table sessions – see table 5.

Table 5. Number and Profile of participants per country

Country	N.º participants	Profile of participants
ESTONIA (EE)	7	Professionals working in the social field and from state level public authority dealing with social insurance, social service provision and supervision
GREECE (GR)	6	Psychologists working with caregivers in Alzheimer Hellas care unit or in the private sector.
IRELAND (IE)	7	Nurse, occupational therapist, carers support development officer, psychologist, academics with research interest in family carers, and adult child caring for mother with dementia
ITALY (IT)	10	Professionals of social field, health field, researcher of social field, formal caregiver, informal caregivers, people belonging to associations for caregivers.
PORTUGAL (PT)	5	Psychologists and Gerontologists
SLOVENIA (SI)	7	Medical profession, psychologist, social workers and workers in institutional care.

Besides the discussion, the attendees participating in the round table sessions, were asked to evaluate the quality of the output ‘Research Report’ (see annex 2) according to each of the following dimensions: accessibility (user-friendly); accuracy; innovation; feasibility; usefulness; acceptability; expected impact. Each participant was asked to allocate a score of 1 to 4 (1 for low or insufficient and 4 for very high or very good) to each dimension. The dimensions with high score were: Accuracy (3,6); Usefulness (3,5); and Feasibility (3,5).

Strengths and weaknesses were also identified with regard to the research report and are presented in table 6:

Strengths	**Weaknesses**
• Clarity of the research report; • Capability to promote debate on the topic; • Innovative methodology and intervention; • Gives voice to informal caregivers (the methodology used allows them to freely talk about their experiences) and highlights some of their needs; • The script for data collection can be viewed as a good road map for detailing the caregivers needs and emotions; • Analysis of data from different countries; • Comparison between different countries in terms of caregiving culture; • Focus on family relationships and the view of 3 different kinships (whole-family and lifecourse approach); • Lifespan perspective; • Comparison between different age groups. • Identification of possible topics to use in the narrative workshop intervention; Activities envisaged are easily expandable; • Original means of expression.	• The executive summary did not explore in depth the impact of the caregiving process in the family dynamics, nor coping strategies; • It focuses more on the negative aspects of caregiving than on coping strategies and resilience; • Gives little information regarding the implementation of the intervention; • It does not highlight particularly the cultural dimension; • Inclusion criteria may raise some questions since they are very broad: - not all the target groups might be ready to cooperate; - difficulties when finding participants; - limited impact based on the participation, caregivers might not be aware of the usefulness.

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Annex 1

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S.IN.CA.L.A.

EXECUTIVE SUMMARY

IO1 - “Tell me about you”: family members’ experiences of caring role

Developed by CASO50+

This report has been coordinated by CASO50+, in close cooperation with the partners of the S.IN.CA.L.A. project.

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Abstract

This document is the executive summary of the research carried out for SINCALA project Intellectual Output One (IO1) “Tell me about you”: family members’ experiences of caring role. It provides an outline of the experiences and needs of families with caring role in six countries - Estonia, Greece, Ireland, Italy, Portugal and Slovenia. The aim of the research was to explore the impact of caring on informal carers, with different kinships or family ties to the older person being cared for, spouses, adult children and grandchildren, , in the different countries. In particular, the research explored 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 and unmet needs.

The report contributes to research on family care of an older person by providing new insights into family relationships from the perspective of different kinship groups and the coping strategies and educational needs associated with their caring role. The research also informs the extent the existing training materials for the other two SINCALA project Intellectual outputs, Narrative Workshops and the Online Training programme, can be transposed to the different country contexts and where it needs adaptation. .

Report Contents

The report consists of the following:

- **Tell Me About You – Methodology:** outlines the methodology used to meet the aims of the research, namely the literature review, focus groups/ interviews and survey.

- The literature review developed by the partnership covered aspects such as: what are the needs of Informal Caregivers (IC); what is the impact of caregiving on the lives of IC; how do 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 on family dynamics; different methodology and instruments employed in other studies looking at the topic of IC and appropriate data collection methods. A 'Methodology Script' was developed outlining the process for the collection of data, such as: techniques to be used; ethical considerations; inclusion and exclusion criteria; tips on focus group facilitation; structure of the 'Data Collection Kit' was also developed to ensure a unified and integrated approach to data collection and analysis by all partners. This kit contained the focus group schedule, along with other documents required such as: Registration form; Consent form (parental consent form for any participant 16 and under); Questionnaire; Data collection checklist; and Reporting framework.

Data Collection: A mixed-methods research design, using both qualitative and quantitative methodologies, was used to meet the aim of this research to learn about the experiences of family members from different kinship groups providing care to an older person. Focus groups, interviews and a survey were undertaken in each of the six European Member States (Estonia, Greece, Ireland, Italy, Portugal and Slovenia. Using a qualitative methodology facilitated the establishment of a closer relationship with the participants - which is in accordance with the objectives of the project to give voice to the subjects - and to get a deeper understanding of their lives.

A ‘Data Collection Kit’ was developed to ensure a unified and integrated approach to data collection and analysis by all partners. This kit contained the focus group schedule, along with other documents required such as: Registration form; Consent form (parental consent form for any participants 16 and under); Questionnaire; Data collection checklist; and Reporting framework.

Each partner was to collect data from all target groups previously defined – grandchildren, children, and spouses. However, due to some constraints related to informal caregivers' availability (inability to attend due to caring demands or timing of focus group did not suit), some of the partners carried out individual interviews. **In total, 11 focus group** discussions (EE-GR-IE-IT-PT-SI) **and 14 interviews** (EE-IT-PT) were undertaken. **The total number of participants involved was 86.**

. For the focus groups, partners were required to recruit at least four caregivers per target group Where this was not possible as in three cases, (GR, IT and PT), the partner organized for a couple of caregivers to attend at the same time, 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). In other instances, it was only possible to do one-to-one interviews due to education/work commitments, hence 11 interviews were carried out mainly with grandchildren.

> The same script was used both for focus group and for the interviews, and it covered topics such as: **Overall experience as a caregiver; Resilience; Intergenerational relationships; and 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 (each participant was given a fictional name). After that, all partners were responsible for reporting the data using the reporting framework developed.

Building also on the outcomes of the literature review, the findings from these focus groups/interviews are intended to inform the adaptation of the workshops to be held in IO2.

Participants' socio-demographic information: Of the total participants (n=86) in the FG and interviews, **40% were children, 33% were spouses and 27% were grandchildren**. This may reflect the culture of care in each country, where adult children are more likely to become responsible for taking care of their parents. Regarding the participants' gender, overall the majority of the participants were female which correlates with that reported in the literature (Buscemi et al., 2010; Roberto & Jarrott, 2008; Silva et al., 2013; Zwaanswijk et al., 2013). The age range of participants **went from 16 years old to 88 years old**.

Data Analysis Reporting: Data analysis followed an established method of content analysis. In undertaking the analysis, partners worked with a predetermined analytical frame of themes, namely those used in the focus groups and interviews script. This framework of themes emerged from the literature review and, was developed into a reporting framework and included in the 'Data Collection Kit'. Partners were asked to report their findings under the different themes and illustrative using quotes for each of the target groups. The data was analysed and presented according to the following themes: i) Overall experience as a Caregiver; ii) Intergenerational relationships; iii) Resilience; and iv) Overall needs. 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 six European countries, however, differences were also explored. The findings include:

I. Overall experience as a Caregiver

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. In most cases, children pointed *to lack of support* from other members of the family (e.g. other siblings take on more of a visiting role). Adult children mentioned *issues with adapting to the caregiving situation*, in that it required them to negotiate with siblings around care provision to facilitate them to work or have a life outside of caregiving to a parent. In many cases, the appointment of family member as the main carer was guided by what was convenient for the family, and this was often the sibling who was not in paid employment and therefore perceived as available.

For **spouses**, overall, becoming a caregiver seemed the *natural step* to take with the onset of a disease or condition that makes the spouse dependent or in need of care. It is motivated either by *love/emotional bond*, or by *a sense of duty/marital responsibility.* Keeping their spouse at home appeared to be the 'natural' solution or thing to do. Spouses from all countries pointed to difficulties and challenges of caregiving. Taking care of a spouse is *financially and emotionally demanding*. Burden, constant tiredness, the feeling of losing their partner, on becoming a caregiver and no longer a spouse, the *sense of being a prisoner*, are some of the negative and difficult aspects mentioned. In general, spouses receive *only very occasional support* from other family members, sometimes because they try to protect their children by keep information from them

For **grandchildren**, the data suggests that their relationships with their grandparents varied 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 disease when they begin to accept the help since they realize they couldn't do it on their own anymore. On the other hand, in some cases, grandchildren do not mention any difficulties on this matter, by contrary they stated that their grandparents develop a *closer relationship* with them.

Most of the participants play a role of secondary caregiver – to the primary caregiver, their parents (often their mother). In fact only two of the grandchildren providing support live with their grandparents, therefore the support they give is not only to their grandparents – e.g. running errands - but also to their parent.

II. Intergenerational relationships

For **adult children**, the relationship with their parents may appear very complex and often conflictual, in some cases. *Conflict can resurface with the changing of roles*: where the parent is now dependent on their child for care. In some cases, the change in role results in a sense of loss of what the parent represented/ meant to the adult child e.g. the mothering role.

Added pressure comes from *financial aspects and the distrust of* professionals, health and social care, they have encountered and care processes they have experienced. Generally, the most difficult part of caring was the emotional element related to accepting their parent's illness and the *constant fear* for their safety and well-being.

In general, **spouses** can *only occasionally rely on children's support*, either because they live some distance away or they don't have the time as they work and have their own families. 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. The caregiving dyads are connected by different means: *love, gratitude, marital responsibility*. Although some of the spouses reported that they *no longer feel like husbands/wives*, but almost exclusively as caregivers, positive feelings can flow from this situation.

Regarding the relationship between grandparents and **grandchildren**, the majority of the participants claimed that the relationship with their grandparents did not suffer major changes. There are, however some aspects that may influence the relationship: the fact that some grandparents don't remember they grandchildren, or the challenges related to generational relationships and to the understanding of the world, since different generations may have different expectations and perspectives about life. Caregiving for an older member of the family can 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.

III. Resilience

In general, for **adult children**, resilience appears as a result of balancing the capacity to adapt and the ability to overcome care difficulties, with i) the *necessity to resist and overcome* the burden involved in the caregiving process*,* and ii) *the recognition and acceptance* of the situation and of the care role. There were some negative feelings expressed in relation to caregiving activity, such as: *anger, frustration, resentfulness.* Having someone to talk to or some activity to escape and have a break, were identified as important aspects in helping aspects in helping adult children cope with their situation and contribute to their well-being.

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

Regarding **grandchildren**, those who live with their grandparents and have the main responsibility for caregiving, experience, evidently, more burden. For those who have a secondary role, the biggest concern is with the wellbeing of their parents. In this sense, their focus is to help their parents, stepping into their shoes, in order to provide support. Some of the participants referred the difficulties that other relatives have in understanding the nature (and consequences) of their grandparents condition.

IV. Overall needs

Regarding challenges and needs of **adult children**, one of the most challenging aspects is not knowing what comes next. Caring is a demanding role that leads to burden and tiredness with the potential to result in health problems for the caregiver; it can have a negative impact on personal relationships; self care is essential in maintaining the role of caregiver. Adult children providing care to a parent often experience feelings of guilt in relation to their partners and children; they feel they are neglecting their own families. Lack of support from other members of the family can compound their situation of coping alone. 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.

For **spouses**, emotionally accepting the disease/condition is one of the first steps that they must overcome. Adapting to all the demands, in terms of time management, 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. Caregiving is physically and emotionally demanding, so having family and professional help to help overcome these difficulties is a need that seems to cross-cut all countries in the partnership.

- **Grandchildren** referred to finding some of the social and physical aspects of caregiving challenging. Social aspects they pointed to were their lack and the lack of other people’s knowledge on how to react in a specific situation regarding the care receiver’s situation, e.g. where a grandparent had dementia. In general, all the participants would like to have more professional help from formal services.

Recommendations for IO2: Based on IO1 report content, the partnership will adapt a programme based on narration and expressive techniques – “Listen to my story” – already tested and used in Greece, exclusively with people with dementia. In this project, the programme will be adapted for informal caregivers of older people in general and with different kinships, in order: i) to help caregivers to express their feelings, ii) to render their experiences meaningful and iii) to familiarise themselves with their situation.

Taking into consideration the findings of the research report ‘Tell me about you’: family member’ experiences of caring role, the following recommendations are being made for the t development of "Listen to my story" Narrative Workshops intervention (IO2). 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 workshop.

- 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.

This data report itself offers insight and encouragement to further develop and test different interventions that are addressed at the building of resilience and mental coping mechanisms of caregivers.

ANNEX 2

Questionnaire and Output Quality Survey

IO1 – "Tell me about you": users' experience of families with caring role

This survey intends to assure the quality of the output developed and to receive your opinion and contribution before its release. We kindly ask you to complete this form in order to provide us feedback. Thank you.

Organization: ....

Person filling questionnaire:
☐ Professional working in the social field (e.g. social worker, care service provider, ...)
☐ Health care professional (e.g. doctor, nurse, ...)
☐ Other, please specify : ....

Date: ....

Do you think S.IN.CA.L.A project can be a contribution for informal caregivers?
Yes ☐ No ☐

Please explain how: ....

....

Regarding what has been discussed, which specific issues should be addressed in the Narrative Workshops for each target group?

Spouses : ....

....

....

Children : ....

....

....

Grandchildren : ....

....

....

Please evaluate the Output's quality in each of the assessment dimensions. Allocate a score of 1 to 4 (1 for low or insufficient and 4 for very high or very good).

Dimensions	1	2	3	4	Justify (Identify reasons for your score)
Accessibility (User-friendly) (does the report uses a clear and transparent language; is it structured in a way that is able to be understood by different kind of people)					
Accuracy (the report explains clearly what was the partnership's aims with this research; the findings are relevant for professionals; the recommendations are relevant for the programme to be adapted)					
Innovation (intensity of distinctive features; the added value of conclusions and recommendations compared to what we already know about the field; what differentiates the approach proposed from other interventions for caregivers)					
Feasibility (adaptability of the methodology of the study to other contexts, capacity of replication; capacity of transferability to other fields)					
Usefulness (benefits and added value for professionals working with caregivers, evidenced in terms of its capacity to assess the needs of carers and to intervene in accordance)					

Dimensions	1	2	3	4	Justify (Identify reasons for your score)
Acceptability (level of acceptance of the report; potential willingness of stakeholders and professionals to take the report into consideration)					
Expected Impact (capacity to produce changes in the current state of play of caregiving interventions and policies)					

Please describe the strengths and weaknesses of the output.

Output Strengths	Output Weaknesses

Recommendations & Suggestions

Thank you for your cooperation!