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Supporting Informal Carers

A whole family & lifecourse approach

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S.IN.CA.L.A.

SUPPORTING INFORMAL CARERS:
A WHOLE-FAMILY & LIFECOURSE APPROACH

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OUTLINE

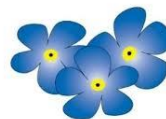
- Overview of SINCALA
- Research Report “Tell me about you: experiences of family members with caring role”
- “Listen to my story” workshops



Partnership



MTÜ Eesti
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ΕΛΛΗΝΙΚΗ ΕΤΑΙΡΕΙΑ ΝΟΣΟΥ ΑΛΖΧΕΙΜΕΡ ΚΑΙ ΣΥΓΓΕΝΩΝ ΔΙΑΤΑΞΕΩΝ



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CASO50+



S.IN.CA.L.A. Project

- Informal care forms a cornerstone of all long-term care (LTC) systems in Europe
- Informal care is likely even more important in future due to demographic change  80+ more likely in need of LTC
- Health care advances
- LTC policy and need for cost-containment  community care over institutional care
- Family support essential – financial, instrumental and psychosocial



S.IN.CA.L.A. Project Objectives

To develop and test a pedagogical method based on narration, adapted to different EU country contexts, targeting households caring for older family members.

To provide informal carers with an opportunity to participate in an intervention designed to support them make meaning of their situation.

To make available to educators and professionals working with family carers the S.IN.CA.L.A E-Learning course (MOOC).

**Building
Resilience
and Coping**



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Research Report

‘Tell me about you: Experiences of Family Members with Caring Roles’

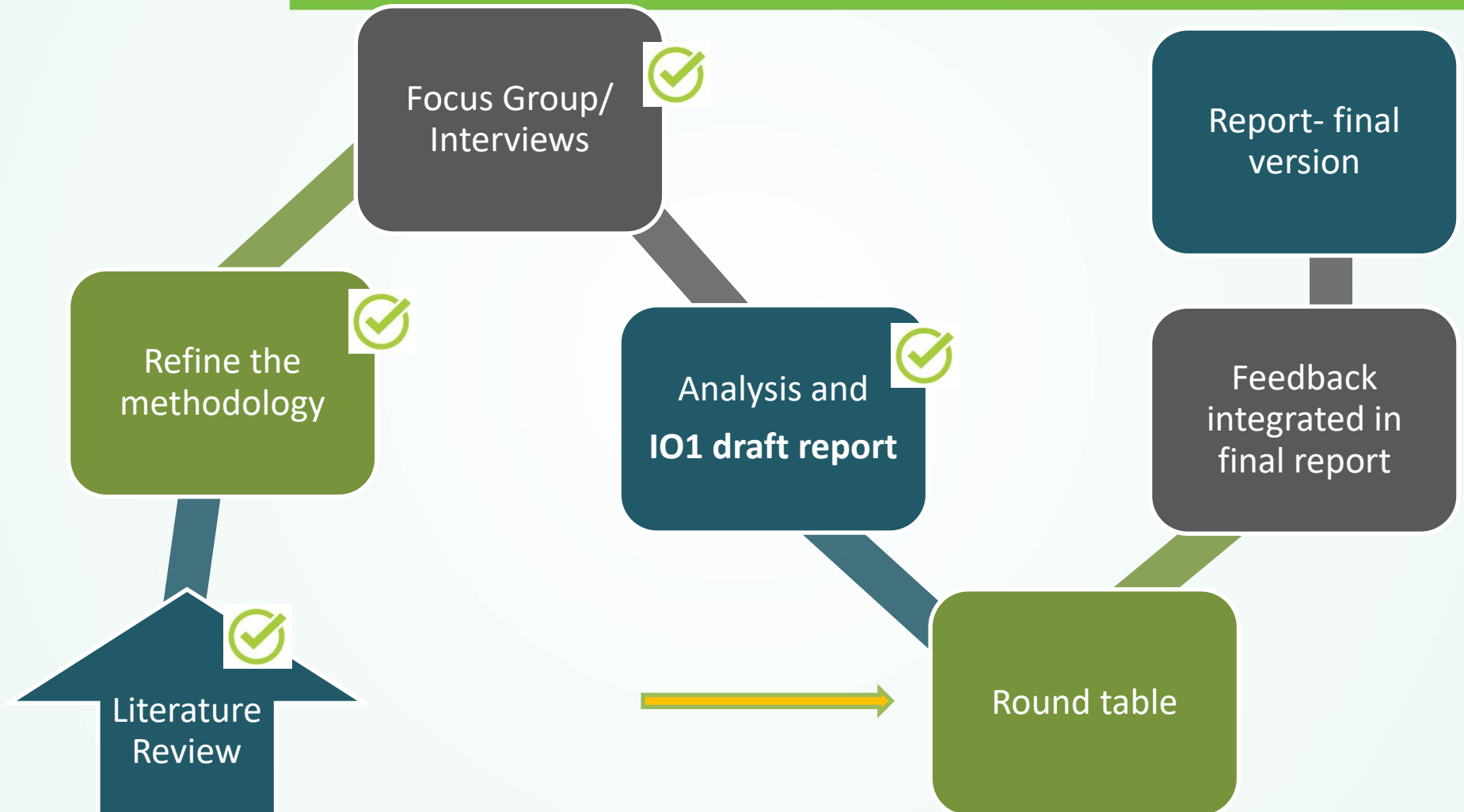


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“Tell me about you”

Aims and methodology





IO1 “Tell me about you”

Aims and methodology

Country	Focus Group			Interviews			Total of Participants
	Spouses	Children	Grandchildren	Spouses	Children	Grandchildren	
ESTONIA		2	-	1		1	12
SLOVENIA	1	1	1	-	-	-	14
GREECE	1	1				1 group interview	12
ITALY	1	1	-	-	-	2 (+1 group interview)	18
PORTUGAL	-	1	-	2 (+1 group interview)	-	5	13
IRELAND	1	1	1	-	-	-	17
							86



“Tell me about you”

Aims and methodology

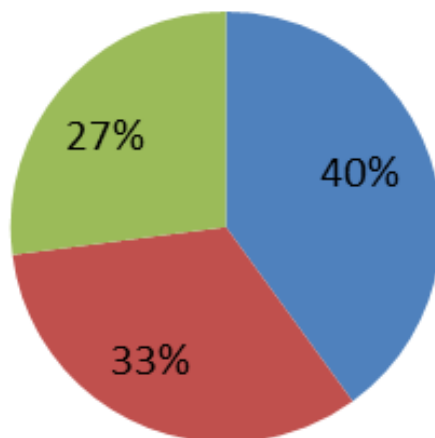
Participants’ details:

Participants

■ Children

■ Spouses

■ Grandchildren



Regarding the participants’ gender, overall the majority of the participants were female which reflects the findings of much of research on informal caregiving



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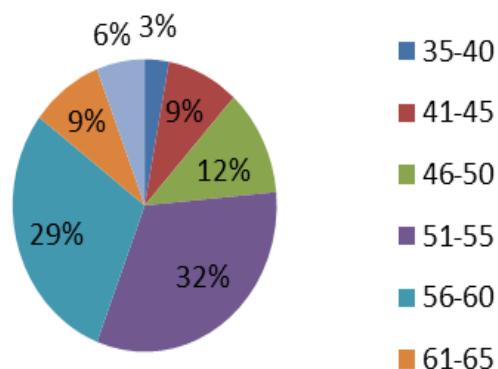
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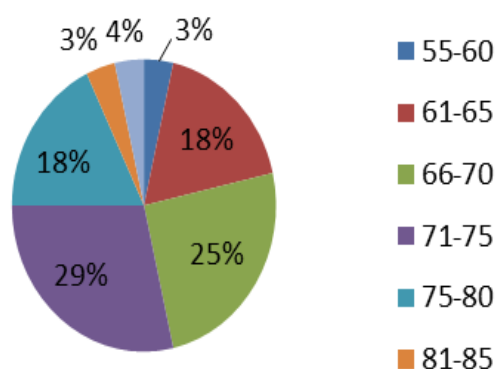
“Tell me about you”

Aims and methodology

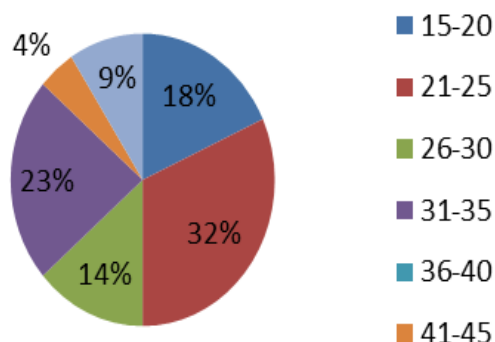
Children's age



Spouses' age



Grandchildren's age



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



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Research Report
“Tell me about you: Experiences of Family
Members with Caring Roles”

RESULTS



“Tell me about you”

Summary of Results

Overall experience as a Caregiver



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Adult Children

Overall experience as a Caregiver

Pathway to caring

Develops over time, often starting as visiting role:

"I started doing it [providing care to her mother] about five years ago or so, initially in her home in town (50km away), up and down twice a week and staying over but then she kept falling"

Family delegation:

- Agreement to share caring between siblings (rota)
- Assumption available sibling will take on role
- Where parent moves into family home adult child, siblings adopt visiting role

Outcome: *"we were all supposed to have her for three months but none of them stepped up the mark"*

"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'"



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Adult Children

Overall experience as a Caregiver

"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)

Motivation

- Duty/ reciprocity;

Responsibility

- Lack of support family members; coping alone

"family members don't feel this huge responsibility, that they are responsible for all this and their own lives"
(Maire, Ireland)

Adapting

- Stifled
- Work and social opportunities

Be Accepted - Role reversal

"My dad was pushing me away at first. He couldn't 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"
Alena, Slovenia

"where are you going, what time will you be back"
Susan, Ireland



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Spouse/partner

Overall experience as a Caregiver

Pathway to caring

‘Natural’ step where spouse needs support or care due to onset of a disease or condition; cultural norm

“The kids said you will have to look after him you know”

Decision to care for spouse at home taken as ‘a given’ in all countries; care demands addressed one day at a time; little joint planning for the future

“when you wake up in the morning they are the first thing on your mind and I said if I could get my breakfast I would live for the day”

Outcome: Crisis guides decision-making:

“I got cancer.. I had nothing in place so I was taken into hospital early on a Monday morning and he had to go into emergency respite”

Not caregiver’s decision: *“he won’t go to respite”*

Shared decision: *“I’m not getting any younger and it’s getting tougher but we have an agreement that when I can’t handle it anymore she will go into nursing home”*



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Spouses

Overall experience as a Caregiver

"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)

Motivation

- Love/ duty/ reciprocity;

Demanding

- Emotional/ physically
- On alert
- Responsibility

"I suppose you have to say there are times you get annoyed or angry or frustrated, frustration that you constantly have to be watching"
(Joan, Ireland)

" it is not the same as [looking after] a parent, the hugs and the bed side of things is gone"
(Ann, Ireland)

Adapting

- Changing role
- Sense of loss
- Give up own life

Rewarding

Delivering
Solving
Appreciation

"my wife became completely immobile and would hardly leave the chair, then the doctor prescribed medication, the situation improved massively and after that I felt very good" (John, Ireland)



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Grandchildren

Overall experience as a Caregiver

Pathway to caring

Secondary role: parent, mainly mother is the primary caregiver.
Some act as primary carer (EST, IT, PT)

Motivation

- Love for grandparent
- Reciprocity

"I do it 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)

Demands

Try and step into parent's shoes where can;

"I can see that she is very worn down and tired with having to constantly think about them and plan things" (Cathy, IR)

"I kind of noticed that my mom has been struggling...because my granny has needed like pretty much full time care ..., in the last year coming down more often" (Jane, IR)



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“Tell me about you” Summary of Results

Intergenerational relationships



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The relationship between adult children and parents appeared complex and often conflictual

Pre-existing relationship with siblings

"caring aspects brings up huge issues if there is any in the family already, you are trying to deal with issues in the family as well as caring and I think that is so difficult because some just don't understand - there are six in our family but like there are only two" (June, IR)

Pre-existing relationship with parents

"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)

Loss of mothering/ fathering role

"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" (Sadie, Ireland)

"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" (Martina, Italy)

Relationship with partner/own children changes: prioritise parent's needs

'she caused a lot of trouble for me with my husband, we would just go for a walk to the beach and then when we came back he would have cooled off' (Liz, Ireland).

Spouse/partner providing care seek to preserve the parent child relationship with adult children

Don't want to burden their children, can give impression that they are managing fine

"My daughters help a bit. But they have their own families you know. I can't burden them with my problems" (Elsa, Slovenia)

Only asking when they are no other options

"I have been able to ask and organize with my sons, 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 myself" (Catarina, Portugal)

Grateful for help they get acknowledging that it is an imposition, something their children are not obliged to give

"they make a special effort to come from Clare or Leitrim or Kildare and Dublin [at weekends], like they all have full time jobs and marriage" (Shiela, IR)

Relationship to caregiver and care receiver: type of support offered

"Her niece and nephew call now and then but they are company, brilliant, she loves them coming but they cannot physically help so they are no help to me. Now my daughter in law in Cork is a nurse and when she comes down she takes over" (John, IR)

Grandchildren's relationship with grandparents did not change, just their way of relating

In many instances participants grandparents had dementia, meaning expectations and ways of relating changed

"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)

"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" (Jane, Ire)

Challenges arose regarding different generations understanding of what is needed

"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)

Relationship with parent may change – reversal of roles

"we normally have a bit of a laugh and a rant in the car coming home from their house" (Freda, Ire)



“Tell me about you” Summary of Results

Resilience and Wellbeing



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Adult children

ACCEPTANCE

"I had to accept what cannot be changed and now I can no longer be hurt" (Elena, Italy)

UNDERSTANDING

"in my head logically I know, I'm angry because I know she doesn't, can't understand how difficult it all is for me" (Sarah, Ire)

CHOICE

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)

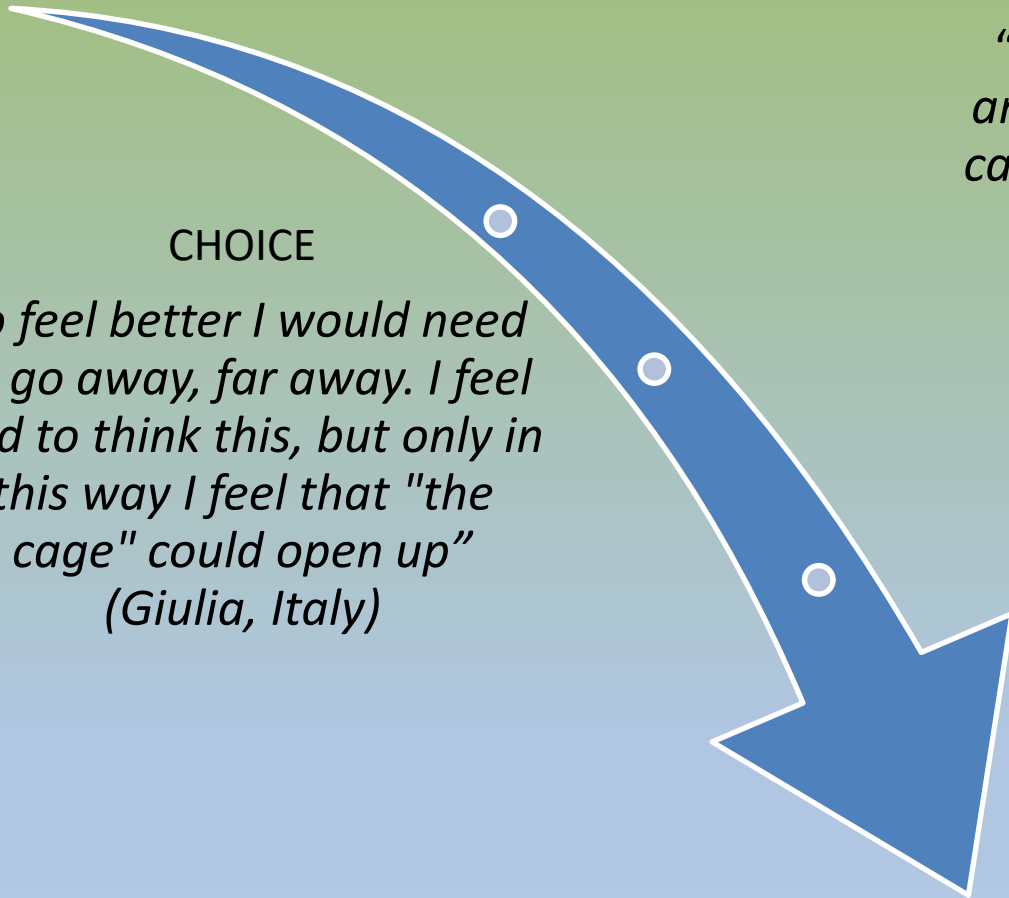
RELATIONSHIP/ PERSONALITY

"my mother is, she is always placid woman...if you asked her to do a headstand she would come and d it for you" (Pat, Ire)

SUPPORT

Opportunity to vent/ talk; outside life, activities

"I just moan at everybody around me" (Bernie, Ire)



Spouses/partners

CARE LOAD

"I had breast cancer and I had to end up bringing James (partner has dementia) with me, I have to drive, get him up washed and dressed and bring him when I'm going for treatment" (Helen, Ire)

CHOICE

"My house now feels more like a prison than a home"
(Sofia, Greece)

"my daughter said to me last night, you really are a prisoner mum. No I said actually I'm not, in my head I'm not" (Ina, Ire)

RELATIONSHIP/ PERSONALITY

"my Dad, he was always so appreciative and he cooperated, but my husbandI don't mind looking after him if he would only cooperate, anything any of us is doing including the kids is for his benefit" (Ina, Ire)

FULLFILMENT

"I feel the value of helping"
(Alessandro, Italy)

SUPPORT

'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, PT)

"I am a part-time farmer' --'yes I have a few cattle, it just gets me out of the house, I just couldn't cope" (Ann, Ire)

Grandchildren

GIVING FROM THE HEART

“I don’t want to lose our family bond, I always want her to see me as her granddaughter not her carer” (Rita, Ire)

RELATIONSHIP

Less impacted by past history /experiences of parent/child relationship. Support is usually appreciated by both parent and grandparent.

CHOICE

Secondary carer can fit care around life.

Primary carer, care dictates life:

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

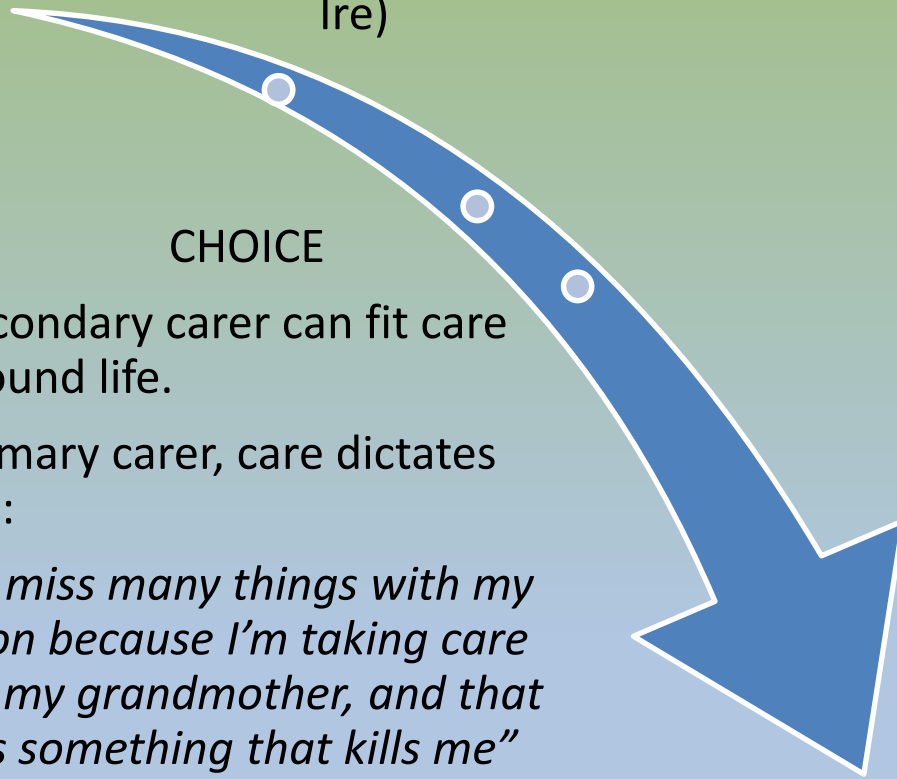
(Ana, Portugal)

SUPPORT

“I can’t stop talking about these kinda things to people I don’t know it is as if it is my brain needs to talk about it’ (Ben, IR).

Emotional support to cope with worry relating to parent, understanding of illness and inevitability of loss of grandparent

“It’s better than them being dead” (Freda, Ire)





“Tell me about you”

Summary of Results

Overall needs

- Physical, emotional and social needs
- Information, communication and instrumental needs



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Adult Children overall needs

Physical care provision

"its really hard to lift her out of the wheelchair, sometimes I have to call my husband to lift her out of the wheelchair, She literally starts falling backwards again" (Bernie, Ire)

Loss of work (income) and social opportunities

"I can't, I don't have money. It is a difficult situation. Roles have changed. I feel responsible for my mother" (Leah, Est)

"this is one of my main problems, when I go away what do you do" (Maire, Ire)

Make meaning of the situation

"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." (Pia, Est)

"actually do you know I found this very helpful, right I'm not very talkative as I say but I wouldn't let my feelings out but I found this very good actually I didn't realize I needed it" (Sarah, Ire)

Information and support services

"If I could get someone to give me a hand to take her [mother] out in the wheelchair for an hour but no that wasn't... it was just home help they offered" (Sandra, Ire)

Spouses/ partners overall needs

Providing
Physical care

"its getting very difficult, I had a standing sally which was brilliant but they took it from me and gave me a standing hoist and that takes about 5 or 6 times longer and I ain't getting younger" (John, Ire)

Opportunities
for social
interaction
limited

"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" (Catarina, Portugal)

Make meaning
of the
situation

"the challenge is to understand how to feel better, not only those we love but us too. What remains in the end is the love that you have given. We save ourselves in this way" (Francesco, Italy)

Information
and support
services

"I didn't know what dementia was. I didn't know where to go for help...I'm years just travelling blind" (Keira, Ireland)
Respite/formal care: *"I have to get treatment myself now for prostate cancer' - 40 days radiation, 8 weeks, 5 days a week" (John, Ire)*

Grandchildren's overall needs

Impact on the family

“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)

Make meaning of the situation

“I think just as a young person in general, we are not told much about our grandparents getting older and all of that and what that will entail with knowing about dementia” (Jane, Ire)

Information and support services

“I think it would help hugely to actually to know more about it [dementia]so to know more about what is going on in my granny's mind that she would say something, or push me away ... like why would she do that” (Rita, Ire)

“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” (Ana, Portugal)



QUESTIONS



From your experience/knowledge do the findings of the Report reflect issues associated with caregiving and needs of caregiver?

Does the Report highlight anything new?

Are there other issues associated with caregiving or needs of caregivers of older people not highlighted by this research?

Any other comment/suggestions about the findings of the report?



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“Listen to my story” Support Programme



Description

- **Aim:** Using the results of research report to adapt the original “Listen to my story” programme from Alzheimer Hellas according to the specific needs of different generations of carers and extend its usability to older people in general.
- A series of **workshops specific to spouses, adult children and grandchildren** based on **narration and expressive and spontaneous expressive techniques**, helping them to acknowledge and express their feelings and make meaning of their situation.



Background

- In Europe, 80% of care for people with chronic illness and disability is provided by informal carers
- Caregivers have difficulty in expressing their feelings to their social network or even on a classic support group, where oral speech is the main tool of expression
- Being able to openly express these feelings and share their personal experiences within a supportive empathetic community can build caregivers' resilience
- Art can serve as a tool to externalize their feelings
- Art-based interventions have been found to have therapeutic effects in recent studies



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Literature

- Poetry may help enhance self-esteem, cope with loss, gain better understanding of others and their experiences, create meaning, increase acceptance
- Poetry reading enhances wellbeing, while the creation of poetry improves communication skills.
- Written emotional expression enhanced the ability to find meaning in caregiving for family caregivers of person with dementia
- Enhanced meaning-making abilities can have psychological benefits for caregivers, such as burden relief.



What is expressive writing?

- Writing with the purpose of putting your own deepest feelings and thoughts into words.
- Focus on expressing personal emotional experiences.
- No grammar, spelling or syntax rules - free to choose whatever style or structure comfortable with, without worrying about having a text with beginning, middle and ending.
- The ultimate goal is that by letting go of restrictions of writing rules, expressive writers can have a deeper connection with themselves and their emotions, allowing their “inner voice” to surface.



Listen to my story intervention used by Alzheimer Hellas

Listen to my story intervention – a support group resorting to poetry and literature as motivation and narration and expressive writing as creative tools to help families of people with dementia to express their thoughts, feelings and experiences and make sense of their situation.

Caregivers use literature and poetry to exchange thoughts and experiences, to answer some of their questions about dementia and caregiving and in the end have a new point of view concerning their role.

Karagiozi K, Margaritidou P, Egkiazarova M, Toumpalidou M, Makri M and Tsolaki M (2017)



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Listen to my story intervention

- “Listen to my story” Support group for family informal caregivers
 - 2 facilitators
 - Up to 10 caregivers
 - Weekly meetings
 - Same day
 - Same room
 - Same time
 - 90 minute sessions
- Safe environment**



Karagiozi et al, 2017



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Listen to my story intervention

Session structure (1):

- The group first reads a text literature or poem selected by the facilitators.
- 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.

Karagiozi et al, 2017



Listen to my story intervention

Session structure (2):

- After spontaneous sharing, facilitators ask caregivers to try to associate arising feelings with something they have felt or experienced in their everyday life with the person they take care of.
- Caregivers write down their story/experience giving voice to their thoughts and emotions and using expressive and spontaneous writing techniques (i.e. rules of grammar do not apply, can use random words, even drawing).
- At the end of each session, caregivers offered the opportunity to share their stories with the group. Although many report being upset during writing, they also find it meaningful and valuable, leaving the sessions feeling deliberated.

Karagiozi et al, 2017



"Listen to my story" in S.IN.C.A.L.A

Adaptation of the original "Listen to my story" intervention from Alzheimer Hellas, with the aim to adapt it to **respond to specific needs of different generations** of informal caregivers, adopting a **whole family approach** and to **extend its usability** not only with carers of people with dementia, but carers of older people in general.



Expected results in **S.IN.CA.L.A. framework**

- "Tell me about you" report provides a clearer view of the needs and expectations from the workshops of families with caring role.
- Development of a programme based on narration and expressive techniques, in order to help caregivers to express their feelings and make meaning of their situation.



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Expected results in S.IN.CA.L.A. framework

- **3 dedicated programmes of workshops** : one for spouses, one for adult children and one for grand-children/young carers.
- Each workshop will take into account the specific issues of the targeted group in terms of kinship with the person they care for.



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Target Groups

PARTICIPANTS

- **Informal carers:** all members of households with caring responsibilities for older adults – spouses, adult children, grandchildren.

FACILITATORS

- **Adult Educators and Professionals:** psychologists, nurses, social workers, community workers, home care workers, etc.



QUESTIONS



Is it clear to you what we intend to do in the narrative workshops?

How relevant do you think this intervention and choice of methods are for caregivers? Explain

The research has highlighted particular issues for informal caregivers, do you think the narrative based workshops have potential to address these issues?

Do you think other intervention instruments should be used alongside with narrative method in the workshops? Please specify which ones and why

Do you have any other suggestion about the narrative based workshops and the methodology to be used?



THANK YOU!



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