Listen to my story:

A narrative based workshop for informal caregivers

GUIDELINES FOR PROFESSIONALS

SUPPORTING INFORMAL CARERS: A WHOLE-FAMILY & LIFECOURSE APPROACH

Co-funded by the
Erasmus+ Programme
of the European Union

2020-1-EE01-KA204-078004

This guide has been coordinated by Greek Association of Alzheimer's Disease and Related Disorders (Alzheimer Hellas), in close cooperation with the partners of the 'S.IN.CA.L.A. II – Supporting Informal Carers: A Whole-Family & Life course Approach' project.

Developed by Alzheimer Hellas:

- Mahi Kozori, Psychologist, Research Associate
- Magda Tsolaki, Neuropsychiatrist, Professor, AUTH, President of the Panhellenic Federation of Alzheimer's Disease, Coordinator of the Laboratory of Neurodegenerative Diseases (KEDEK)

Project partners:

- Women's Support and Information Centre (WSIC) - Estonia
- University of Tartu (UT) - Estonia
- Union of Women Associations of Heraklion Prefecture (UWAH) - Greece
- Greek Association of Alzheimer's Disease and Related Disorders (Alzheimer Hellas) - Greece
- Anziani e Non Solo - Italy
- Centro de Atendimento e Servicos 50+, Associacao - Portugal
- Spominčica (Forget-me-not) – Alzheimer Slovenia - Slovenia

CONTENTS

INTRODUCTION

Background of the project

In Europe, 80% of all chronically ill people are taken care of by informal carers – people who provide unpaid care outside of a professional or formal framework. While caring for a loved one can be a source of great personal satisfaction, it also creates challenges, like physical and mental health problems, a feeling of social exclusion, difficulty in balancing paid work with care responsibilities and other possible financial worries (Eurocarers).

Although, when a family member has a chronic illness or disability, one of the relatives often acts as the “primary care provider”, in which roles are often reversed (i.e. a child taking care of their parent) which often affects all family members (Wright & Leahey, 2000).

> A functional relationship among caregivers and care recipient is the key for a successful change of roles and the adaptation of the family, therefore, supporting only the primary carer is not enough. Furthermore, people belonging to different age groups and with different kinships to the care-recipient (young/adult children, grandchildren, spouses) can have different experiences and perspective on the burden of care, so it is necessary to take all of them into account in order to be able to provide comprehensive and effective support.

Research has also demonstrated that the caregiver stress that often arises in informal caregiving situations can lead to situations of abuse. Almost 10% of older people who are cared for by family caregivers are at risk of elder abuse (Ananias & Strydom, 2014).

From a family-resilience perspective, families are regarded as a unit with intrinsic strengths and resources, and potential for growth (Black & Lobo, 2008; Zauszniewski et al., 2010), with positive relational bonds and connections between family members being integral to maintaining their ability to weather adversity (Walsh, 2016). However, it should be considered that resilient abilities are not innate, but can and should be learnt and cultivated through dedicated pedagogical methods, such as that of the therapeutic narrative. In order to respond to all these needs, the partnership believes in the importance of developing and piloting a model of pedagogical interventions based on a family-focused approach able to identifying strengths as well as vulnerabilities of all family members, addressing the challenges that might arise from the disease and building individual and family resilience.

The SINCALA II project

The "Supporting Informal Caregivers: A Whole Family & Life course Approach – SINCALA" 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 partnership will build upon the work started within the Erasmus+ funded SINCALA project started in 2018. Within this previous project, work was begun on developing family-focused pedagogical interventions that would identify the strengths and vulnerabilities of family members in caregiver situations. As a result, the intervention was intended to build individual and family resilience. Due to financial problems with the original lead partner, this previous incarnation of the project was ended prematurely, however, they did complete a report on the needs and experiences of families in informal caregiving situations. The report has given specific suggestions on how to make our proposed pedagogical intervention more applicable to our partner countries. In SINCALA II, we shall finish development of the intervention and pilot it in the same partner countries. In recognition that such an intervention will almost certainly uncover complicated issues (such as domestic violence/elder abuse), we will also create a guide for facilitators of the intervention to instruct them on how to identify and respond to situations of domestic violence, caregiver burnout and to ensure adult safeguarding. Finally, we will create an online version of the materials (MOOC) to greatly increase the reach of this initiative.

> “ 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 Alzheimer Hellas, and will be adapted and transferred to all other country contexts. The main practical results expected on the completion of the project are: (1) a tested narrative based workshop for informal caregivers, adapted to different EU-country contexts, and targeting households who are caring for older dependent family members with the goal of increasing their family-resilience; (2) guide for professionals to identify and address issues that emerge from workshops; (3) a MOOC, to transfer the results achieved and the lessons learnt to a wider audience of professionals; and (4) E-course and online educational platform for informal care givers and professional support providers.

We, therefore, expect to make available a methodology that educators, social workers and carer support workers can use in their local contexts to engage with families with caring responsibilities in order to improve the resilience of the household and mitigate the negative impacts of caring in the households.

The project is coordinated by NPO Women’s Support and Information Center (domestic violence org, Estonia) and developed by a diverse partnership of NGOs working with older persons and their carers or domestic violence victims in Portugual (CASO50+), Italy (Anziani e non solo), Slovenia (Spominčica, Slovenia) and Union of Women’s Association in Heraklion Prefecture (Greece, Creta). The expert partner, is the Greek Association of Alzheimer’s Disease and Related Disorders (Alzheimer Hellas). University of Tartu will be responsible for developing & managing the MOOC for the project due to its strong expertise on designing and developing e-learning courses.

For professionals and stakeholders, we expect an increased consciousness of how providing care can impact on the whole family and the capacity to use this deeper understanding to improve and innovate their services, including through the introduction of narrative techniques. On local stakeholders and communities, we expect an increased awareness of the challenges of caring at societal level and on innovative experiences and practices carried out in other countries that could be of inspiration for new policies and services. We also expect increased openness towards other European countries and cultures, increased awareness of the importance to adopt a whole-family approach and an increased awareness about the contribution of the European Union activities towards the support to informal carers.

Purpose and scope of this document

This document is part of the first Intellectual Output of the project and is considered a draft of the guidelines for the adapted Listen to my story workshops. Alzheimer Hellas, who is the leader partner of this intellectual output, have drafted the guidelines of the adapted workshops in English, combining the experience gained by implementing the original workshops and taking into account the results of “Tell me about you” report of family members’ needs and experiences of caring role from the previous SINCALA project. All project partners have provided their feedback, in order to ensure a good quality document.

This document will be used as the main training material for the online ‘Train the trainers’ workshop that will be organized by Alzheimer Hellas. Participants in the training event will then use these guidelines to adapt and implement the workshops as facilitators in their respective countries. After facilitators and caregivers provide their feedback on the implementation of the workshops, the partnership, under the coordination of Alzheimer Hellas, will release the finalized guidelines.

The final version of this document is expected to be read together with the Guide for professionals to identify and address issues that emerge from “Listen to my story” workshops, that will be the result of Intellectual Output 2. The guide will introduce basics concepts of domestic violence, including its various forms (physical, psychological, financials, etc.), risk factors and warning signs. It will also introduce the concepts of caregiver burden and burnout and how these link to violence and abuse. The guide will describe how best to respond to cases of violence, according to the specific circumstances: if the abuser is the recipient or carer; if the relationship is between partners or between parent/child; living conditions (such as whose house they live in); and/or the health status of the care recipient. The guide will also cover how these responses can be used to safeguard the wellbeing of elderly care recipient.

LISTEN TO MY STORY WORKSHOPS

Theoretical Background

The stress of a chronic health condition or disability of a family member can impact on families as a whole, 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. A primary threat to communication is the repression of affect, when family members suppress negative feelings like being overwhelmed, guilt, uncertainty, conflict and confusion within relationships associated with their situation. Moreover, carers have difficulty of orally express their feelings to their social network or even a classic support group due to personal limitations or the environment itself.

> “ Being able to openly express these feelings and share emotions can build caregivers’ resilience. ”

As shown by recent studies, art can be an easier way for caregivers to externalize their variety of feelings concerning their role. Art in general and creative arts-based interventions for caregivers are well known for their therapeutic effects. In recent studies, art and music therapy have a positive effect on caregivers in enhancing self-care (Murrant et al., 2000), expressive writing has helped caregivers to adapt to their role in a more efficient way (Caldwell et al., 2005), and also have improved their physical health by helping reducing anxiety (Mackenzie et al., 2007). In a study using a poetry reading intervention to people with dementia and their caregivers have showed that poetry may help enhance self-esteem, cope with loss, gain better understanding of others and their experiences or create meaning and also poetry had also subjective benefits such as achievement, catharsis, increased acceptance and self-awareness, greater empathy, reflection, fun and creativity, helping others, and positive challenge (Kidd et al, 2011). Additionally, poetry reading enhances wellbeing, while the creation of poetry improves communication (Swinnen, 2014). In another study, written emotional expression enhanced the ability to find meaning in caregiving for dementia family caregivers. Enhanced meaning-making abilities can have psychological benefits for caregivers, such as burden relief (Butcher et al, 2016).

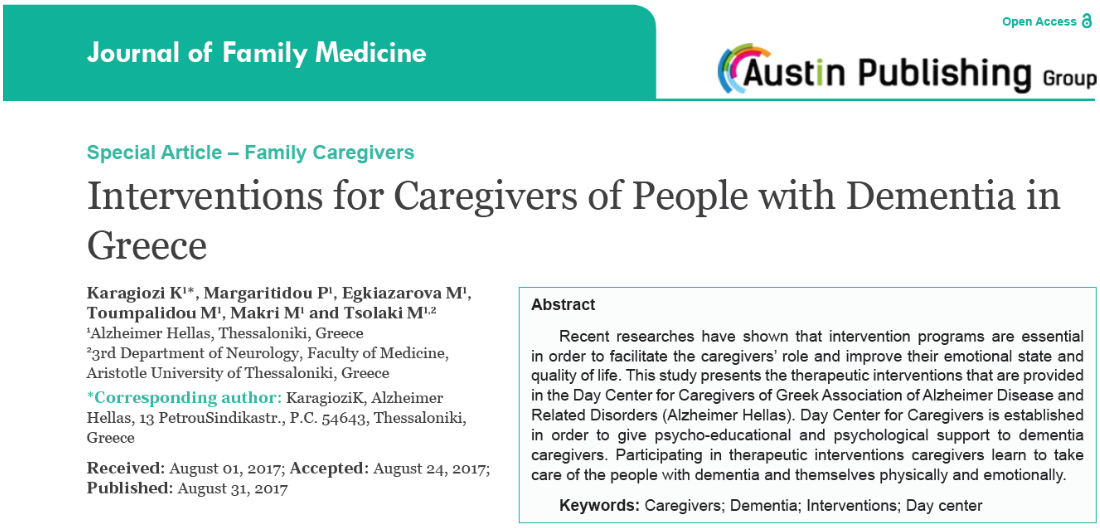
Useful Terms

Below, there are some useful terms that can help deepen the knowledge and understanding of the theoretical background of the workshops.

- Expressive writing is writing with the purpose of putting your own deepest feelings and thoughts into words. In Expressive writing, the focus is on expressing personal emotional experiences and there are no grammar, spelling or syntax rules. Expressive writers are free to choose whatever style or structure they feel more comfortable, without worrying about having a text with begging, middle and ending. The ultimate goal is that by letting go of restrictions of writing rules, expressive writers could have a deeper connection with themselves and their emotions, allowing their “inner voice” to surface (Butcher et al., 2016).
- Narrative learning falls under the larger category of constructivist learning theory, which understands learning as construction of meaning from experience. Narrative Learning highlights the role of narrative and narration in an individual learning and an understanding of how they act in the world. The ‘interior conversations’ whereby a person defines their personal thoughts and courses of action and creates their own stories and life missions, is situated at the heart of a person’s map of learning and understanding of their place in the world. Constructing a narrative for ourselves enables us to deal with an experience. An example would be responding to a trauma by constructing a narrative of restoration and strength, as opposed to a narrative of victimization or struggle. Narrative is also how we craft our sense of self, our identity. Understanding identity as a narrative construction is another way of conceptualizing personal change. Randall (1996) in fact describes transformative learning as a process of re-storying. An example would be a care professional at risk of burn out that start the reconstruction of his caring role through self-narration.
- User-led approach: User led design and implementation means that the users are involved throughout the design and development of all our outcomes. Actively involving formal and informal carers, care-managers, academics, and citizens throughout the process allows for a clear understanding of the problem at hand. Also, the active involvement of the user means feedback can be integrated into the design.
- Entertainment Education: is a process of purposely designing and implementing a media message to both entertain and educate, in order to increase audience knowledge about an educational issue, create favorable attitudes, and change overt behaviors. (Singhal & Rogers, 1999)
- Socio-drama: The term “sociodrama” refers to several theater techniques (such as narrative techniques) used in educational and training settings. Sociodrama implies the utilization of some form of theater or dramatic technique in order to approach or deal with a social issue or topic that impacts society on some level.

‘Listen to my story’ original intervention in Alzheimer Hellas

Caregivers Unit of Greek Association of Alzheimer's Disease and Related Disorders (Alzheimer Hellas) in Thessaloniki, Greece developed a support group using poetry and literature as stimuli 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.



Journal of Family Medicine

Open Access

Austin Publishing Group

Special Article – Family Caregivers

Interventions for Caregivers of People with Dementia in Greece

Karagiozi K[1]*, Margaritidou P[1], Egkiazarova M[1], Toumpalidou M[1], Makri M[1] and Tsolaki M[1,2]
[1]Alzheimer Hellas, Thessaloniki, Greece
[2]3rd Department of Neurology, Faculty of Medicine, Aristotle University of Thessaloniki, Greece

***Corresponding author:** KaragioziK, Alzheimer Hellas, 13 PetrouSindikastr., P.C. 54643, Thessaloniki, Greece

Received: August 01, 2017; **Accepted:** August 24, 2017; **Published:** August 31, 2017

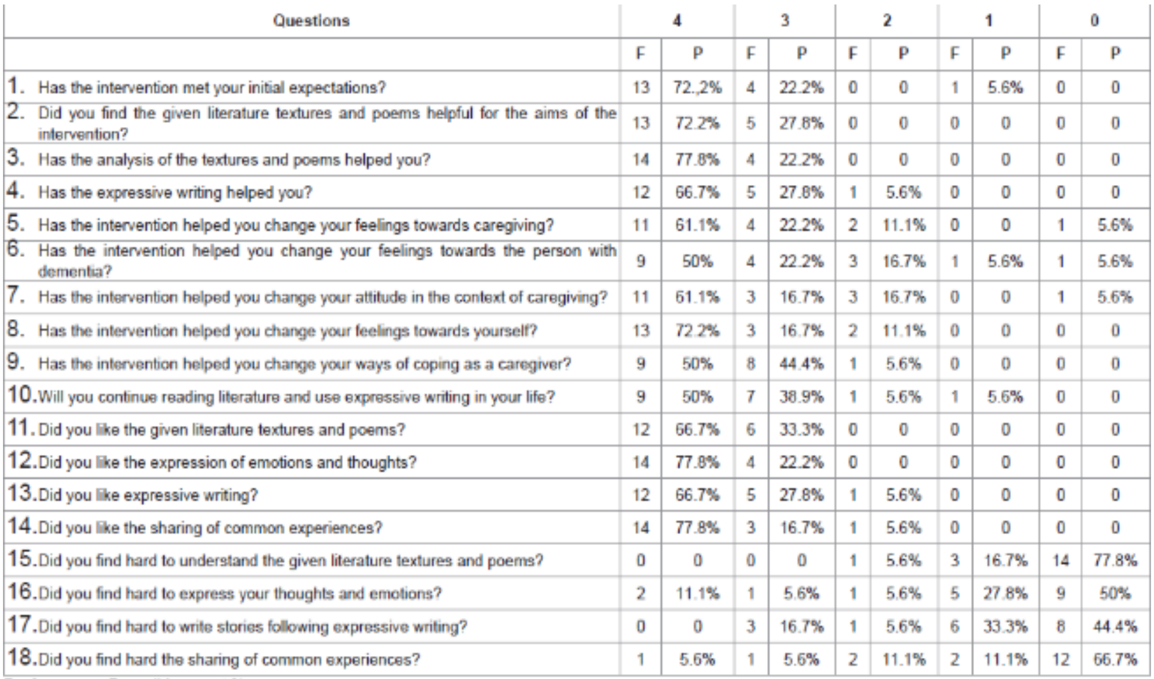
Abstract

Recent researches have shown that intervention programs are essential in order to facilitate the caregivers' role and improve their emotional state and quality of life. This study presents the therapeutic interventions that are provided in the Day Center for Caregivers of Greek Association of Alzheimer Disease and Related Disorders (Alzheimer Hellas). Day Center for Caregivers is established in order to give psycho-educational and psychological support to dementia caregivers. Participating in therapeutic interventions caregivers learn to take care of the people with dementia and themselves physically and emotionally.

Keywords: Caregivers; Dementia; Interventions; Day center

For the last 4 years, a group of caregivers meet with two expert psychologists weekly, in the same room and at the same day and time every week. On each session, that lasts about 90 minutes, the group first reads a text literature or poem selected by the psychologists. 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, psychologists ask caregivers to try to associate arising feelings with something they have felt or experienced in their everyday life with their patient with dementia. 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. Although many reports being upset during writing (and often crying), they also find it meaningful and valuable, leaving the sessions feeling deliberated. (Karagiozi et al., 2017)

To explore the effects of the intervention, the Caregiver Unit of Alzheimer Hellas conducted a clinical study with a group of caregivers who attended 30 sessions (over a span of a year). 18 participants with different age, education, family status and kinship with the patient attended the intervention and at the end they answered a 5-point Likert Scale (Very High to Very Low) questionnaire about the effectiveness of it. The results, as seen in the table below, showed that participants found the intervention very helpful to their overall experience as caregivers. (Karagiozi et al., 2017)



Questions	4		3		2		1		0	
	F	P	F	P	F	P	F	P	F	P
1. Has the intervention met your initial expectations?	13	72.,2%	4	22.2%	0	0	1	5.6%	0	0
2. Did you find the given literature textures and poems helpful for the aims of the intervention?	13	72.2%	5	27.8%	0	0	0	0	0	0
3. Has the analysis of the textures and poems helped you?	14	77.8%	4	22.2%	0	0	0	0	0	0
4. Has the expressive writing helped you?	12	66.7%	5	27.8%	1	5.6%	0	0	0	0
5. Has the intervention helped you change your feelings towards caregiving?	11	61.1%	4	22.2%	2	11.1%	0	0	1	5.6%
6. Has the intervention helped you change your feelings towards the person with dementia?	9	50%	4	22.2%	3	16.7%	1	5.6%	1	5.6%
7. Has the intervention helped you change your attitude in the context of caregiving?	11	61.1%	3	16.7%	3	16.7%	0	0	1	5.6%
8. Has the intervention helped you change your feelings towards yourself?	13	72.2%	3	16.7%	2	11.1%	0	0	0	0
9. Has the intervention helped you change your ways of coping as a caregiver?	9	50%	8	44.4%	1	5.6%	0	0	0	0
10. Will you continue reading literature and use expressive writing in your life?	9	50%	7	38.9%	1	5.6%	1	5.6%	0	0
11. Did you like the given literature textures and poems?	12	66.7%	6	33.3%	0	0	0	0	0	0
12. Did you like the expression of emotions and thoughts?	14	77.8%	4	22.2%	0	0	0	0	0	0
13. Did you like expressive writing?	12	66.7%	5	27.8%	1	5.6%	0	0	0	0
14. Did you like the sharing of common experiences?	14	77.8%	3	16.7%	1	5.6%	0	0	0	0
15. Did you find hard to understand the given literature textures and poems?	0	0	0	0	1	5.6%	3	16.7%	14	77.8%
16. Did you find hard to express your thoughts and emotions?	2	11.1%	1	5.6%	1	5.6%	5	27.8%	9	50%
17. Did you find hard to write stories following expressive writing?	0	0	3	16.7%	1	5.6%	6	33.3%	8	44.4%
18. Did you find hard the sharing of common experiences?	1	5.6%	1	5.6%	2	11.1%	2	11.1%	12	66.7%

F = frequency; P = valid percent %.

Participants found the intervention very helpful to their overall experience as caregivers. Some of the more important results include:

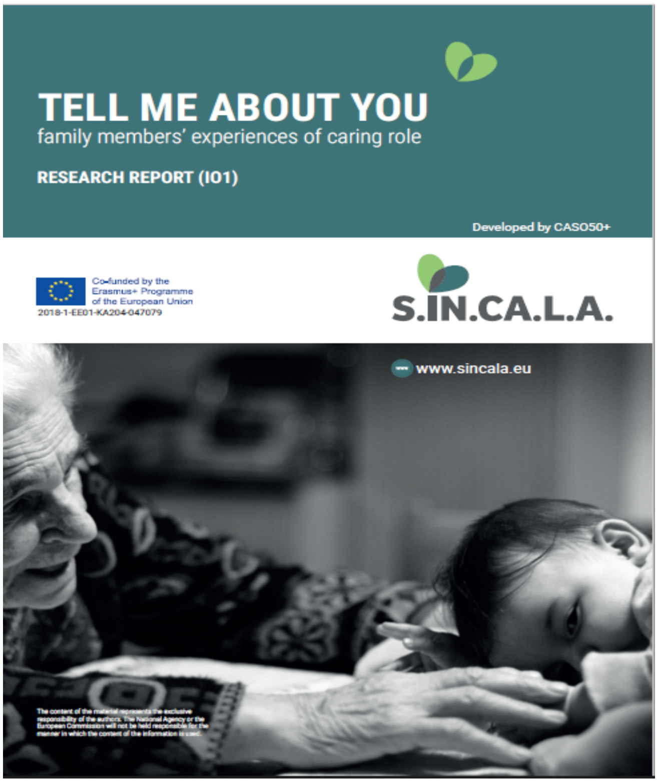
The majority of caregivers found the intervention very helpful concerning their attitude towards caregiving (61.1%), the PwD (50%), the way they cope with difficult situations (50%) and the way they feel about themselves (72.2%). Given literature texts and poems were perceived as helpful by the participants (72.2%). The intervention has met participants' initial expectations (72.2%). The activities liked the most were the expression of their emotions and thoughts (77.8%) and the sharing of common experiences (77.8%). The majority of the participants didn't have difficulties in any part of the intervention, although some of them were unclear about expressive writing (16.7%). (Karagiozi et al., 2017)

> “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)”

Some limitations to this study were the small size of the sample and the lack of control group. So, further research should be done on this field in order to generalize these results and to study in depth the effectiveness of literature reading and expressive writing in caregivers of older people. (Karagiozi et al., 2017)

RECOMMENDATIONS FOR NARRATIVE WORKSHOPS FROM ‘TELL ME ABOUT YOU’ REPORT

The “Tell Me About You – family members’ experiences of caring role” Report outlined the experiences and needs of families with a caring role in six countries: Estonia, Greece, Ireland, Italy, Portugal and Slovenia. Researchers explored with focus groups of 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 explored how caring can have different impact on carers from different kinship groups (spouses / adult children / grandchildren); 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.



TELL ME ABOUT YOU
family members’ experiences of caring role

RESEARCH REPORT (IO1)

Developed by CASO50+

Co-funded by the Erasmus+ Programme of the European Union
2018-1-EE01-KA204-047079

S.IN.CA.L.A.

www.sincala.eu

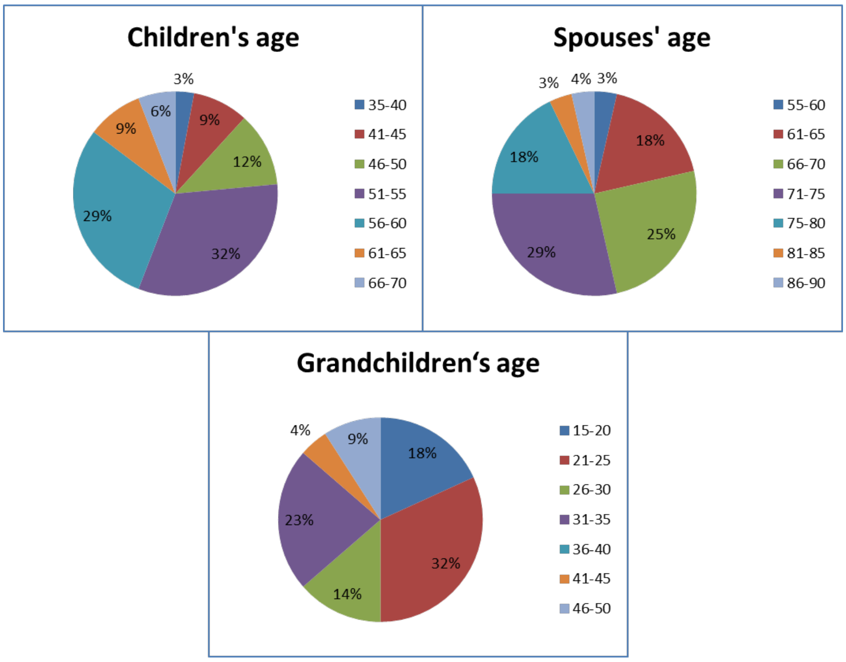
The content of the material represents the exclusive responsibility of the authors. The National Agency or the European Commission will not be held responsible for the manner in which the content of the information is used.

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.

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

Table 2. Participants' age



Taking into consideration the findings of this research report “Tell me about you: family members’ experiences of caring role”, the partnership will develop a programme based on narration and expressive techniques in order to help caregivers to express their feelings, to help them make meaning of their experiences and to become more aware of their situation as carers. 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.

Inclusion 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.

‘LISTEN TO MY STORY’ WORKSHOPS IN SINCALA PROJECT

SINCALA partnership has planned Intellectual Output 1 (IO1) to be focused on adaptation of the original "Listen to my story" intervention of Alzheimer Hellas, with the aim to adapt it to respond to specific needs of different generations of informal caregivers (spouses / adult children / grandchildren), 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.

After the report "Tell me about you" of the initial project, SINCALA consortium has a clearer view of the needs and experiences of families with caring role and, thus, their expectations from the workshops. Based on this report, the partnership will develop a programme based on narration and expressive techniques in order to help caregivers to express their feelings, to render their experiences meaningful and to familiarize themselves with their situation.

Moreover, 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 of the targeted group in terms of age and type of kinship with the person they care for. We believe that each group will be related to specific issues. For example, the workshop for spouses can be more focused on loss, that for adult children is expected to deal with sense of guilt and reconciliation, while that for grand-children will be more focused on understanding the illness and reshaping the relationship with their loved one on a new basis.

Each of the three workshops will be based on 3 to 5 sessions of approximately 90 minutes each and will be tested with at least 18 informal caregivers per partner (6 per group). Each session will have adapted content, but will be based on the structure of the original programme of Alzheimer Hellas, as described above: caregivers will be given a text literature or a poem and they share thoughts and feelings that arise spontaneously. After this, they will be asked to associate these arising feelings (for example sadness, satisfaction, stress, anger, happiness) with something that they have felt or experienced in their daily life with the care-recipient. At the end of each session, caregivers will write their own stories using expressive and spontaneous expressive techniques, like writing but also drawing, movement, photography and video.

In order to achieve the aforementioned outcomes, this first Intellectual Output will follow the next steps:

- Adaptation of existing programme to fit the aims of this project and drafting of the adapted guidelines by Alzheimer Hellas, taking into account the results of initial needs report from previous project and the feedback from all partners.

- A 3-day Train the trainers session by Alzheimer Hellas, with the goal for all partners to acquire the necessary skills and tools to adapt and implement the Listen to My Story workshops in their own countries.
- Development of the local adapted versions of the workshops for each country. All partners will adapt the workshops to their national contexts, choosing, for example, different literature texts and poetry.
- Piloting of the workshops in the countries of the project with at least 18 carers per country from three groups (spouses/children/grandchildren). Feedback on the workshops will be collected from the participants immediately afterwards.
- Evaluation and Finalization of workshop materials: Follow-up Interviews will be conducted with the facilitators of the pilot workshops (from task 1.4) to understand what worked best and to identify any difficulties that arose. Feedback from participants will also be analyzed to understand their perception of the workshop and what their satisfaction level is with the experience. Based on this, changes will be made to the workshop. The final workshop description and guidelines will be fine-tuned by all partners and then released in electronic format in all partner languages and made available through the project website.

The workshops guidelines are expected to be read together with the methodological guide that will be developed in IO2 and, thus, provide professionals across Europe with the skills to apply the workshops in more services and countries. This will support transferability and exploitation of the IO beyond the scope of the implementing partnership.

GUIDELINES FOR ‘LISTEN TO MY STORY’ WORKSHOPS:

Objectives

The main objectives that facilitators should have in mind when planning and implementing the workshops for informal caregivers are to help them:

- to express their feelings,
- to make meaning of stressful experiences,
- to render their experiences meaningful and
- to familiarize themselves with their role as caregivers.

Facilitators

Professionals working in informal carers support who will act as facilitators of the ‘Listen to my story’ workshops may have diverse academic and professional background, such as for example: psychologists, social workers, nurses, community workers, social educators. However, it is preferable to have a good professional experience in working with informal caregivers, because of the specific experiences and needs that arise from their caregiving role and will be addressed during the workshops.

One professional can deliver this workshop, but we propose to have two facilitators, because of the number of participants in the group and the needs that may surface. Moreover, the two facilitators can support, reflect, correct and encourage each other when delivering the workshops. It is also important for trainers to provide constructive feedback to each other.

Facilitators should encourage participants to be open to the activities included in the workshops and willing to participate. To achieve this, it is important that facilitators encourage people to participate and reassure them throughout the sessions. Their efforts should be focused on creating a safe and non-judgmental environment, where caregivers will be able to openly express themselves.

Facilitators are also likely to need a good understanding of the personal interests and backgrounds of the participants so that the approach can be tailored accordingly. This will require excellent interpersonal skills as well as a good understanding of each other's feelings or ideas, and rapport with the participants.

It is essential that facilitators maintain an open channel of communication with the caregivers even after the workshops. This will not only help caregivers to feel supported, but also facilitators to better plan for each session.

As during these workshops, many different feelings can arise, it is of vital importance that facilitators provide the participants with information they may need about where to find extra (professional) support, such as psychological, educational etc. Also, facilitators should make sure they will be able to follow-up with the participants and make clear to them that they will be available for help even after the end of the intervention.

Another important tip for the facilitators is that they should refrain from talking to participants about the author of the stimuli, their CV and the circumstances they wrote the text/poem under. If participants hear this information before reading the literature text/poem, their thinking may be limited by what the author's intention was.

Participants

Participants in the 'Listen to my story' workshops will be informal caregivers of older people. There will be three groups of family caregivers, as previously identified within the SINCALA II project, namely spouses, adult children and young grandchildren of the care recipients.

Participation will be on a volunteer basis, after a call for participants that facilitators will launch before the implementation of the workshops.

The minimum number of participants in the workshops within the SINCALA project will be 6 per group, for a total of 18 per country (12 in Estonia, due to its smaller size). In general, number of participants should be guided by the appropriateness of the space and specific requirements of the group.

Inclusion criteria for participating in the 'Listen to my story' workshops will be:

- being 16+
- being an informal carer of an older person for at least 6 months
- providing care at least in one Activity of daily living (ADL) -basics or instrumental- or in supervision
- being able and willing to share their experiences about informal caregiver role with the other participants.

Social inclusion

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. In such cases, the second facilitator or trained volunteers can help the participant/-s with writing down their thoughts and feelings.

Some informal carers could face some difficulties in participating to the workshops. For example, spouses are likely to be older themselves, and they might have physical impairments such as visual, hearing or mobility impairments because of age. Should this be the case, facilitators should take precautions such as: venues with no access barriers for people with physical impairments; activities should be conceived to be adapted to people with physical impairments (for example, should an activity require standing up, an alternative can be used in case of participants with mobility impairments, for example preventing them to stand up); all written material should be designed with attention to usability, for example fonts and graphics will be conceived for facilitated reading for people with visual impairments etc. Concerning people with hearing impairments, facilitators can support communication by adopting recommended strategies such as face the hearing-impaired person directly; speak clearly, slowly, distinctly, but naturally, without shouting or exaggerating mouth movements; try to minimize extraneous noise when talking etc.

As far as adult informal carers are concerned, the main obstacle will most likely be a lack of time. Full time carers might have difficulties in leaving their care-recipient to attend a workshop. In this case, facilitators should make sure that the scheduling of activities will be flexible, held on days and times (such as weekends and evenings) in which carers could find short term replacements (such as other relatives). Also in some sites, it might be possible for informal carers to take their care-recipient with them. For example, offering a room where the care recipient can wait with the supervision of trained staff or even participate in activities and interventions specifically designed for them.

Concerning younger carers, special care should be taken in order to make sure that they can easily access the workshops, for example as far as scheduling (making sure it doesn’t overlap with school hours or other activities).

For all participants, it is advised that locations that are easily accessible by public transportation should be used.

Team bonding

The groups that will receive these workshops will be cohesive, in the sense that they have a clear and easily identifiable common bond: the role caregiving for a loved one. It is expected that they will feel connected once they start talking about why they are attending the workshops and share common experiences.

There are many cases in which informal caregivers experience social isolation as a result of their caring role. This intervention should be able to promote an environment where the participants feel safe and comfortable to share their experiences 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.

Through observation of the groups at Alzheimer Hellas over the years, it is possible that there will be friendships between member of the groups that will last even after the end of the workshops.

Time

For this project's piloting phase, we propose to have 5 sessions, because we expect them to be enough for participants and facilitators to familiarize themselves with the intervention and start to feel/see some results. In general, the workshops with weekly sessions can last as long as the facilitators deem necessary and have new stimuli (up to 1-2 years or more).

Meetings of the group will be weekly, at the same day and time every week, that will be agreed on among facilitators and caregivers. In an effort to create a safe environment, it is important that facilitators as well as participants respect the time of the meetings and in case of absence, they inform as soon as possible.

Each session will last about 90 minutes.

Caregivers should be aware of the length of each session (90 mins) and the duration of the workshops (5 over the span of 5 weeks) before they agree to take part in the intervention.

The timing of the sessions is described in detail in the structure part of these guidelines, but facilitators should keep in mind that every group and every session can be different in terms of topics that need to be addressed and time that need to be dedicated to them. So, timing can be adaptable during the sessions, but always respecting everyone's schedule and trying to meet the agreed time session needs to be ended.

Setting

The setting for the workshops should be a well-lit, quiet room, appropriate for the numbers attending, with particular attention given to wheelchair and mobility needs. Comfortable seating is important.

The group will be sitting in a circle. It is also important to have the exact number of chairs according to the number of the participants that will attend each meeting, in order to avoid empty chairs that may cause discomfort to some participants.

Another important thing to keep in mind is that facilitators ensure the privacy of the room, avoiding any disturbances or interruptions. Participants in this group may share deep personal feelings that do not want to be heard by someone outside the group.

If there are any people who will be present for educational reasons and will not actively take part in the intervention (e.g. volunteers, trainees), facilitators should introduce them to the group in the beginning, explaining the reason of their presence, but they should be seated outside of the circle.

If it is needed, the sessions can be held online. Facilitators can set up unique links for each group in their preferred platform and help the participants connect. All participants should be encouraged to have their cameras on, so they can meet each other even in an online form and build bonds. The structure of the online sessions will not change much, except for the stimuli will be shared electronically and not printed and also the writings of the participants can be sent to the facilitators by photo after the end of each session.

Materials needed

Before each session, facilitators should be sure they have printed enough copies of the literature text or poem to share with the participants and enough paper sheets and pens/pencils for them to write with.

Preparation

Before the start of the workshops, at least one of the facilitators should have a one-to-one meeting with each caregiver, in order to plan and be better prepared for the sessions. During this meeting, facilitator should explore if there are any special requirements (see Participants section) and attempt to make arrangements so that they can participate. In addition, facilitator should explore participant’s caregiving experiences, in order to identify the main concerns/ constraints/ obstacles and encompass and relate those with the material to be used during the sessions.

Stimuli

The stimuli can be either a literature text or a poem. Facilitators should have a pool of stimuli to choose from for each group, according to the specific experiences and needs of the participants, that emerge from the individual preparatory meetings and also the sessions. It is helpful to have a variety of stimuli pre-prepared, but facilitators should keep in mind that in many cases they may need to change their scheduled stimuli to better meet the emerging needs of their group.

Moreover, facilitators should take into account the caregiving culture of each country, in order to choose texts or poems that caregivers could connect more effortlessly to. Over the span of the workshops, facilitators should choose literature texts or poems with an increasing difficulty of meanings.

It is not necessary that the stimuli have an immediate connection to a topic the facilitators have in mind (e.g. dementia), as we can never be sure about the thoughts, experiences and feelings that may arise.

However, facilitators should try to distinguish the different caregivers' groups by choosing texts or poems that have the most possibilities of stimulating topics related to each group. Different topics can be identified in recent studies and in the "Tell Me About You – family members' experiences of caring role" Report. In fact, the choice of stimuli is what mainly distinguishes the three different workshops, as described below.

Workshop for spouses

In most countries, for spouses, becoming a caregiver seems 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. As rewarding as this could be, difficulties and challenges of caregiving may arise. 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 spouses can experience. In general, spouses receive only very occasional support from other family members, sometimes because they try to protect their children by keeping information from them. 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, needs to be integrated into a narrative that brings sense to the situation in which the spouses are involved in.

> “Literature stimuli for spouses can focus on topics like love, marital relations, sense of duty and loss.”

Workshop for adult children

In general, adult children perceive their role as carers of their parents as a way to reciprocate what they have done for them in the past. Among children, the lack of support from other members of the family (e.g. their siblings take on more of a visiting role) is common. Adult children usually present issues with adapting to the caregiving situation, in that it requires them to negotiate with siblings, spouses or their own children around care provision to facilitate them to work or have a life outside of caregiving to a parent. Also, the change of roles between adult children and parents who now require their care can result in complex feelings, sense of loss and conflicts.

> “Some topics that could be used in the stimuli for the workshops for adult children are: anger, frustration, resentfulness, reciprocation, obligation, parental relationships, guilt and acceptance.”

Workshop for grandchildren/young carers

As grandchildren tend to share the caregiving role with someone else (e.g. another family member), their relationships with their grandparents may vary. On one hand, their grandparents may have difficulty in accepting care from them at first, but this situation 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 can feel that their caregiving role resulted in developing a closer relationship with their grandparents. 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 (either positive by bringing the family members closer or negative by growing apart). A unique challenge that grandchildren my face is also worrying about the wellbeing of their parents. In this sense, their focus is to help their parents, stepping into their shoes, in order to provide support.

> “Topics proposed to be included in the workshops for grandchildren are emotional wellbeing, time management, social life, life planning and relationships.”

Structure

1st session

- STEP ONE (5 mins)

Facilitators introduce themselves if they are not known to the group. Facilitators explain to the group that they are a group of caregivers that are going to partake in an intervention that uses expressive writing techniques, which involves sharing ideas, experiences, deep thoughts and feelings. They can contribute as much as they feel comfortable to, but facilitators should encourage them to be open and willing to share, because they are in a safe environment with people that may have similar experiences with them.

After that, the facilitators explain the rules of the group:

They kindly ask the carers to be consistent with the time, as we have to respect the each other's time. Of course, emergencies can happen and will be perfectly understandable, but if they know beforehand that they will miss a session or be late, it is better to inform the facilitators. Also, facilitators highlight that this group is a safe environment, where no one should judge or be offensive to anyone, as every idea, thought or feeling is valid. Finally, facilitators state that everyone should respect confidentiality: what is talked about in group stays in the group.

- STEP TWO (5 mins)

Pass String- Name & 'How are you today?'

The group is in a circle and begins by passing a ball of wool around from participant to participant. When each participant receives a length of the wool, it can be looped around their thumb/ finger and they can reveal their name and how they are feeling today.

The facilitator cuts the string after the final person and explain that this links all the participants as a group, because we can see the many lines that connect us all. After that, facilitator wraps the piece of wool that was used and puts it

This exercise can be done while the group are in a circle, sitting or standing. If there are mobility restrictions among the group, the facilitator can be the one who share the string around participants randomly, giving a criss-cross effect.

Tip: you can store this particular piece of wool from each group and have it at a point where everyone can see it (eg. the table you use for the papers), so that participants can be silently reminded of the moment they shared in their first meeting.

STEP THREE (5 mins)

Introduction: The first session should begin with members of the group introducing themselves and sharing why they are in this group. Facilitators can help with questions like “Would you like to share with the group who you are caring for? For how long? What is your living situation?” etc. This way, caregivers are able to get to know each other, connect and create a trusting relationship.

STEP FOUR (10 mins)

Learning about the techniques and structure that will be used in the session

Facilitators should now explain in a simple way, but in detail what they will be doing during the workshops. They will firstly share a literature text (or poem) with the group, they will read it together, the group will discuss about it and then they will ask from each participant to write something about it. Facilitators make the clarification that the discussion will not be a literary analysis of the text, but rather a spontaneous sharing and discussion about what are the first thoughts and feelings after reading it. Also, they clarify that in the writing part, caregivers should try to give voice to their thoughts and emotions and using expressive and spontaneous writing.

As most of the caregivers will not know what expressive and spontaneous writing is, facilitators should explain this technique in a way that everyone will understand and be open for further questions. For example, they can say that “Expressive writing is writing with the purpose of putting your own deepest feelings and thoughts into words. In expressive writing, the focus is on expressing personal emotional experiences and there are no grammar, spelling or syntax rules. Expressive writers are free to choose whatever style or structure they feel more comfortable, without worrying about having a text with begging, middle and ending. It can be just words unlinked to each other written on a paper. Whatever is going through your mind right now, even if it is not linked to the text, we just read.”

STEP FIVE (20 mins)

Facilitators pass across the circle a copy of the literature text or poem they have chosen for that particulate day. For the group of spouses especially, where the participants may be of an older age, the font and graphics should be suited accordingly.

Tip: you can choose a smaller text for the first time, because of the extra activities you need to do.

Facilitators, then, ask if someone from the group would like to read the text out loud. If not, one of them can read it out loud one time and then allow participants to take another look at it for 2-3 minutes.

Immediately after that, facilitators start the discussion about the text, reminding everyone of what they would like to be discussed and giving the time for everyone to express themselves. Questions that may help to facilitate the flow of the conversation can be, for example: “What do you feel / think after reading this text? Please, remember to talk in the first person about the feelings / thoughts that arose. Please, be free to share any feeling / thought or experience that comes to mind, even if it is not linked to the text, we just read. Did you find anything in the text that reminded you of something from your life or your caregiving experience?”

STEP SIX (20 mins)

Facilitators make a quick recaption of the main points discussed and announce that is now time for caregivers to write down any more they have using expressive writing. Once again, they remind briefly what expressive writing is and urge caregivers to try and write in the first person, about their feelings/thoughts and not in general. By doing so, the speech becomes personal, expresses our inner voice, allow us to take responsibility for our words and no one can disagree, because it is our experience.

Facilitators suggest everyone should start to wrap up their writings 1-2 minutes before it is time to move to the next step.

STEP SEVEN (25 mins)

Facilitators now ask for carers to share their writings with the group by reading it out loud. They ask who would like to go first and then they go around the circle, thanking everyone individually for sharing and making a small comment/conclusion after each reading. If anyone does not wish to share their writings, facilitators try to encourage them and remind them that this is a safe environment, but they respect their decision.

If there is time and/or need at the end of the session, facilitators can encourage a last small discussion be asking for example “Does anyone have to add something/ want to share anything else after hearing everyone’s readings?”

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. Facilitators should try to create a space where everything is valid.

END OF THE SESSION

Facilitators thank everyone for their presence, congratulate the group on a job well done and collect everyone’s writings.

After the participants leave the room, facilitators can put the writings in a folder with a copy of the stimulus and the date on it, for future reference.

Tip: Facilitators can use a different binder folder for each group and have their writings in different pockets in chronological order, so they can see the progress made.

- STEP ONE (10 mins)

Facilitators ask caregivers to remind the group of their names and tell them how they are feeling this particular day.

Then, they very briefly remind everyone of what they did last time and that they will use the same techniques and structure today.

- STEP TWO (30 mins)

Facilitators pass across the circle a copy of the literature text or poem they have chosen for that particulate day. For the group of spouses especially, where the participants may be of an older age, the font and graphics should be suited accordingly.

Facilitators, then, ask if someone from the group would like to read the text out loud. If not, one of them can read it out loud one time and then allow participants to take another look at it for 2-3 minutes.

Immediately after that, facilitators start the discussion about the text, reminding everyone of what they would like to be discussed and giving the time for everyone to express themselves. Questions that may help to facilitate the flow of the conversation can be, for example: “What do you feel / think after reading this text? Please, remember to talk in the first person about the feelings / thoughts that arose. Please, be free to share any feeling / thought or experience that comes to mind, even if it is not linked to the text, we just read. Did you find anything in the text that reminded you of something from your life or your caregiving experience?”

- STEP THREE (20 mins)

Facilitators make a quick recaption of the main points discussed and announce that is now time for caregivers to write down any more they have using expressive writing. Once again, they remind briefly what expressive writing is: “Expressive writing is writing with the purpose of putting your own deepest feelings and thoughts into words. In expressive writing, the focus is on expressing personal emotional experiences and there are no grammar, spelling or syntax rules. Expressive writers are free to choose whatever style or structure they feel more comfortable, without worrying about having a text with begging, middle and ending. It can be just words unlinked to each other written on a paper. Whatever is going through your mind right now, even if it is not linked to the text, we just read.” Also, they urge caregivers to try and write in the first person, about their feelings/thoughts and not in general. By doing so, the speech becomes personal, expresses our inner voice, allow us to take responsibility for our words and no one can disagree, because it is our experience.

Especially during the first sessions, participants may need constant reminders, in order to achieve expressive and spontaneous writing.

Facilitators suggest everyone should start to wrap up their writings 1-2 minutes before it is time to move to the next step.

STEP FOUR (30 mins)

Facilitators now ask for carers to share their writings with the group by reading it out loud. They ask who would like to go first and then they go around the circle, thanking everyone individually for sharing and making a small comment/conclusion after each reading. If anyone does not wish to share their writings, facilitators try to encourage them and remind them that this is a safe environment, but they respect their decision.

If there is time and/or need at the end of the session, facilitators can encourage a last small discussion be asking for example “Does anyone have to add something/ want to share anything else after hearing everyone’s readings?”

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. Facilitators should try to create a space where everything is valid.

END OF THE SESSION

Facilitators thank everyone for their presence, congratulate the group on a job well done and collect everyone’s writings.

After the participants leave the room, facilitators can put the writings in a folder with a copy of the stimulus and the date on it, for future reference.

3rd session

STEP ONE (10 mins)

Facilitators ask caregivers how they are feeling this particular day or how their day or week has been so far.

Then, they very briefly remind everyone of what they did last time and that they will use the same techniques and structure today. Alternatively, they can ask the group if someone would like to be the one that briefly reminds the techniques.

STEP TWO (30 mins)

Facilitators pass across the circle a copy of the literature text or poem they have chosen for that particulate day. For the group of spouses especially, where the participants may be of an older age, the font and graphics should be suited accordingly.

Facilitators, then, ask if someone from the group would like to read the text out loud. If not, one of them can read it out loud one time and then allow participants to take another look at it for 2-3 minutes.

Immediately after that, facilitators start the discussion about the text, reminding everyone of what they would like to be discussed and giving the time for everyone to express themselves. Questions that may help to facilitate the flow of the conversation can be, for example: “What do you feel / think after reading this text? Please, remember to talk in the first person about the feelings / thoughts that arose. Please, be free to share any feeling / thought or experience that comes to mind, even if it is not linked to the text, we just read. Did you find anything in the text that reminded you of something from your life or your caregiving experience?”

STEP THREE (20 mins)

Facilitators make a quick recaption of the main points discussed and announce that is now time for caregivers to write down any more they have using expressive writing. Once again, they remind briefly what expressive writing is: “Expressive writing is writing with the purpose of putting your own deepest feelings and thoughts into words. In expressive writing, the focus is on expressing personal emotional experiences and there are no grammar, spelling or syntax rules. Expressive writers are free to choose whatever style or structure they feel more comfortable, without worrying about having a text with begging, middle and ending. It can be just words unlinked to each other written on a paper. Whatever is going through your mind right now, even if it is not linked to the text, we just read.” Also, they urge caregivers to try and write in the first person, about their feelings/thoughts and not in general. By doing so, the speech becomes personal, expresses our inner voice, allow us to take responsibility for our words and no one can disagree, because it is our experience.

Facilitators suggest everyone wraps up their writings 1-2 minutes before it is time to move to the next step.

STEP FOUR (30 mins)

Facilitators now ask for carers to share their writings with the group by reading it out loud. They ask who would like to go first and then they go around the circle, thanking everyone individually for sharing and making a small comment/conclusion after each reading. If anyone does not wish to share their writings, facilitators try to encourage them and remind them that this is a safe environment, but they respect their decision.

If there is time and/or need at the end of the session, facilitators can encourage a last small discussion be asking for example “Does anyone have to add something/ want to share anything else after hearing everyone’s readings?”

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. Facilitators should try to create a space where everything is valid.

- END OF THE SESSION

Facilitators thank everyone for their presence, congratulate the group on a job well done and collect everyone's writings.

After the participants leave the room, facilitators can put the writings in a folder with a copy of the stimulus and the date on it, for future reference.

4th session

- STEP ONE (5 mins)

Facilitators ask caregivers how they are feeling this particular day or how their day or week has been so far.

Then, they very briefly remind everyone of what they did last time and that they will use the same techniques and structure today. Alternatively, they can ask the group if someone would like to be the one that briefly reminds the techniques.

- STEP TWO (20 mins)

Facilitators pass across the circle a copy of the literature text or poem they have chosen for that particulate day.

Tip: for this session, it might be helpful to choose a text that includes storytelling by a narrator or a well-known story told by a different point of view by one of the protagonists (e.g. the story of Little Red Riding Hood narrated by the Big Bad Wolf from his point of view).

Facilitators, then, ask if someone from the group would like to read the text out loud. If not, one of them can read it out loud one time and then allow participants to take another look at it for 2-3 minutes.

Immediately after that, facilitators start the discussion about the text, reminding everyone of what they would like to be discussed and giving the time for everyone to express themselves. Questions that may help to facilitate the flow of the conversation can be, for example: "What do you feel / think after reading this text? Please, remember to talk in the first person about the feelings / thoughts that arose. Please, be free to share any feeling / thought or experience that comes to mind, even if it is not linked to the text, we just read. Did you find anything in the text that reminded you of something from your life or your caregiving experience?"

- STEP THREE (15 mins)

Facilitators make a quick recaption of the main points discussed and announce that is now time for caregivers to write down any more they have using expressive writing. Once again, they remind briefly what expressive writing is: “Expressive writing is writing with the purpose of putting your own deepest feelings and thoughts into words. In expressive writing, the focus is on expressing personal emotional experiences and there are no grammar, spelling or syntax rules. Expressive writers are free to choose whatever style or structure they feel more comfortable, without worrying about having a text with begging, middle and ending. It can be just words unlinked to each other written on a paper. Whatever is going through your mind right now, even if it is not linked to the text, we just read.” Also, they urge caregivers to try and write in the first person, about their feelings/thoughts and not in general. By doing so, the speech becomes personal, expresses our inner voice, allow us to take responsibility for our words and no one can disagree, because it is our experience.

This time, though, facilitators ask for caregivers to remember a specific event/ a story of their experience with their care recipient and write it down using expressive writing, trying to explore and focus on how they were feeling at the different points of the short story. It can be a funny, uncomfortable, sad, true or fictional story; whichever comes to mind first.

Facilitators suggest everyone wraps up their writings 1-2 minutes before it is time to move to the next step.

STEP FOUR (15 mins)

Facilitators now ask for carers to share their writings with the group by reading it out loud. They ask who would like to go first and then they go around the circle, thanking everyone individually for sharing. If anyone does not wish to share their writings, facilitators try to encourage them and remind them that this is a safe environment, but they respect their decision.

STEP FIVE (20 mins)

For this session, facilitators inform caregivers that since they still have some time left, they now will ask them to rewrite the same stories they just shared, but this time from the point of view of their loved one. They should try to reflect on what their care recipient’s feelings might be during the story and write down whatever comes to mind first. This technique can reveal to caregivers’ new perspectives that they may have not think about before and can it help them improve their ability to cope with challenging or frustrating behaviors.

STEP SIX (15 mins)

Facilitators once again ask for carers to share their new stories with the group by reading it out loud. They ask who would like to go first and then they go around the circle, thanking everyone individually for sharing and making a small comment/conclusion after each reading. If anyone does not wish to share their writings, facilitators try to encourage them and remind them that this is a safe environment, but they respect their decision.

If there is time and/or need at the end of the session, facilitators can encourage a last small discussion be asking for example “Does anyone have to add something/ want to share anything else after hearing everyone’s readings?”

END OF THE SESSION

Facilitators thank everyone for their presence, congratulate the group on a job well done and collect everyone's writings.

After the participants leave the room, facilitators can put the writings in a folder with a copy of the stimulus and the date on it, for future reference.

5th session

STEP ONE (10 mins)

Facilitators ask caregivers how they are feeling this particular day or how their day or week has been so far.

Caregivers should know beforehand that this will be their last session.

Then, facilitators very briefly remind everyone of what they did last time and that they will use the same techniques, but a slightly different structure today. In particular, they will firstly share a literature text (or poem) with the group, they will read it together, then they will ask from each participant to write something about it using expressive and spontaneous writing and in the end the group will have a discussion about the text or topics that arose after hearing each other's writings. We propose this different structure for the last session, because we want participants to try to use expressive and spontaneous writing without having any prompts from the initial discussion.

STEP TWO (30 mins)

Facilitators pass across the circle a copy of the literature text or poem they have chosen for that particulate day. For the group of spouses especially, where the participants may be of an older age, the font and graphics should be suited accordingly.

Facilitators, then, ask if someone from the group would like to read the text out loud. If not, one of them can read it out loud one time and then allow participants to take another look at it for 2-3 minutes.

Immediately after that, facilitators for caregivers to write down any more they have using expressive writing. Once again, they remind briefly what expressive writing is: "Expressive writing is writing with the purpose of putting your own deepest feelings and thoughts into words. In expressive writing, the focus is on expressing personal emotional experiences and there are no grammar, spelling or syntax rules. Expressive writers are free to choose whatever style or structure they feel more comfortable, without worrying about having a text with begging, middle and ending. It can be just words unlinked to each other written on a paper. Whatever is going through your mind right now, even if it is not linked to the text, we just read." Also, they urge caregivers to try and write in the first person, about their feelings/thoughts and not in general. By doing so, the speech becomes personal, expresses our inner voice, allow us to take responsibility for our words and no one can disagree, because it is our experience.

Facilitators suggest everyone wraps up their writings 1-2 minutes before it is time to move on to the next step.

STEP THREE (20 mins)

Facilitators make a quick recaption of the main points discussed and announce that is now time to share their writings with the group by reading it out loud. They ask who would like to go first and then they go around the circle, thanking everyone individually for sharing and making a small comment/conclusion after each reading. If anyone does not wish to share their writings, facilitators try to encourage them and remind them that this is a safe environment, but they respect their decision.

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. Facilitators should try to create a space where everything is valid.

STEP FOUR (20 mins)

Facilitators now ask for carers to start the discussion about the text or what they just heard by the rest of the group, reminding everyone of what they would like to be discussed and giving the time for everyone to express themselves. Questions that may help to facilitate the flow of the conversation can be, for example: "What do you feel / think after reading this text? Please, remember to talk in the first person about the feelings / thoughts that arose. Please, be free to share any feeling / thought or experience that comes to mind, even if it is not linked to the text, we just read. Did you find anything in the text that reminded you of something from your life or your caregiving experience?"

STEP FIVE (10 mins)

Since this is the last session of the pilot workshops, at the end of this discussion, facilitators can ask for caregivers if they would like to comment on their overall experience of these workshops, using 1-2 phrases.

Before facilitators end the session, they should share with the participants the evaluation form of the workshops (prepared by our evaluation partner, Spominčica) and kindly ask them to provide their feedback, as it is very valuable.

END OF THE SESSION

Facilitators thank everyone for their presence, congratulate the group on a job well done and collect everyone's writings.

After the participants leave the room, facilitators can put the writings in a folder with a copy of the stimulus and the date on it, for future reference.

Since this was the last session, facilitators should also provide their feedback by completing the evaluation form of the workshops (prepared by our evaluation partner, Spominčica).

Tip: Facilitators can take notes after each session with their feedback, so it will be easier to complete the evaluation form at the end without forgetting anything.

REFERENCES

- Butcher, H. K., Gordon, J. K., Ko, J. W., Perkhounkova, Y., Cho, J. Y., Rinner, A., & Lutgendorf, S. (2016). Finding Meaning in Written Emotional Expression by Family Caregivers of Persons with Dementia. American Journal of Alzheimer's Disease and Other Dementias, 31(8), 631–642. https://doi.org/10.1177/1533317516660611
- Ananias, J., & Strydom, H. (2014). Factors contributing to elder abuse and neglect in the informal caregiving setting. Social Work/Maatskaplike Werk, 50, 268-284. https://doi.org/10.15270/50-2-6
- Black, K., & Lobo, M. (2008). A conceptual review of family resilience factors. Journal of family nursing, 14(1), 33–55. https://doi.org/10.1177/1074840707312237
- Butcher, H. K., Gordon, J. K., Ko, J. W., Perkhounkova, Y., Cho, J. Y., Rinner, A., & Lutgendorf, S. (2016). Finding Meaning in Written Emotional Expression by Family Caregivers of Persons with Dementia. American Journal of Alzheimer's Disease and Other Dementias, 31(8), 631–642. https://doi.org/10.1177/1533317516660611
- Caldwell, R. L. (2005). At the Confluence of Memory and Meaning—Life Review With Older Adults and Families: Using Narrative Therapy and the Expressive Arts to Re-member and Re-author Stories of Resilience. The Family Journal, 13(2), 172–175. https://doi.org/10.1177/1066480704273338
- Karagiozi, K., Margaritidou, P., Egkiazarova, M., Toumpalidou, M., Makri, M. & Tsolaki, M. (2017). Interventions for Caregivers of People with Dementia in Greece. Journal of Family Medicine, 4(5). https://doi.org/10.26420/jfammed.2017.1125
- Kidd, L. I., Zauszniewski, J. A., & Morris, D. L. (2011). Benefits of a poetry writing intervention for family caregivers of elders with dementia. Issues in Mental Health Nursing, 32(9), 598–604. https://doi.org/10.3109/01612840.2011.576801
- Leahey, M., & Wright, L. M. (2016). Application of the Calgary Family Assessment and Intervention Models: Reflections on the Reciprocity Between the Personal and the Professional. Journal of family nursing, 22(4), 450–459. https://doi.org/10.1177/1074840716667972
- Mackenzie, C. S., Wiprzycka, U. J., Hasher, L., & Goldstein, D. (2007). Does expressive writing reduce stress and improve health for family caregivers of older adults? Gerontologist, 47(3), 296–306. https://doi.org/10.1093/geront/47.3.296
- Murrant, G. M., Rykov, M., Amonite, D., & Loynd, M. (2000). Creativity and self-care for caregivers. Journal of Palliative Care, 16(2), 44–49.
- Randall, W. (1996). Restorying a Life: Adult Education and Transformative Learning. In J. E. Birren (Ed.), Aging And Biography: Explorations In Adult Development (pp. 224–247). New York: Springer Publishing.
- Singhal, A., & Rogers, E. M. (1999). Entertainment-education: A communication strategy for social change. Lawrence Erlbaum Associates Publishers.
- Swinnen, A. M. C. (2016). Healing words: A study of poetry interventions in dementia care. Dementia, 15(6), 1377–1404. https://doi.org/10.1177/1471301214560378

- Walsh, F. (2016). Applying a Family Resilience Framework in Training, Practice, and Research: Mastering the Art of the Possible. Family process, 55(4), 616–632. https://doi.org/10.1111/famp.12260
- Zauszniewski, J. A., Bekhet, A. K., & Suresky, M. J. (2010). Resilience in family members of persons with serious mental illness. The Nursing clinics of North America, 45(4), 613–vii. https://doi.org/10.1016/j.cnur.2010.06.007

ANNEX I

Examples of literature stimuli used in SINCALA pilots:

- You learn (Borges)
- Little Prince (De Saint-Exupéry)
- Old man and the sea (Hemingway)
- Moby Dick (Melville) – Chapter 82 / The Symphony
- Tone Pavček: Simple words
- Ivana Malkoč: Shadow
- Božo Rustija: Stories for conversation: Monster in the field
- Tone Pavček: Beeing in the moment
- Greek Mythology: Theseus story (the death of Aegeus)
- A.Tšehhov „Elu igavus ja teisi jutte“ lk 6-23 (A.Chekhov "The boredom of Life and other tales")
- Doris Lessing "Hea naabri päevik" lk 148-156 (Doris Lessing "The diary of a good neighbour")
- B. Alver „Oh jeerum“ (luuletus) (B.Alver poem)
- Eric-Emmanuel Scmitt "Oscar ja Roosamamma" lk 7-17 (Eric-Emmanuel Schmitt "Oscar and the Lady in Pink")
- Velho (Old) – Mafalda Veiga
- O Paraíso são os Outros (Paradise is other people) - Valter Hugo Mãe
- A poem to friends – José Luís Borges
- O caminho não trilhado (The road not taken) - Robert Frost
- Não te rendas (Don’t give up) - Mario Benedetti
- Algo Estranho Acontece (Something Strange Happens)– António Zambujo
- Viagem (Journey) – Tiago Bettencourt
- Ανέβα (Go up) - Menelaos Lountemis
- Το σκάκι (The chess) - Manolis Anagnostakis

- Περιμένοντας τους βαρβάρους (Waiting for the Barbarians) - Constantine P. Cavafy
- Memory in My Hands - Pedro Salinas
- Ο δυσφημισμένος λύκος (The defamed wolf) - Daphne Filippou, Pola Karantana