



RESIL4CARE

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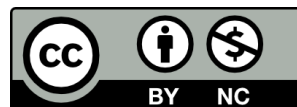
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TABLE OF CONTENTS

Executive summary.....3

Chapter 1. Statistical analysis of the questionnaire’s results.....4

Chapter 2. General conclusions.....13

Annex 1.....15

References

EXECUTIVE SUMMARY

With the development of the RESIL4CARE questionnaire, project partners aimed to gather valuable information regarding the role of social media as a supporting tool for informal caregivers.

To stipulate the needs of caregivers, the project partners developed and addressed the present questionnaire to 20 people each (FRODIZO, ISRAA, IAT, IVASS), summoning up a total of 84 people.

In the first section there are some basic socio-demographic data that will provide conclusions around the educational status of the respondents.

The main corpus of the questionnaire, aims to examine various parameters that affect the usage of social media among the respondents, as well as to define the needs of the respondents that could be supported by the use of social media.

CHAPTER 1 - STATISTICAL ANALYSIS OF RESULTS

1. The average age of respondents between the 4 countries is:

SPAIN: 52,6

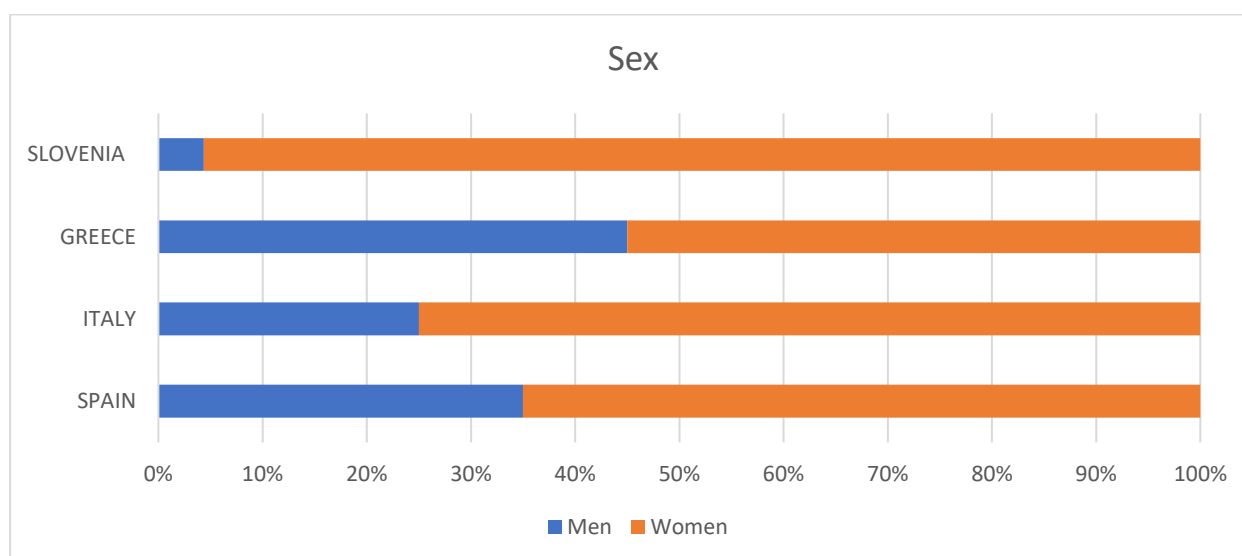
ITALY: 57,3

GREECE: 55,5

SLOVENIA: 59,8

2. Sex

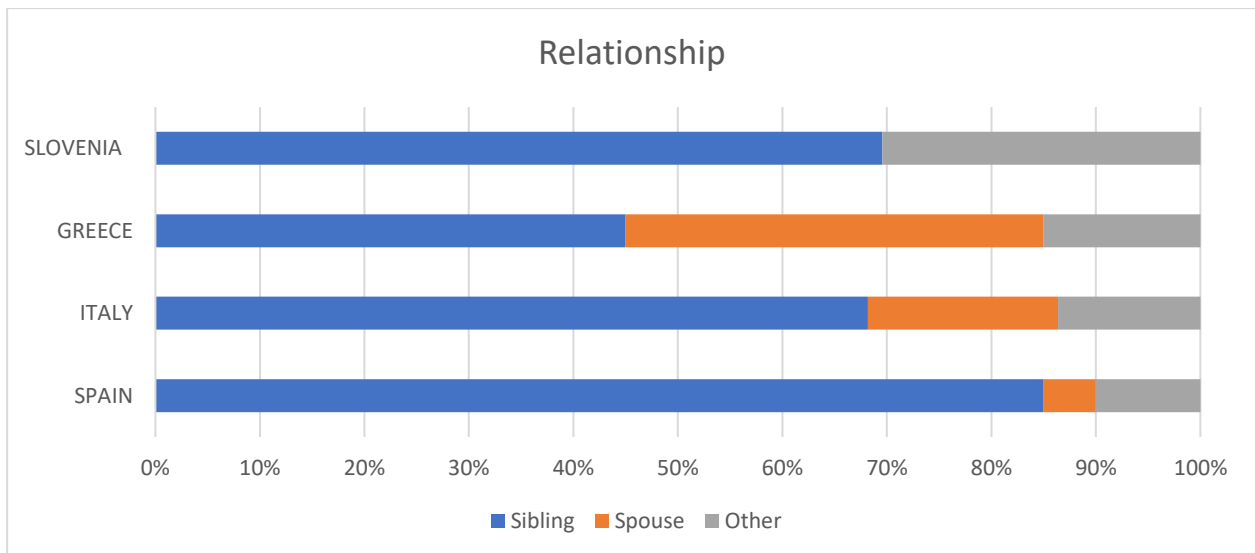
	SPAIN	ITALY	GREECE	SLOVENIA
Men	7	3	9	1
Women	13	9	11	22
Other				



Comment: From the results we can see that women are the majority among the participant's samples in all project countries, especially in Slovenia the sample consists almost entirely by women, something totally justified from all relevant research and studies that point out the leading role of women in informal care across Europe.

3. Relationship:

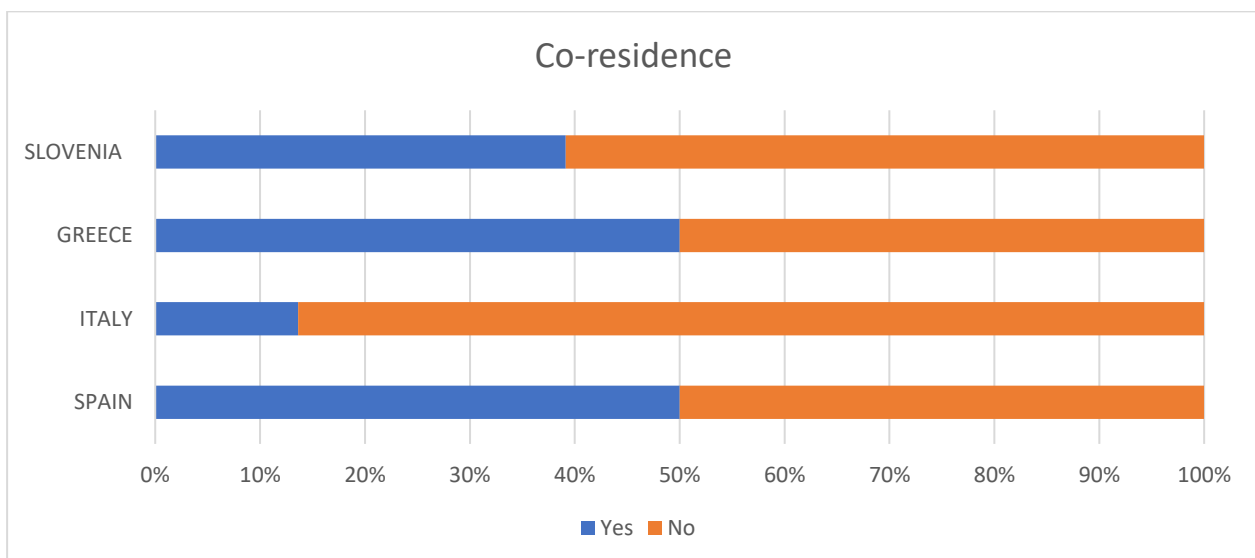
	SPAIN	ITALY	GREECE	SLOVENIA
Sibling	17	15	9	16
Spouse	1	4	8	
Other	2	3	3	7



Comment: Here in this result, we can see that children in all project countries, probably due to their younger age and energy, have the leading role in the care of older people, followed by the spouses. Another conclusion is that relatives in general possess a very big share of what we call informal care.

4. Co-residence

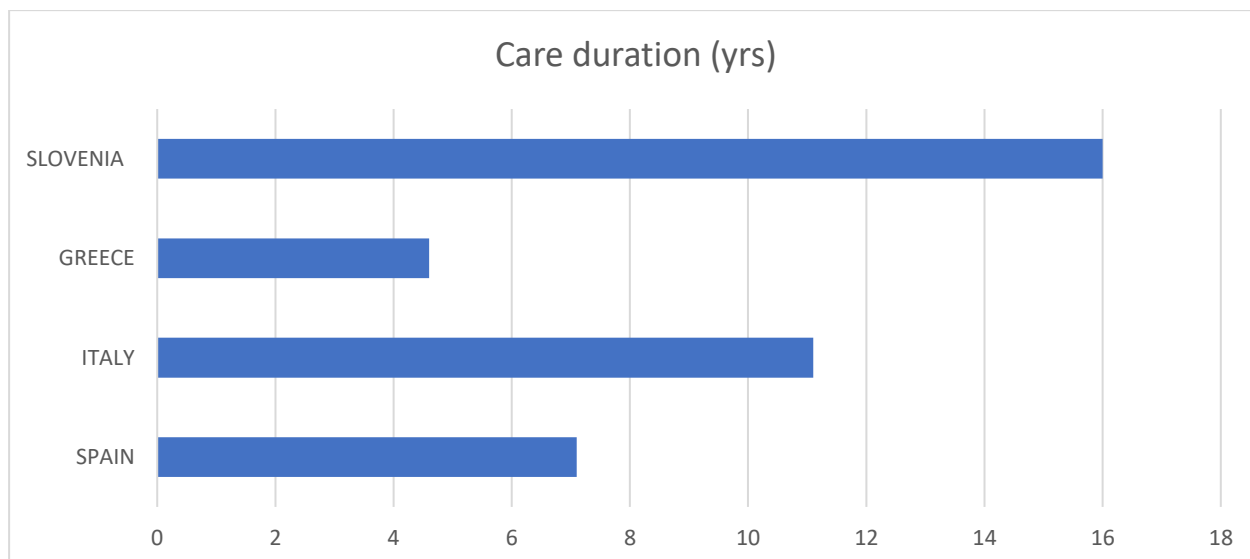
	SPAIN	ITALY	GREECE	SLOVENIA
Yes	10	3	10	9
No	10	19	10	14



Comment: Co-residence is a crucial factor for the immediacy of the care services. Here in this result, we see that in project countries sample more or less there is a balance between the provision of care from distance or in home.

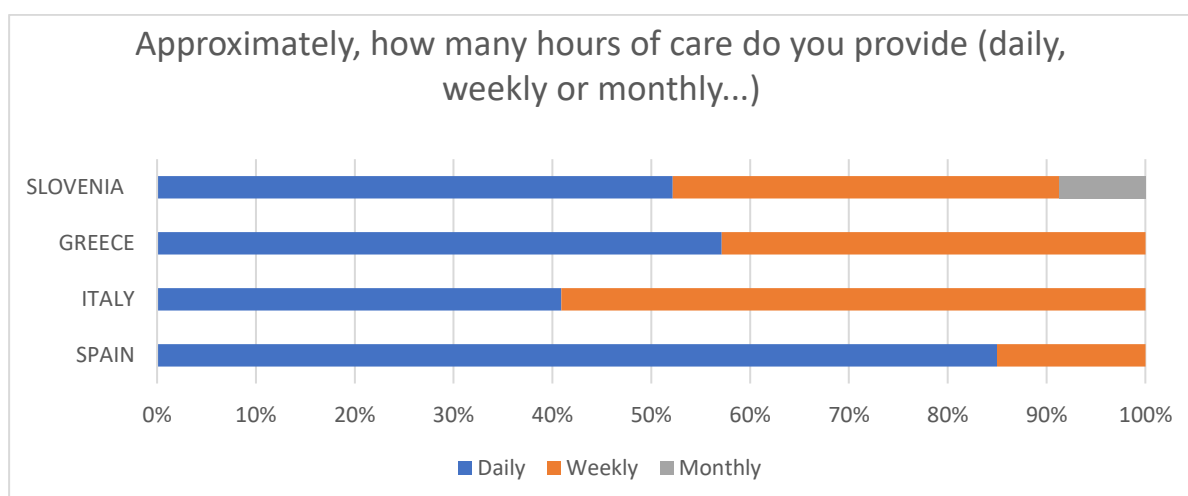
5. Care duration (yrs)

	SPAIN	ITALY	GREECE	SLOVENIA
	142/20 = 7,1	222/20 = 11,1	92/20 = 4,6	0



6. Approximately, in which time frame do you provide care (daily, weekly or monthly...)

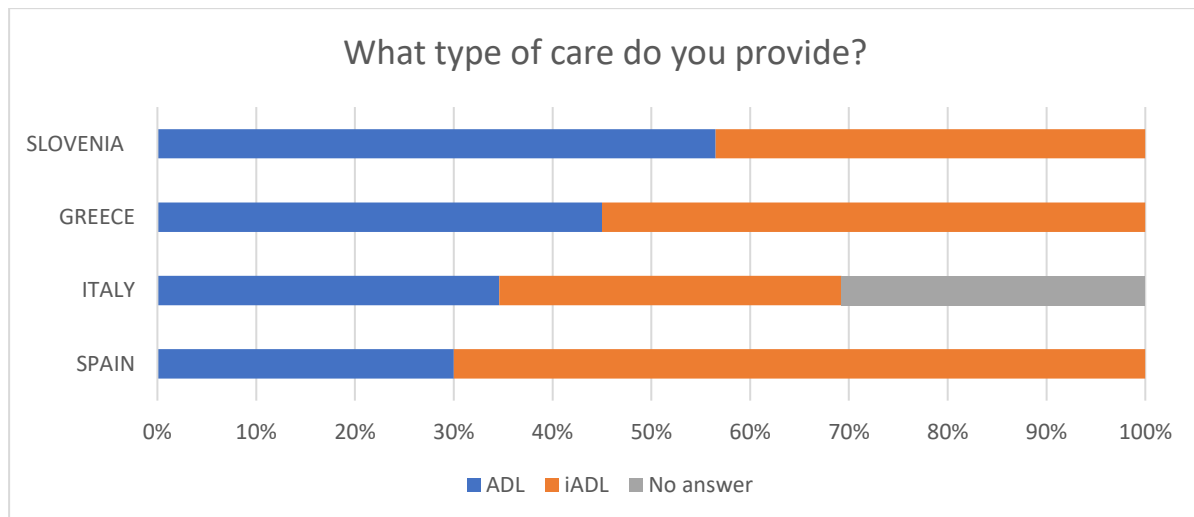
	SPAIN	ITALY	GREECE	SLOVENIA
Daily	17	9	12	12
Weekly	3	13	9	9
Monthly	0	0	0	2



Comment: In this chart we can see that care is a task that it is provided mostly daily or weekly. This in a way depicts the magnitude of commitment that informal caregivers usually undertake, and the possible subsequent aggravations they might experience.

7. What type of care do you provide?

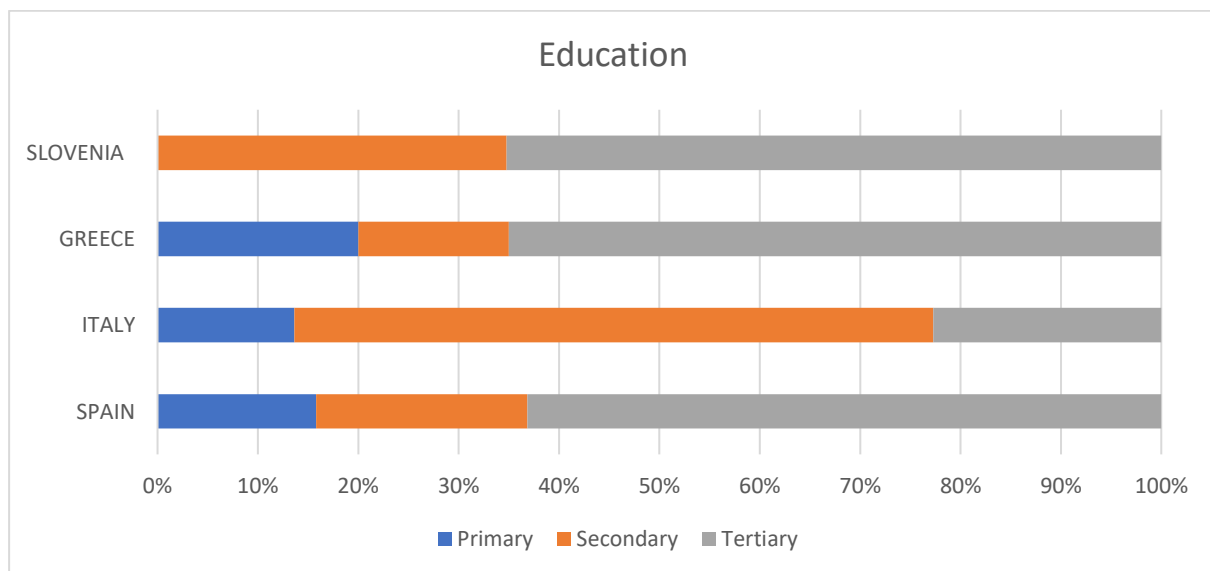
	SPAIN	ITALY	GREECE	SLOVENIA
ADL	6	9	9	13
iADL	14	9	11	10
No answer		8		



Comment: More or less it seems that there is an even distribution among project countries on the type of care the caregivers provide, as both activities of daily living and instrumental daily activities seem to have equal demand from the care recipients.

8. Education:

	SPAIN	ITALY	GREECE	SLOVENIA
Primary	3	3	4	0
Secondary	4	14	3	8
Tertiary	12	5	13	15

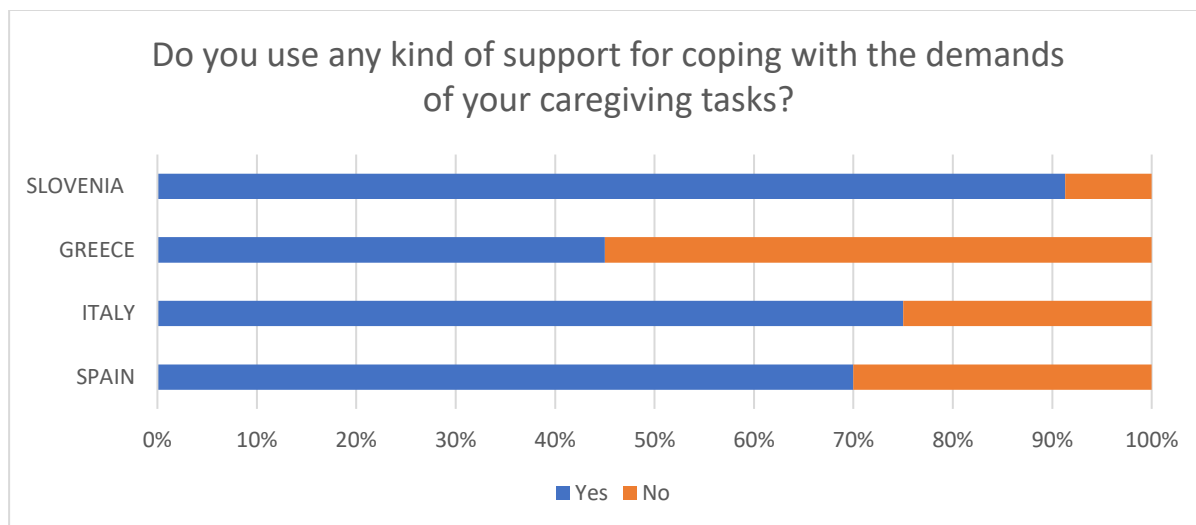


Comment: As younger generations assume the role of caregiving they are more educated and this is showed also by the big number of people having tertiary level education among all project countries.

QUESTIONS

1. Do you use any kind of support for coping with the demands of your caregiving tasks?

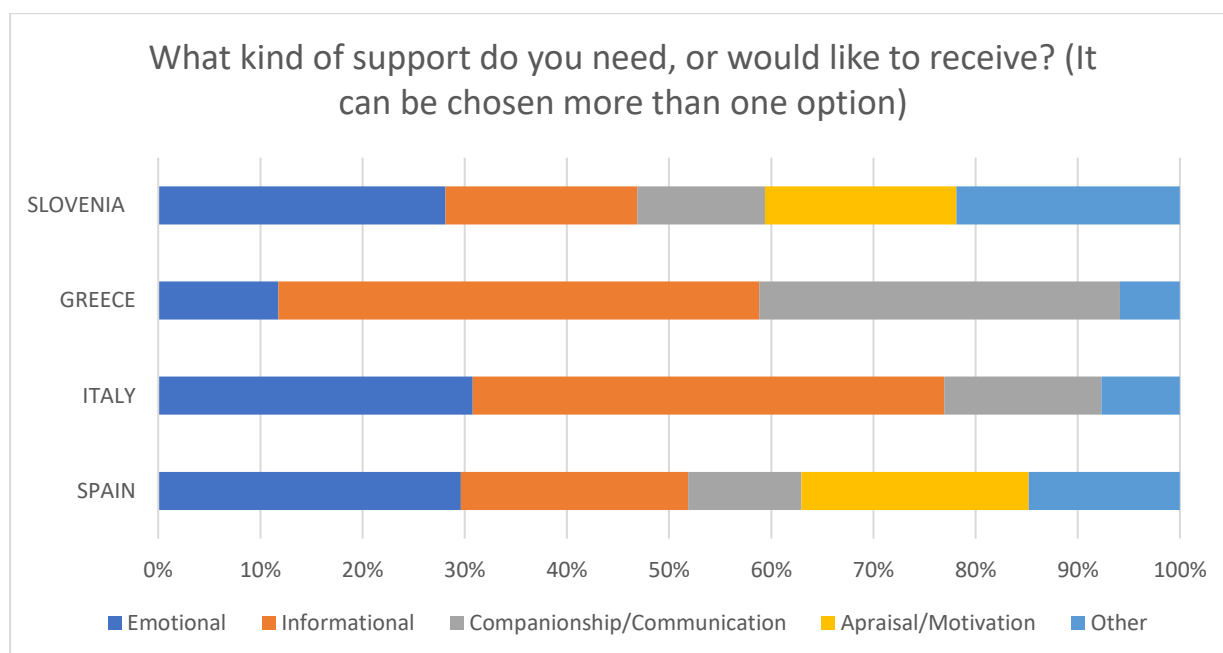
	SPAIN	ITALY	GREECE	SLOVENIA
Yes	14	15	9	21
No	6	5	11	2



Comment: Here we can see that support is proportionately highly used in three of the project countries (Spain, Italy, Slovenia). In Greece, support is equally important, nevertheless fewer people seek for help, something that can be connected with the still under development governmental support mechanism.

2. What kind of support do you need, or would like to receive? (It can be chosen more than one option)

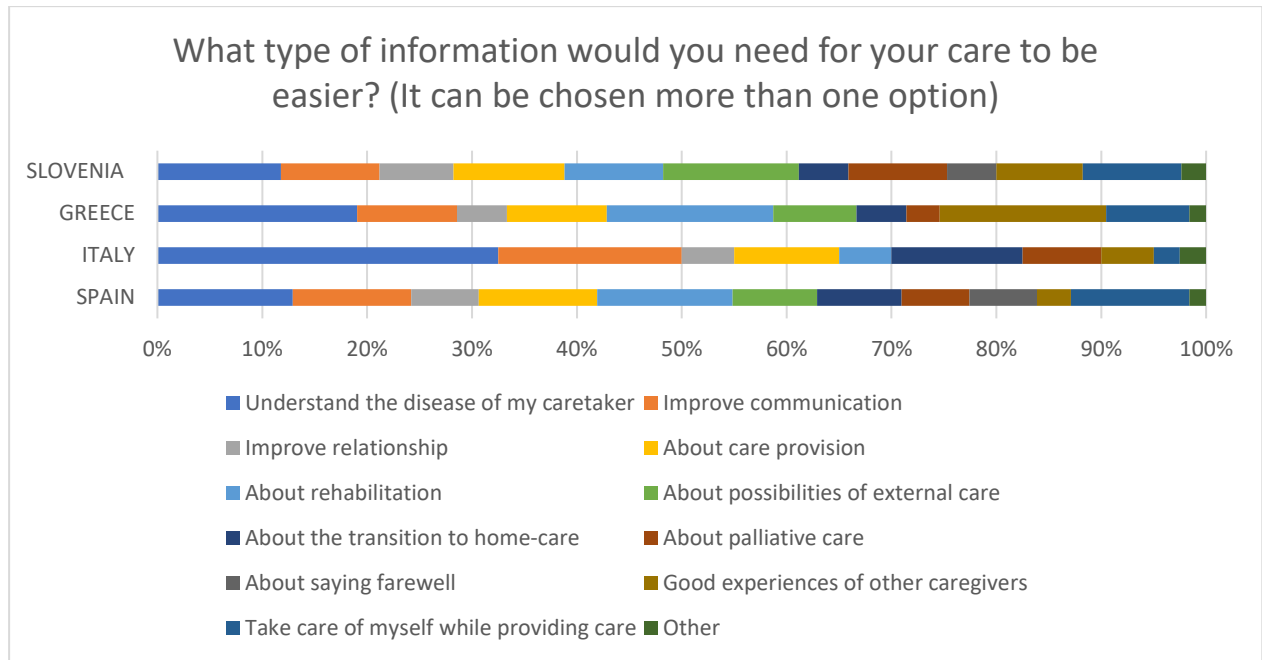
	SPAIN	ITALY	GREECE	SLOVENIA
Emotional	8	8	2	9
Informational	6	12	8	6
Companionship/Communication	3	4	6	4
Apraisal/Motivation	6	0	0	6
Other	4	2	1	7



Comment: All kind of support is very important. We can assume by the results that the great dispersion of answers in a way reflects on the versatility of so many different factors that may have impact on care giving procedure. From the answers received informational needs come first, followed by emotional support needs.

3. What type of information would you need for your care to be easier? (It can be chosen more than one option)

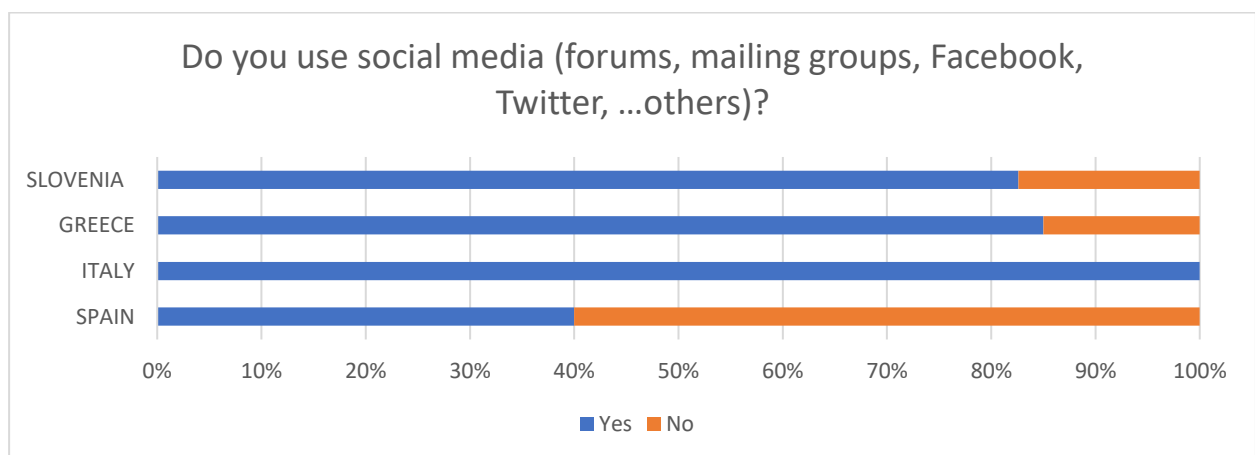
	SPAIN	ITALY	GREECE	SLOVENIA
Understand the disease of my caretaker	8	13	12	10
Improve communication	7	7	6	8
Improve relationship	4	2	3	6
About care provision	7	4	6	9
About rehabilitation	8	2	10	8
About possibilities of external care	5	0	5	11
About the transition to home-care	5	5	3	4
About palliative care	4	3	2	8
About saying farewell	4	0	0	4
Good experiences of other caregivers	2	2	10	7
Take care of myself while providing care	7	1	5	8
Other	1	1	1	2



Comment: Again here we see that several types of information can be useful, and this seems to be an important conclusion regarding the range of information that social media might provide, covering completely different needs. Nevertheless, despite some mismatches in the results between the project countries, understanding about the disease is the biggest need among all country samples.

4. Do you use social media (forums, mailing groups, Facebook, Twitter, ...others)?

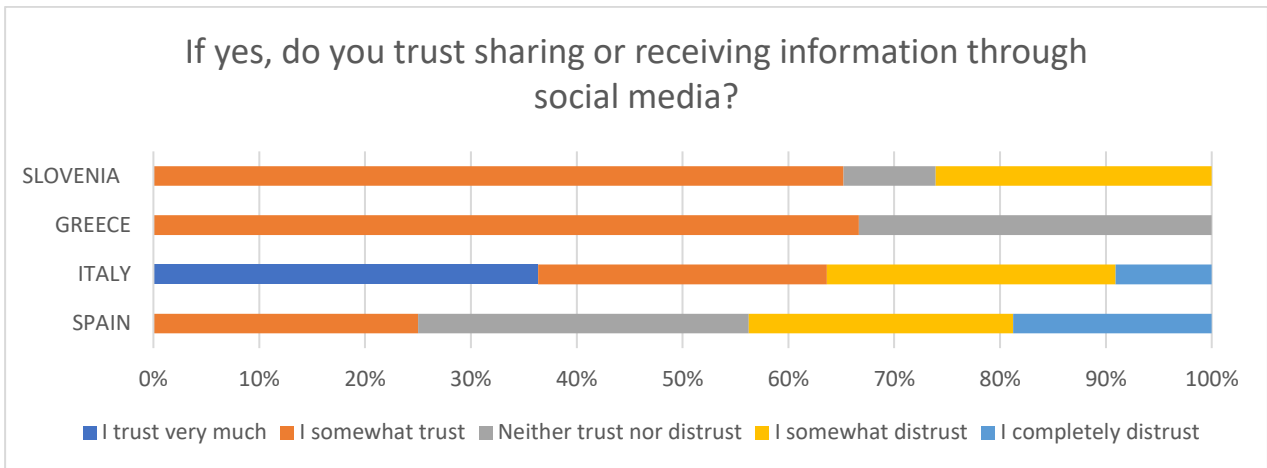
	SPAIN	ITALY	GREECE	SLOVENIA
Yes	8	22	17	19
No	12	0	3	4



Comment: In three of the project countries (Italy, Greece, Slovenia), is obvious the high usage of social media, something that justifies the essence of RESIL4CARE project to enhance their promotion towards the support of informal caregivers. In Spain the results show that still a big proportion of the respondents does not use social media.

5. If yes, do you trust sharing or receiving information through social media?

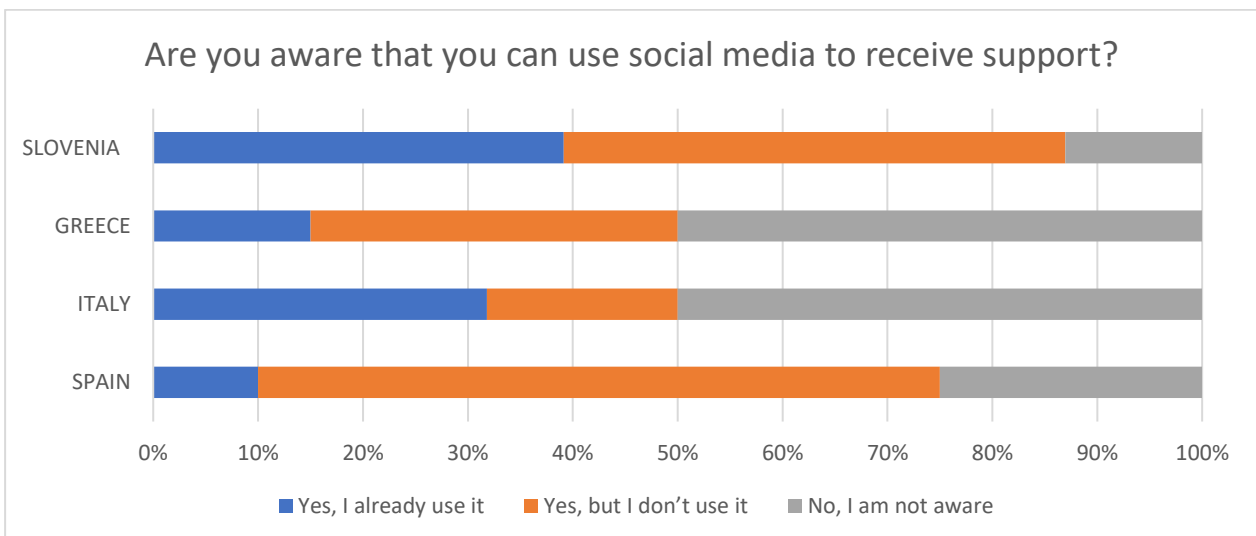
	SPAIN	ITALY	GREECE	SLOVENIA
I trust very much	0	8	0	0
I somewhat trust	4	6	12	15
Neither trust nor distrust	5	0	6	2
I somewhat distrust	4	6	0	6
I completely distrust	3	2	0	0



Comment: In this question the answers show a skepticism of the respondents in all project countries apart Italy, concerning their total trust towards social media, nevertheless there is a clear propensity towards a positive or neutral stance towards social media, something that can serve as a good basis for the scopes of the project.

6. Are you aware that you can use social media to receive support?

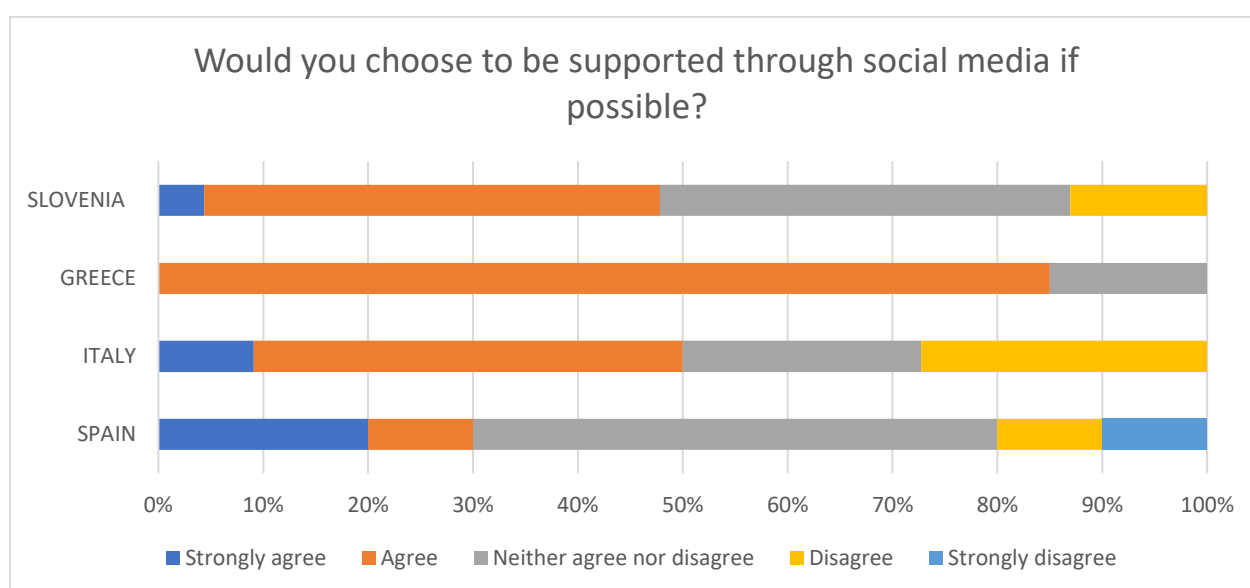
	SPAIN	ITALY	GREECE	SLOVENIA
Yes, I already use it	2	7	3	9
Yes, but I don't use it	13	4	7	11
No, I am not aware	5	11	10	3



Comment: The usability of social media as bearers of more specific information, apart from the social connectedness domain which is the well know function of social media, is under the awareness of the biggest percentage of the respondents, nevertheless, apart from Slovenia who shows a noticeable rate, in all other countries the number of participants that already use them for support, remains low.

7. Would you choose to be supported through social media if possible?

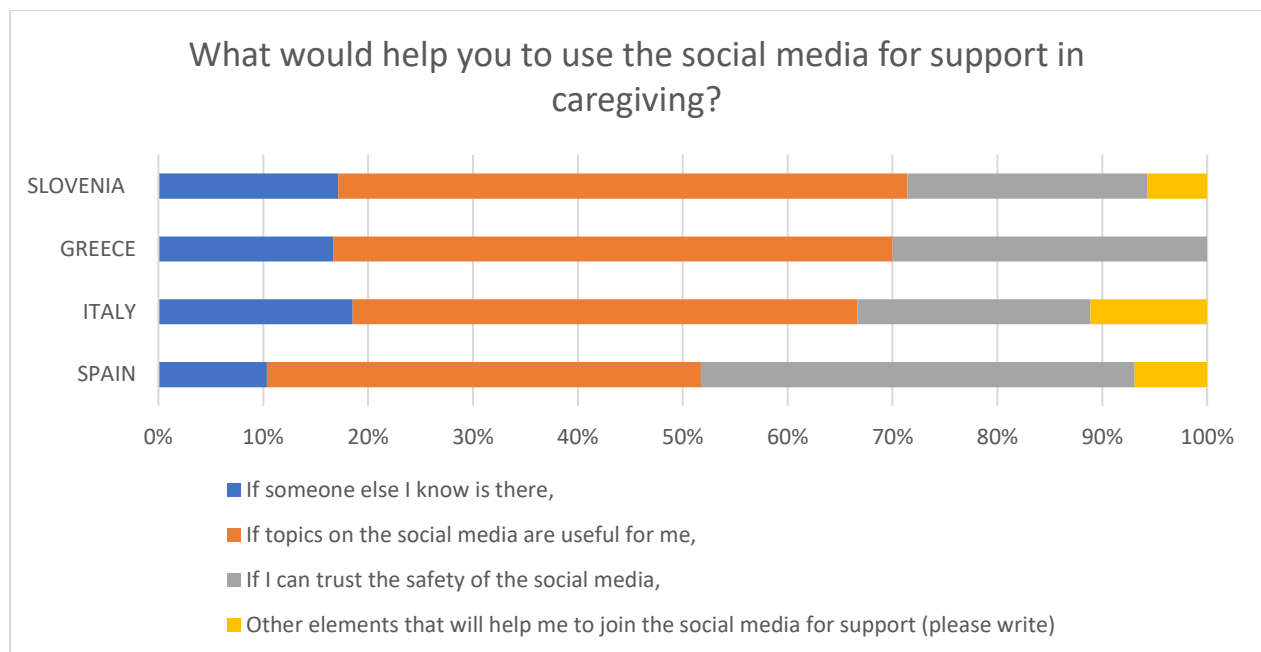
	SPAIN	ITALY	GREECE	SLOVENIA
Strongly agree	4	2	0	1
Agree	2	9	17	10
Neither agree nor disagree	10	5	3	9
Disagree	2	6	0	3
Strongly disagree	2	0	0	0



Comment: Again in this question, and in relation with the previous one, we can discern the skepticism of the respondents, in terms of not choosing to strongly agree with the possibility of getting support from the social media, nevertheless the positive responses towards social media by far underscores the negative ones.

8. What would help you to use the social media for support in caregiving?

	SPAIN	ITALY	GREECE	SLOVENIA
If someone else I know is there,	3	5	5	6
If topics on the social media are useful for me,	12	13	16	19
If I can trust the safety of the social media,	12	6	9	8
Other elements that will help me to join the social media for support (please write)	2	3	0	2



Comment: Respondents placed the usability of the social media for support in caregiving, as their first choice (and security the second), and this result may be justifiably correlated with question N.3, about the type of information needed by the participants, as understanding the disease of the care recipient is extremely useful for successful caregiving tasks.

Chapter 2 - General conclusions

This questionnaire gave the opportunity to the project partners to provide another aspect of evidence towards the mapping of the role and use of social media as a tool for improving the behavioral and emotional resilience of those providing informal care giving tasks.

It also depicts certain tendencies and needs that may emphasize the function of social media as a supportive tool for caregivers in various ways, either through information sharing, or through various types of psychological support.

In general, it seems that while social media are up to an extend known to people above 50,, there is still margin regarding raising awareness in terms of:

- Their role as tools for support of informal caregivers, through increasing speed of communication, distributing accurate information, and promoting knowledge of support, treatments and self-care options
- Their effectiveness in providing reliable and customized information
- Their importance in promoting patients and their informal caregivers as central figures in decision-making and delivery of care, allowing patients, older people and caregivers to interact within an online social structure and network of relationships.

Social media tools, and their ability to serve as real-time communication, educational material, and self-management platforms, connects them in the so-called health literacy domain and decision-making process to aid caregivers with making informed decisions regarding their loved one's care.

In conclusion, social media tools might enable informal caregivers to gain the knowledge that they need in order to feel empowered, involved, and satisfied. Nevertheless, there is a declared caution on social media applications and networking sites so as not to compromise patient's and caregiver's privacy. In sum, social media represents a flexible medium to support the caregiving tasks, and the versatility of the information and individuality that caregivers can obtain through using social media may promote an invaluable collaborative relationship when caring for critically ill patients.

ANNEX 1

PROJECT RESIL4CARE: QUESTIONNAIRE ENG

The questionnaire is an activity of the Project Result1: it is a qualitative tool that will be administered, from each pilot site, to 20 informal caregivers with the aim of measuring the main variables that influence psychosocial resilience. The questionnaire can be administered in 2 ways: either by a professional face to face or via a link with a Microsoft Form. The aim of the Microsoft Form is to collect all data from all participating countries. An informed consent will be made to sign before completion.

PERSONAL DATA PROCESSING NOTICE
Art. 13 of EU Reg. 2016/679

Dear interested party,
in accordance with the current legislation on the protection of personal data, we are hereby providing you with information on the processing of personal data collected through this questionnaire within the framework of the RESIL4CARE Project.

Purposes and methods of data processing

Your personal data are collected to provide you with suitable support in the creation, use and management of social network content in order to improve the quality of care provided as a caregiver. The data will be collected in a paper or a computer format by connecting to
The legal basis guaranteeing the lawfulness of the processing is provided by Art. 6(e) and, with regard to special data, Art. 9(2)(h).

Storage

Your personal data will be stored for the entire period of the Project and in any case no longer than 10 years after the conclusion of the Project in order to guarantee the legal controls.

Recipients

The data will not be communicated outside the project and will be shared in an anonymous form with other RESIL4CARE partners.

Rights concerned

You may at any time exercise your rights according to articles 15-22 (request access, deletion, modification, ...) of the EU Reg. 20216/679 by contacting the Data Controller I.S.R.A.A (dpo@israa.it)
You may lodge a complaint with the Guarantor Authority for the protection of personal data P.zza Venezia - ROMA (RM).

Data Controller and Data Protection Officer

The Data Controller is: I.S.R.A.A., Borgo Mazzini 48 Treviso, Italy 31100
Data Protection Officer - DPO: dpo@israa.it

- I consent to processing of my personal data
- I do not agree to processing of my personal data

Demographic data

- Age:

- Sex:
 - Male

- Female
- I prefer not reply

- Relationship:
 - Spouse
 - Daughter/Son or Daughter-In-Law/Son-In-Law
 - Other

- Co-residence:
 - Yes
 - No

- Distance (km) from the person you provide care for:

- Care duration (yrs):

- Approximately, how many hours of care do you provide (daily, weekly or monthly...)
 - Daily
 - Weekly
 - Monthly

- What type of care do you provide?
 - I help with one or more activities of daily living: grooming/personal hygiene, dressing, toileting/continence, transferring/ambulating, and eating
 - I help with one or more instrumental activities: using of the phone (this includes answering and calling others); shopping for groceries; with planning, heating or serving meals; with managing the medications (this includes refilling them when needed and taking them correctly); with cleaning of the house or apartment; with getting around (for example driving around by car or accompanying by taxi or public transport); with managing the money and paying the bills.

- Education:
 - Primary / Primary school certificate or Secondary school certificate
 - Secondary / High school diploma
 - Tertiary /University or more
- Occupation:

QUESTIONS

1. Do you use any kind of support for coping with the demands of your caregiving tasks?

2. What kind of support do you need, or would like to receive? (It can be chosen more than one option)
 - Emotional
 - Informational
 - Companionship/Communication

- Appraisal/Motivation
- Other (write what)

3. What type of information would you need for your care to be easier? (It can be chosen more than one option)

- About how to better understand the disease of my caretaker (for example dementia)
- About how to improve communication
- About how to improve relationship
- About care provision (how to change sheets, help with the hygiene, how to help with eating ect.)
- About rehabilitation (how to help caretaker with gaining strength, to walk again ect.)
- About possibilities of external care
- About the transition to home-care
- About palliative care
- About saying farewell
- About good experiences of other caregivers who went through similar situation
- About how to take care of myself while providing care
- Other (write what):

4. Do you use social media (forums, mailing groups, Facebook, Twitter, ...others)?

- Yes
- No

5. If yes, do you trust sharing or receiving information through social media?

- I trust very much
- I somewhat trust
- Neither trust nor distrust
- I somewhat distrust
- I completely distrust

6. Are you aware that you can use social media to receive support?

- Yes, I already use it
- Yes, but I don't use it
- No, I am not aware

7. Would you choose to be supported through social media if possible?

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

8. What would help you to use the social media for support in caregiving?

- If someone else I know is there,

- If topics on the social media are useful for me,
- If I can trust the safety of the social media,
- Other elements that will help me to join the social media for support (please write)