REPORT
CARE4DEM PILOT OF THE ONLINE
MUTUAL AID GROUPS

as part of the Intellectual Output 2

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About CARE4DEM Project

The European Commission (EC) has highlighted the advantages of supporting informal carers, including via training, as part of a range of strategies to face the challenges attached to long-term care. Based on this acknowledgment, the EC supports the European project CARE4DEM (2017-2020) through the programme Erasmus+. By doing so, the EC also pursues the objective of facilitating the inclusion in the labour market of the most disadvantaged, through the development of a partnership for adult education.

The project's partnership is coordinated by Anziani e Non-Solo (Italy), and gathers five organisations from Italy (Anziani e Non Solo - Societa Cooperativa Sociale), Portugal (CASO50+, Centro de Atendimento e Serviços 50+ Association and APROXIMAR, Cooperativa de Solidariedade Social, CRL), Romania (EaSI – European Association for Social Innovation), Spain (Instituto de Salud Carlos III) and a European umbrella organisation (EUROCARERS – European Association Working for Carers).

CARE4DEM stands for creating opportunities for all caregivers to take part in interventions likely to help them in their role, by developing an innovative model of web-based mutual aid group (MAG).

The specific objectives of CARE4DEM are:

- To design and develop an innovative web-based model of mutual aid group for informal caregivers of people with dementia, including learning materials for caregivers;
- To identify the profile and competences that are the most suitable to the role of facilitator of such a group;
- To develop a multimedia training course to enhance the competences of mutual aid groups' facilitators;
- To pilot a web-based mutual aid group model;
- To create a network of professionals across Europe who work towards better support of informal caregivers of people with dementia.

Executive summary

The piloting of the Online Mutual Aid Groups was delivered in 3 European countries (Italy, Portugal and Romania). The pilots were delivered by 4 partner organizations:

- ANS – Anziani e non solo (Italy) is an organization working in the field of informal care and with specialized trainers in that area of expertise. See more at: www.anzianienonsolo.it;

- Aproximar (Portugal) is an organization with the mission to value the social and human capital of organizations and people, as a strategy to respond sustainably to challenges and opportunities raised by the environment. See more at: www.aproximar.pt;

- CASO50+ (Portugal) is non-profit association dedicated to the community of older adults, developing activities in view of promotion of health and well-being, active aging, and quality of life of old people. See more at: www.facebook.com/cas050mais/.

- EaSI - European Association for Social Innovation is a European network (Romania), representing more than 30 organizations from 15 European countries which aim is the advancement of Social Innovation in Europe. At national level, EaSI has collaborated with several organizations and public institutions. See more at: http://easi-socialinnovation.org/.

The piloting of the online mutual aid groups (MAG) for informal carers of people with dementia – that took place in Italy, Portugal and Romania -, raised the interest of 90 informal carers, who registered for the piloting. From these, 7 MAGs were implemented with a total of 34 informal carers participating.

Every group followed the co-facilitation model, so there were two facilitators in each group: in Italy and Romania the co-facilitation was guaranteed by a senior informal carer and a professional; in Portugal, the co-facilitations was made by two professionals. All facilitators involved in the piloting also participated in the C4D training for facilitators.

Overall, the feedback from the participants was very positive. Being able to get relevant information, meeting new people dealing with similar experiences, sharing their experience and the sense of being useful were the most important aspects of participating in the MAG. Regarding recommendations for improvement: choosing the right platform – easy to use - for the sessions is very important as well as thinking about different ways of enhancing the asynchronous dimension and possibly to offer more ICT support to interested parties (as the use of ICT might have been an obstacle for some informal carers to even express an interest to join the groups).

Despite of the privacy issues it may rise, using a WhatsApp group could be a possibility. Also, creating a library with relevant information (eg. care centres, social care institutions, articles on how to communicate with people with dementia, and how to provide better care, etc) is one of the recomendations.

Framework for pilot action

The process for delivering the pilot in the 3 countries (Italy, Portugal and Romania) was (Figure 1):

Training of facilitators	Scout of informal carers	Delivering the MAGs	Evaluation of MAGs
• September/October 2019 • A total of 36 certified facilitatores	• From November 2019 until March 2020 • Through professional networks and social media channels	• The implementation of the online MAGs last from November 2019 to July 2020; • 7 groups, on a biweekly or weekly basis; • 34 informal caregivers involved.	• Pre-test • Post-test • Follow-Up

Figure 1. *Process for delivering the piloting*

For the scouting of facilitators and informal carers, all the organizations involved in the pilot resort to their professional networks and social media channels (posts in partners own social media pages but also on several Facebook Groups) to disseminate the information. Organizations and public bodies with work and responsibilities in the field of ageing, caregiving or dementia were also contacted via phone, e-mail or face-to-face. The facilitators who participated in the train for facilitators (Output 4) were also involved in the recruitment process by displaying promotional posters in their organizations or through social media.

Through these strategies it was possible to get a total of 90 registrations. However, due to several aspects not all persons were able to participate. Listed below are the main reasons:

- Incompatible time schedule;
- Death of the care recipient;
- Overloading caused by the care recipients' needs;

- Complexity of the recruitment process (the need to provide signed consent forms);
- Low level of technical skills.

At the end of the recruitment phase, the partnership was able to implement 7 Online MAGs with a total of 34 informal carers involved (see Table 1).

Table 1. *Number of MAGs and Informal Carers involved in the pilot*

Country	Number of registrations	Number of Online MAGs	Number of Informal Carers
Italy	22	3	10
Portugal	26	2	9
Romania	42	2	15
Total	90	7	34

For several reasons, and differently from the original plan, in some groups, the sessions were held weekly, instead of biweekly. Some of these reasons were: the need expressed by informal carers; logistics in terms of fitting in with the timings of the project; strategy for motivating the groups. The partners involved in the pilot also made sure to schedule the sessions for different days and times in order to meet the needs of the informal carers. Each group was facilitated by two facilitators, one professional and one former/ experienced informal caregiver in Italy and Romania, and two professionals in social area in Portugal.

The implementation of the pilot of the **Online Mutual Aid Groups,** took place as showed on Table 2.

Table 2. Implementation of the Online Mutual Aid Groups

Indicators	Country		
	Italy	Portugal	Romania
Number of groups	3	2	2
Number of participants	15	9	26
Average nr. of participants per group	5	5	5
Profile of participants (gender, age, caring role)	10 females – 5 males Mean age: 49 years old Mostly caring for a parent	8 Females – 1 male Mean age: 50 years old, Mostly caring for a parent	Females Mostly caring for a parent (or both); in some cases, the care recipient was another relative: grandparent, sister/brother or a friend.
Video-conferencing platform used	Skype	Zoom and Skype	Skype
Drop out %	0%	31%	≈50%

Some comments about the Spanish process of implementing the pilot.

The Instituto de Salud Carlos III (ISCIII) should have implemented the MAG pilot in Spain as originally planned. However, a number of constraints have limited this implementation, from a very early stage, still in the training of facilitators (IO4). In fact, ISCIII found barriers from the moment of recruitment of professionals for the facilitators training (IO4). Following the strategy defined for scoping the potential facilitators, the Social and Professional body, Faculties and Associations working in the field of dementia and caregiving, were contacted in order to disseminate and participate in the training (IO4) and in piloting of MAG (IO2), agreeing in helping with the dissemination, but refusing to participate in both initiatives. The reasons for that difficulties were related with:

- lack of time to attend the course because of their job duties;
- the timing was not the most appropriate, due to the returning to work after the summer holiday period, which translates into fewer human resources in the institution and cumulatively with a very busy time in terms of work;
- job burden;
- unpaid participation;
- lack of ICT skills.

Considering all the difficulties presented, ISCIII didn't managed to implement the pilot. However, they continued to massively disseminate the training course (IO4), with the expectations to have the opportunity to implement both the training of facilitators and MAGs.

Results and evaluation

The pilots were delivered between November 2019 and July 2020.

The schedule timetable varied according to group/ country. Duration of all groups was 9 sessions, approximately 2,5 months, both on a weekly or biweekly basis.

Italy – Carpi (IT)

Portugal – Porto and Lisbon (PT)

Romania – Bucharest (RO)

The MAGs were launched in October 2019, with the goal to start the pilots in early November 2019.

To promote the MAG, a poster and a leaflet were developed to be disseminated on-line through social networks and mailing-lists and in strategic places like primary health centres, pharmacies, parish councils, coffee, groceries shops, among others, by each partner. The dissemination and recruitment lasted until March 2020, as some partners were unable to gather the minimum number of participants to start the groups in November.

Quality Indicators

The CARE4DEM project foresees the achievement of a series of quality indicators. Below are the results for those related to the Mutual Aid Group implementation (IO2) (Table 3). Indicators related with subjective experience or impact of caring of someone with dementia (like satisfaction with care and stress/burnout) are analysed in the following sections.

Table 3. Quality Indicators

Indicator	Goal per country / Total Goal	Results obtained				Total achievement
		Italy	Portugal	Romania	Spain	
No. of pilots	1/4	1 (100%)	1 (100%)	1 (100%)	0 (0%)	3 (75%)
No. of MAGS piloted	8/32	3 (37,5%)	2 (25%)	2 (25%)	0 (0%)	7 (23,3%)
No. of caregivers participating in MAGs	48/192	15 (31,25%)	9 (18,75%)	26 (54,17%)	0 (0%)	50 (26,04%)

Evaluation of the results

The pilot of IO2 followed an evaluation model pre post-test type, in order to asses if some dimensions of the informal caregivers, find previously in the literature and evidence review as relevant, enhance with the participation in the mutual aid group. Several problems came unexpected that prevented to compare the results in the pre-test and post-test moment:

- The pre-test evaluation form was sent to every person that applied to participate in the MAGs. Some of them continue to participate, and some gave up before the beginning of the MAG. For the reasons explained in the next points, we were not able to distinguish all the ones that actually participated in the MAGs from the ones that dropout;

- In order to keep all data anonymous, people that filled the pre-test questionnaire generated a code using some personal data, not easily changeable, at least in the period of two months (namely the first letter of IC mother's baptism name; the month of the IC birthday; the first letter of IC father's baptism name; number of the

IC door in the address). This method was found in the literature to be reliable and widely used for anonymization;

- The same method was used in the post-test questionnaire, and this would allow i) to match the participants' pre and post-test questionnaires and make comparable analysis; ii) to select which questionnaires in the pre-test belonged to effective participants in the MAGs, if everyone participating in the MAGS filed the post-test questionnaire;

- From the 25 people in the pre-test and 20 people in the post-test that correctly filled their questionnaires, it was possible to match only 4 participants; we believe that most of the participants filled the code in different ways in the pre and post-test questionnaires, but still we could not rigorously match them;

- Some participants seem to have filled the pre and/or the post-test more than once. In this case, the following criteria (in this order) were used to decide on which questionnaire to be considered- i) check for resemblances regarding code, gender and age, the ones that match in all variables are considered duplicate; ii) check for missing data in the duplicates, and choose the more completed data; ii) if not, chose the first questionnaire filled and eliminate the other ones;

- Participants with missing data in all or almost all scales were eliminated from the data base;

- Participants with missing data in one or two tools, but with reliable data in the others were considered for the analyses of the last ones.

Considering all these constraints, it wasn't possible to make more sophisticated and comparable analysis. Even though, there is a lot of relevant information to take from this assessment that give us some clues on the effects of the participation on MAGs.

So, data was analysed and is presented in the following manner:

- Sociodemographic profile of the people that applied to participate in the on-line MAGs and that correctly filled the pre-test questionnaire VS sociodemographic

profile of people that actually participated in MAGs and correctly filled the post-test questionnaire (for simplification purposes, henceforth referred to as participants in the pre-test and participants in the post-test, respectively);

- Context and relationship of care;
- Subjective dimensions of care;
- Experience and satisfaction with MAGs (only in the post-test moment).

The evaluation protocol was constituted by the following tools, for which the project has been authorised for use:

- **Resources Utilization in Dementia** (RUD©, Wimo, Wetterholm, Mastery & Winbald, 1998) aims to collect data on resource utilization in order to calculate costs of patient care (healthcare resource utilization) and caregiver time in Dementia. With it is possible to collect data about the informal caregiver, the care receiver and the context of care. Although it is a very large instrument with a big number of items, relevant items should be selected to integrate the sociodemographic questionnaire, which may be complemented with questions considered important. RUD© was developed to be used in multinational studies to ensure consistency in data collection across countries and has been largely tested and has validation translations in 58 languages, including English, Portuguese, Spanish, Italian and Romanian (https://rudinstrument.wordpress.com/home/languages/). RUD© has a large and short version (RUD Lite).

- **The General Self-Efficacy Scale** (GSE, Schwarzer & Jerusalem, 1995). GSE is a 10-item measure of general sense of perceived self-efficacy, in accordance with the definition that self-efficacy is the belief that one can perform a novel or difficult task, or cope with adversity. In literature related with care, self-efficacy can be conceptualized as global, specific to caring or specific to particular caring domain/tasks. Considering criteria like feasibility to be performed online, number of items and versions (in the different languages of the project partners), this measure of global self-efficacy was

chosen. The GSE is translated to 30 languages (http://userpage.fu-berlin.de/~health/selfscal.htm) and is free of use.

- **Care Related Quality of Life** (CarerQol, Brouwer, van Exel, van Gorp & Redekop, 2006) The CarerQol is a measure to assess the care related quality of life (QoL), assessing the impact of providing informal care, subdivided in two measures, one assessing subjective burden (CarerQoL-7D) and another with the valuation of informal care in terms of well-being (CarerQoL-VAS). This measure allows to evaluate the impact of an intervention in terms of burden/QoL, but also from an economic point of view. The CarerQol measure is part of the Institute for Medical Technology Assessment (iMTA) Valuation of Informal Care (iVICQ) questionnaire (www.imta.nl/careqol), is available in several languages, namely English, Portuguese, Spanish and Italian (not in Romanian) and has been used in other projects, namely a European study named Actifcare (http://actifcare.eu/). The CarerQol is short (8 items in total), and although not assessing individually all the dimensions that interventions like peer-support groups seem to have effect in, it is a measure of burden and includes relevant items regarding for instance mental health, which was used for that purpose in this project. Although it is not a measure of depression, mental health is covered in a global subjective way.

- **Experience of participation in the peer-support group** (only in the post-test moment)- Besides well stablished constructs, it is important to collect also the subjective experience of participating in the peer-support group. Within the CuiDem Project (www.cuidem.pt) a tool, including items from several measures and others developed to assess the subjective experience of participating in a face-to-face MAG was developed, including also a question on general satisfaction with the participation in the peer-support group, and a qualitative question on positive and negative aspects of it. The original questionnaire has 23 questions, but for the purpose of this project, some items that don't fit within the project's scope were eliminated and others adapted, resulting in a total of 19 items (Projeto CuiDem, 2015-2017).

- **Informed consent** consistent with the General Data Protection Regulation is also included in the evaluation protocol. It needs to be signed by caregivers involved in the process, confirming they agree to provide information and data about their participation in the project and in evaluation activities through questionnaires and interviews.

Sociodemographic profile

Although not comparable, since there is only certainty about four of the participants being the same in the pre and post-test data, looking at the sociodemographic characteristics of participants in each moment is interesting in order to understand if there are some characteristics that differentiate both groups. Yet, we should always keep in mind that these are two different groups. As can be seen from table 4, there are more participants in the pre-test evaluation than in the post-test, although it seems clear that not all the participants completed, or at least in a valid way the pre-test questionnaire (for instance there is data from more participants in the Italian post-test moment than in the pre-test).

Table 4. Sociodemographic profile in pre and post-test samples

Indicators		Pre-test				Post-test			
		Total	IT	PT	RO	Total	IT	PT	RO
Participants (n)		25	7	13	5	20	9	9	2
Sex (n)	Male	5	3	2	0	3	2	1	0
	Female	20	4	11	5	17	7	8	2
Age ($\overline{X}$)		51.80	49.00	53.31	51.80	51.16	51.78	55.00	33.00
Children currently living with IC ($\overline{X}$)		0.44	0.43	0.54	0.20	0.26	0.11	0.50	0.00

There is a slightly percentage of men in the pre-test (20% against 15% in the post-test), and age is similar considering the total number of participants, but when looking at the Romanian case, age mean is much lower in the post-test. We can speculate on the reasons for this difference: for example, younger people may be more competent with the technologies, facilitating their maintenance in MAG, but also the use of online assessment tools; and younger people may be more resilient, better able to cope with stress and the burden of informal care and therefore feel more able to stay in MAG. However, mean age increased slightly in Italy and Portugal from the pre-test to the post-test. Although this increase does not seem to be very significant, it may be related to a greater homogeneity of the MAGs they have attended in terms of age, which is in line with the national profiles of the informal

caregiver, in addition to the fact that they are 2 countries in southern Europe where the generations just below assume responsibility for care. The number of children is lower in all countries between pre and post-test, which may be related with the burden of caring/ dealing with children at home, plus the burden of care, and responsibilities in other areas in life (work, marital relationship, social, etc.). Perhaps having children living at home can be a factor that makes it difficult to reconcile all these responsibilities with participating in an MAG, or just fulfilling the tasks associated with it, such as filling in the evaluation questionnaires.

Pre-test evaluation

a. Socio-demographic profile of the group of people that applied to the on-line MAGs

The number of registrations in total (Italy, Portugal and Romania) was 90, only 25 people completed a valid pre-test evaluation, which is only half of the participants that actually participated in MAGs (both in a continuous or sporadic basis). The mean age of these 25 participants is 51.80 (Graphic 1), 20 are female and five are male (Graphic 2), three males are from Italy and the other two are from Portugal. Eight informal carers related having children living with them, with a mean number of 0.26 (for the 25 participants), ranging from zero to two (Graphic 3).
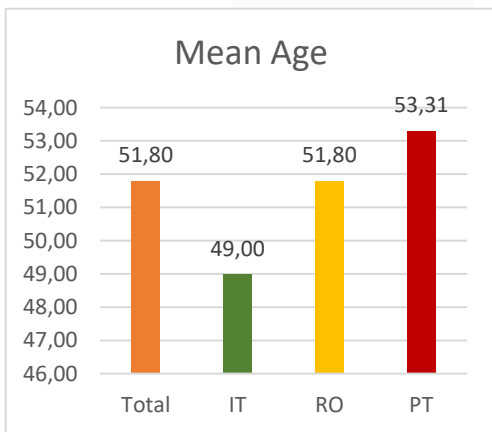
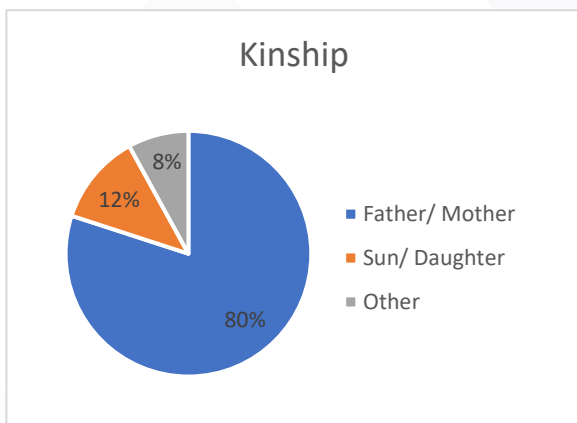**Graphic 1.** *Mean age in pre-test*
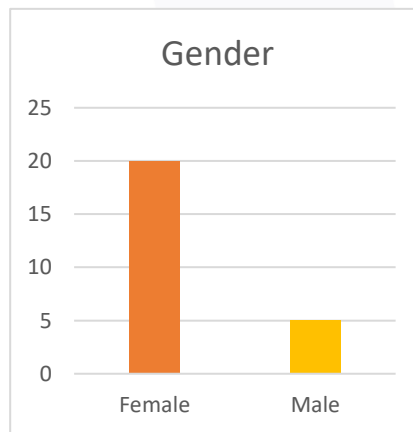

Graphic 2. *Gender in pre-test*
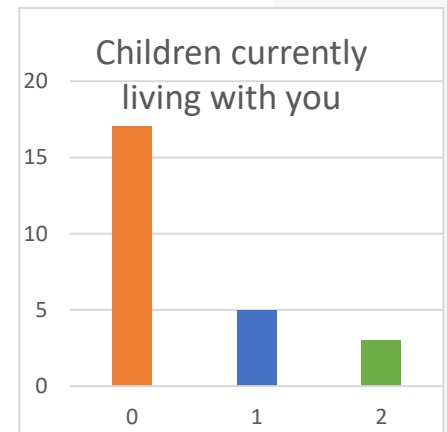
Graphic 3. *Children living with IC in pre-test*

b. Context and Relationship of Care

Looking at the context of care, the vast majority of the participants take care of their parent (n=20) (Graphic 4). Regarding living arrangements, about 56% (n=14) of participants live with the person they take care of (Graphic 5).


Graphic 4. Degree of kinship of the person cared for in relation to the CI
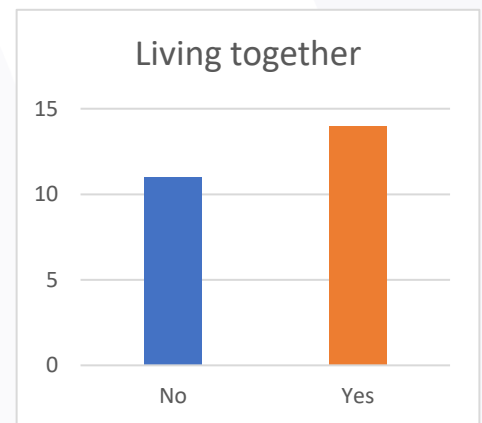
Graphic 5. Living arrangements

Considering the objective burden of care, several indicators were evaluated: the level of contribution to care, the presence of other informal carers and professional help, the number and type of tasks performed, and time providing care. Additional information on time of sleep was also reported.

The level of contribution to care varies. Almost half of the participants that completed the pre-test (44%, n=10) provide on average between 80 and 100% of informal care, and 30% of the participants (n=7) between 61 and 80% (Graphic 6), which means that most of them provide and are responsible for much of the care.
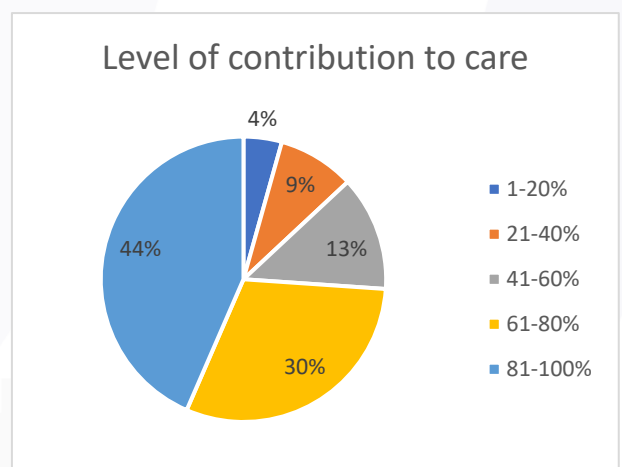
Graphic 6. Level of contribution to care in pre-test

Other informal caregivers involved in care

- 4 or more Informal Caregivers: 1
- 3 Informal caregivers: 1
- 2 Informal Caregivers: 6
- (orange): 9
- (blue): 8

Graphic 7. *Number of other informal carers involved in care*
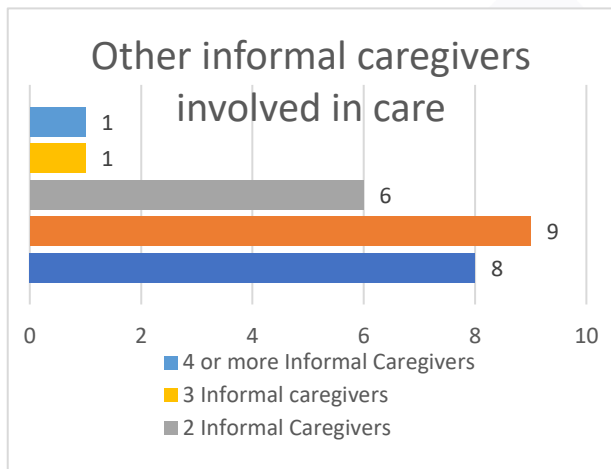
Nevertheless, almost 70% (n=17) of them have help from at least one other IC, while 32% of the IC (n=8) have no support at all (Graphic 7). Professional help is a reality for 9 of the IC, like formal caregivers, physiotherapist, psychiatrist, among others. In a regular day, IC sleep in average 6,68 hours, ranging 4 to 8.5 hours.

Informal Caregivers perform on average 7,24 care tasks out of a universe of 13 ADLB and ADLI, which is more than half of the caregiving tasks, presenting an objective burden of caregiving, but also giving some cues on the dependence level of the person with dementia being taking care of. These tasks are described in Graphic 8, where it is also possible to observe the number of caregivers performing each task. Taking medication (n=21), taking a shower (n=17) and get dressed (n=17) are the activities of daily living which are performed by more of the participant, while, taking care of clothes (n=9) is the ADL less performed by caregivers. In average, the informal caregivers spend 8,73 hours a day caring for their relative/friend, ranging from 1,5 hour to 19,7 hours. The average amount of time that IC spend in caregiving is more than one third of the day, and almost half of the "useful time" (considering the time they spend agreed) IC have during the day.
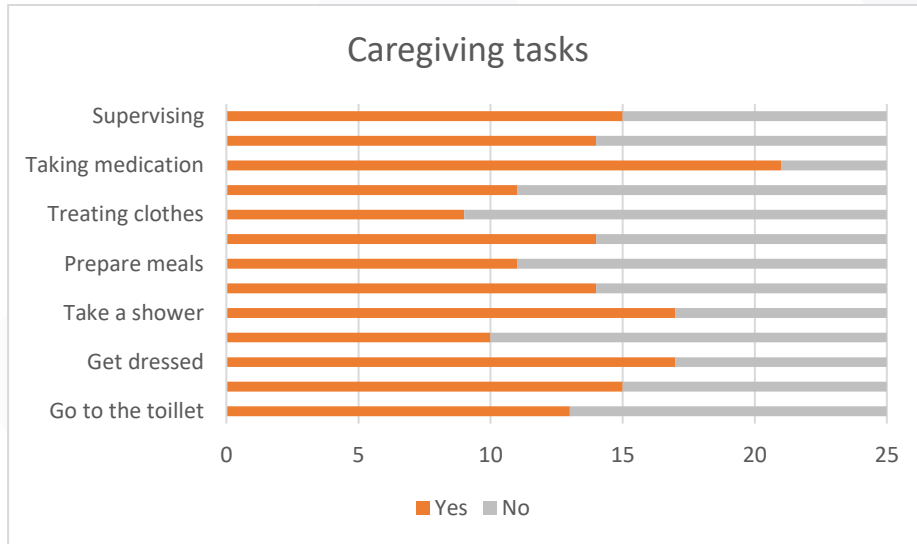
Graphic 8. *Performance of Basic ADL and Instrumental ADL (caregiving tasks) in pre-test*

c. Subjective dimensions of Care

Impact of care was measure considering dimensions that would change positively with participation in the MAG- self-efficacy, mental health and quality of life.

Considering all the constraints mentioned before, it will not be possible to compare systematically the results between pre and post-test. However, it is still interesting to look at this data to have a picture of what are the persons that register for the MAG and willing to fulfil the pre-test questionnaire. The mean score of general self-efficacy measured by the General Self-Efficacy Scale (GSES- Schwarzer & Jerusalem, 1995) before the beginning of the MAG was 29,2 [min-10; max-40, the higher the score, higher the general sense of self-efficacy]. Results in this sample ranged from 16-40. The GSES Score is very interesting for stablishing a baseline and then compare it within a time frame after an intervention, like the participation in a MAG. Since we cannot match participants between the pre and post-test, and since there isn't a cut-off point, there is studies that may give us some clues on how our sample is in what regards self-efficacy. For instance, in a study with people living in the community from student to old people in Germany, the mean score on the GSES was 29.28 (Schwarzer, 1993), this may indicate that the informal carers in our sample do not have a sense of self-efficacy very different from the adult population living in the community in a European country.

Mental health problems were assessed through item b of the CarerQol-7 questionnaire ["I have- no, some, or a lot- of problems with my own mental health (e.g., stress, fear, gloominess, depression, concern about the future]. In response to this item, 9 IC said they had a lot of problems with their mental health, while 11 said they had some problems, which represents about 80% of the carers who answered the question, stressing the impact that caregiving can have on the mental health of informal caregivers.

Quality of life was assess using the CarerQol-7D (Brouwer, van Exel, van Gorp, & Redekop, 2006), where scores range from 0 to 14, with higher scores translating better perceived quality of life. The mean score for the 25 participants was 6,32. Additionally a measure of general happiness was used (CarerQol-VAS, Brouwer, van Exel, van Gorp, & Redekop, 2006), a visual analogic scale ranging from 0 (totally unhappy) to 10 (totally happy). Our participants score on average 5.48 points in this scale. In a sample Dutch heterogenous caregivers, the

average score of the CarerQol-Vas was 5.7, slightly higher than our sample average (Brouwer, van Exel, van Gorp & Redekop, 2006).

Post-test evaluation

a. Socio-demographic profile

Only 20 of participants completed a valid post-test questionnaire. The mean age of these participants is 51.16 (Graphic 9), 17 are female and three are male (Graphic 10), two males are from Italy and the other one is from Portugal. The mean of children living with the informal caregivers is 0.26, ranging from zero to two (Graphic 11), but only four participants have children living with them, one from Italy and three from Portugal. IC sleep in average 7,83 hours a day.
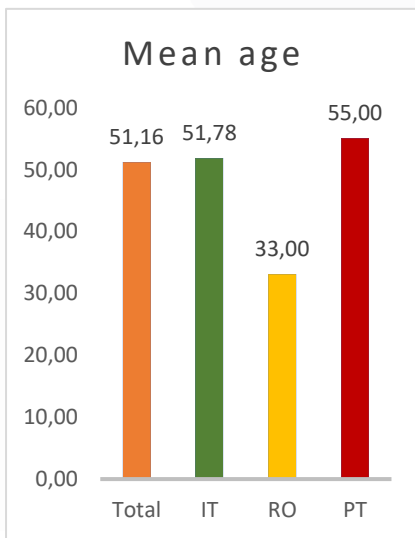

Graphic 9. *Mean age in post-test*
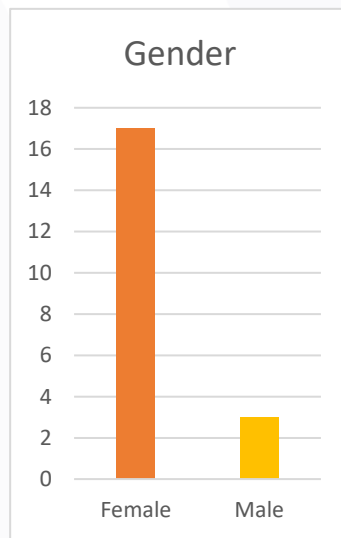

Graphic 10. *Gender in Post-test*
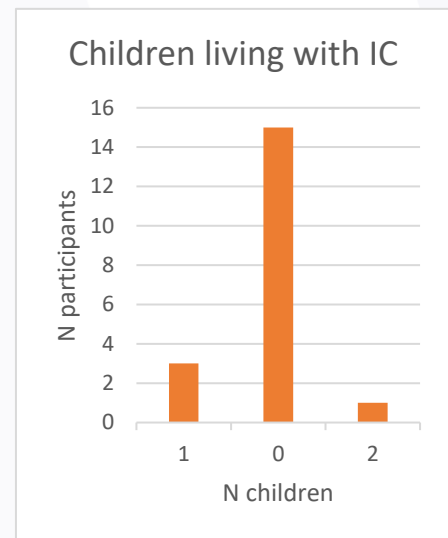
Graphic 11. *Number of children living with IC*

b. Context and Relationship of Care

Looking at the context of care, the vast majority of the participants take care of their parent (n=16), and all the other take care of someone from their family, except one, which takes care of a friend (Graphic 12). Regarding living arrangements, about 55% (n=11) of participants live with the person they take care of (Graphic 13).
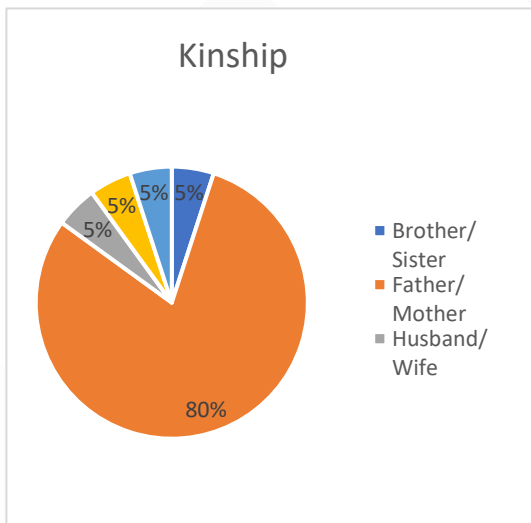
*Graphic 12. Degree of kinship of the person cared for in relation to the CI*
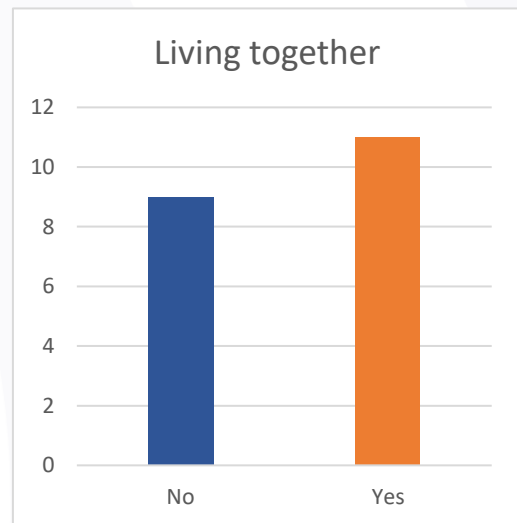
Graphic 13. Living arrangements

Considering the objective burden of care, several indicators were evaluated: the level of contribution to care, the presence of other informal carers and professional help, the number and type of tasks performed, and time providing care. Additional information on time of sleep was also reported.

The level of contribution to care varies. It should be noted that 25% (n=5) of IC provide on average between 80 and 100% of informal care, and 30% of the participants (n=6) between 0 and 20% (Graphic 14). A great number of IC (n=11) have help from one other IC. In total, fifteen of them have support from at least another IC, while 25% of the IC (n=5) have no support at all (Graphic 15). Professional help is a reality for 7 of the IC, varying from formal
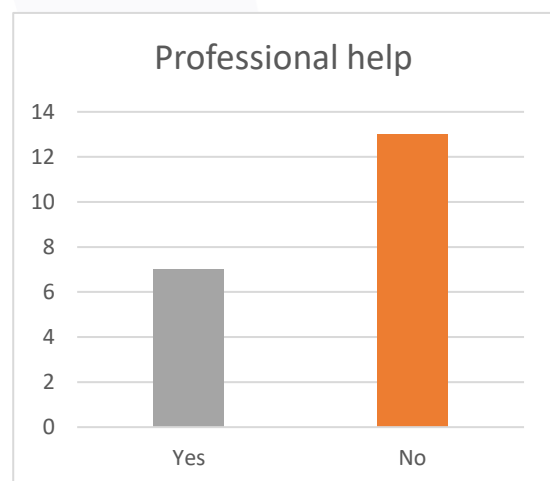
caregivers, to physiotherapist, psychologist, home care and general practitioner (Graphic 16). In a regular day, IC sleep in average 7.79 hours, ranging 5.5 to 12 hours.
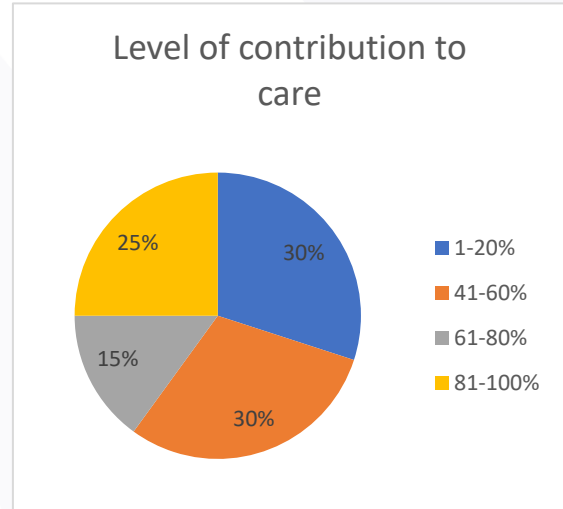
Graphic 14. Level of contribution to care in post-test
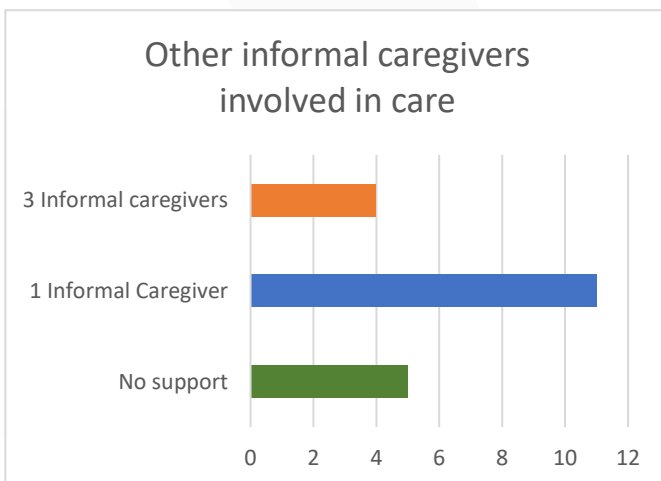
Graphic 15. Number of other informal carers involved in caregiving

Graphic 16. Professional help in post-test

Informal Caregivers perform on average 7,10 care tasks out of a universe of 13 ADLB and ADLI. These tasks are described in graphic 17, where it is also possible to observe the number of caregivers performing each task. Taking medication (n=17), supervising (n=15), treating clothes (n=13), taking a shower (n=12), get dressed (n=12) and feed himself (n=12) are the activities of daily living which are performed by more of the participant, while, transportation (n=5), preparing meals (n=7) and go shopping (n=9) are the ADL less performed by caregivers. In average, the informal caregivers spend 7,42 hours a day caring for their relative/friend, ranging from 1 hour to 18 hours.
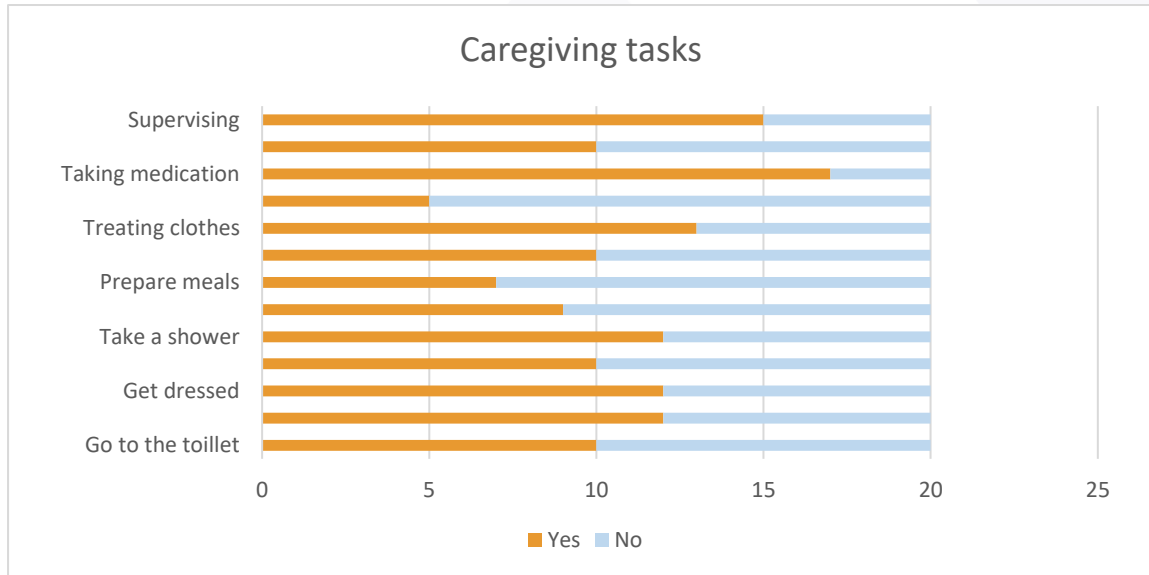
Graphic 17. *Performance of Basic ADL and Instrumental ADL (caregiving tasks) in pre-test*

c. Subjective dimensions of Care

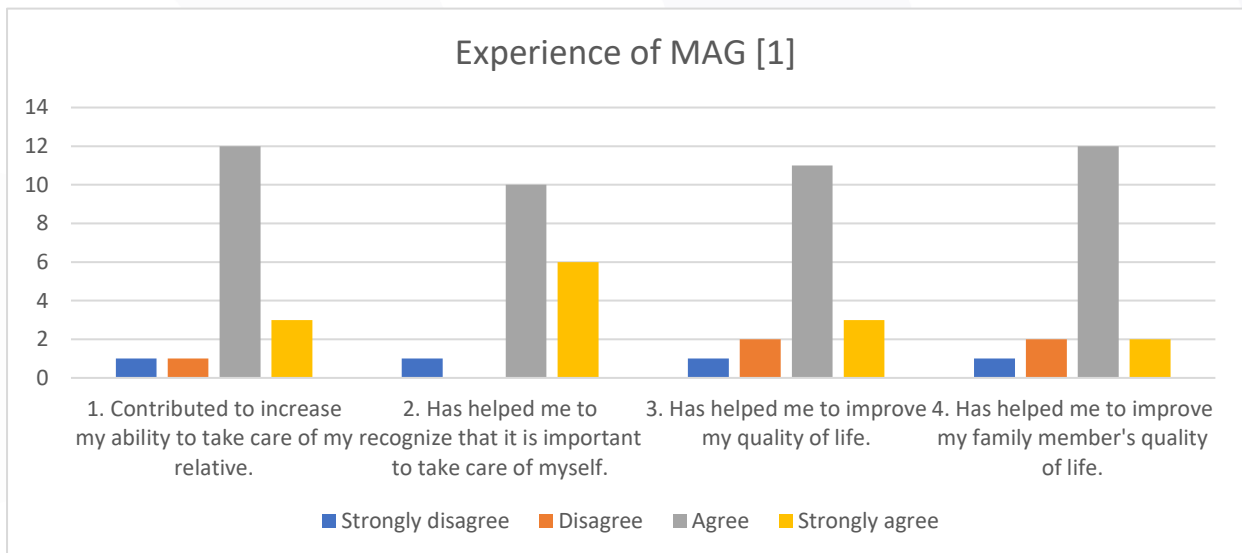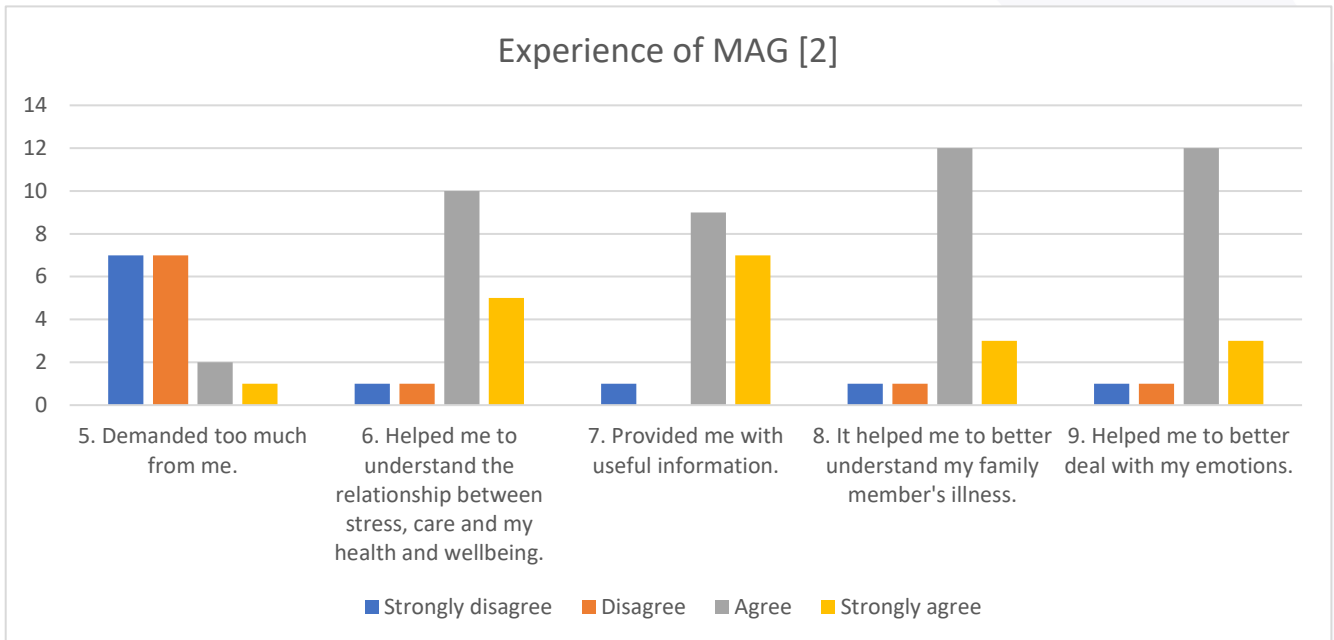The mean score of general self-efficacy measured by the General Self-Efficacy Scale at the end of the MAG was 27,12 [min-10; max-40, the higher the score, higher the general sense of self-efficacy], which is lower than the average score for the pre-test sample. Since the samples are not constituted by the same subjects, we cannot say that the sense of self-efficacy has decreased. However, we can look at other variables that were assessed, in order to have a clearer picture of these people at post-test. People in the pre-test contribute in a higher level to care than people in the post-test, which may contribute to their sense of self-efficacy based on the experience and acknowledgment they had to gain. Also, participants in the post-test have less help from other, when comparing with people from pre-test, which may contribute to more difficulties not only in the performance of tasks, making it harder to have enhanced sense of self-efficacy. However, 62.5% of people in the post-test refer having some or a lot of mental health problems, a better sense of quality of life related with care (mean score 7.87), but lower general happiness (mean score 4.64). As stated previously, we cannot make assumptions on the effects of participating in MAG, since the people from the pre and post-test may not be the same. However, it is very interesting to see how people describe their participation in MAG, even reporting lower levels of general happiness and sense of self-efficacy.

1. Satisfaction

Graphics 18 to 21 show how people experienced the effects of participating in the MAG. Most of the participants refer that participating in the MAG has helped/ enabled them to recognize the importance of taking care of themselves, feel confident and more secure in their caregiver role, meet new people and make new friendships, and provided useful them with information. There is one participant that strongly disagree with almost all items of the questionnaire related with the experience of participating in MAG, but the same participant referred to be overall very satisfied with the MAG.

Graphic 18. *Participants subjective experience of participating in the MAGs*

Experience of MAG [2]

Legend: Strongly disagree · Disagree · Agree · Strongly agree

- 5. Demanded too much from me.
- 6. Helped me to understand the relationship between stress, care and my health and wellbeing.
- 7. Provided me with useful information.
- 8. It helped me to better understand my family member's illness.
- 9. Helped me to better deal with my emotions.

Graphic 19. Participants subjective experience of participating in the MAGs (cont.)

Experience of MAG [3]

Legend: Strongly disagree · Disagree · Agree · Strongly agree

- 10. Helped me how to take better care of myself.
- 11. Helped me feel more secure and confident in my role as caregiver.
- 12. Allowed to meet new people and make some friendships.
- 13. Helped me to better understand the changes in my relative and to acquire strategies that allow me to deal adequately with those changes.
- 14. It made me accept my situation better.

Graphic 20. Participants subjective experience of participating in the MAGs (cont.)

Experience of MAG [4]

Categories:
- 15. It gave me knowledge that allowed me to improve the relationship I have with my relative.
- 16. It made me feel useful for sharing my experience with other caregivers.
- 17. It made me realize that there are other people in the same situation as me and that what I feel is normal.
- 18. It made me feel happy for being able to help the other peer-support group elements to solve their problems
- 19. Caregivers, by speaking about their experiences, helped me to solve/overcome my problems/ difficulties.

Legend: Strongly disagree · Disagree · Agree · Strongly agree

Graphic 21. Participants subjective experience of participating in the MAGs (cont.)

Looking at participants' general satisfaction with the MAG in Graphic 22, it is possible to observe that participants were very satisfied, with no participants reporting being unsatisfied or very unsatisfied. Actually, more than 50% of them were totally satisfied and almost quarter (24%) of the participants were very satisfied. All the others were satisfied (23%).

General satisfaction with MAG

- 0%
- 0%
- 23%
- 24%
- 53%

Legend: Very unsatisfied · Unsatisfied · Satisfied · Very Satisfied
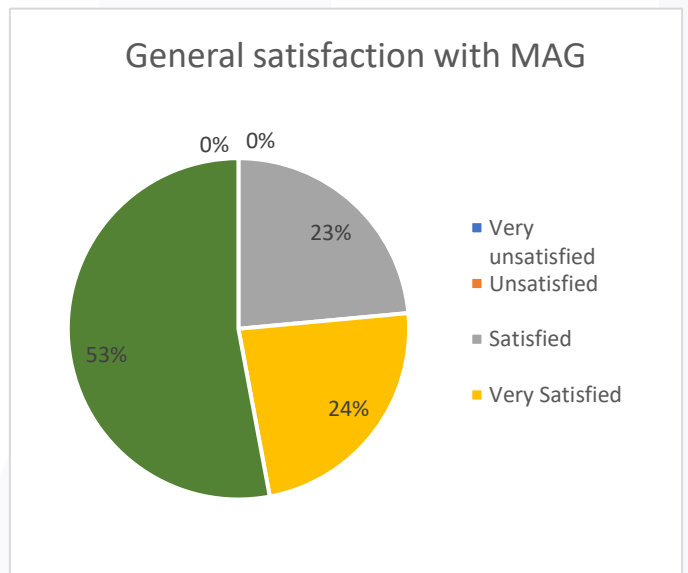
Graphic 22. General satisfaction with MAG

Participants also had the opportunity to express the most positive and negative aspect and the importance of being in the support group they took part of. The positive and negative aspects are systematised in table 5.

Table 5. Positive and negative aspects of the MAG

Positive Aspects	Negative Aspects
Better understanding of the carer role	Limited time of the meetings
Possibility of improving the role of carer	Limited number of sessions
Identification and acceptance of their current situation	No script or topics previously defined
Awareness of the disease	No face to face support
Enhanced knowledge about the disease and caregiving	Lack of practical help (economic help, help with the caregiving tasks, link to resources that may give this help without financial burden, etc…)
On-line meetings	

The positive and negative aspects reflect the aims proposed model and definition of mutual aid group adopted in the CARE4DEM Project. Peer-support can be defined as the process of giving and receiving nonprofessional, nonclinical assistance from individuals with similar conditions or circumstances. A peer support group (or mutual-aid group – MAG) happens when people experiencing similar conditions, voluntarily gather together to receive support and provide support by sharing knowledge, experiences, coping strategies, and offering understanding (In CARE4DEM, 2020, Web-based mutual aid groups model and implementation guide- Intellectual output 2). Naturally, some of the decisions and options taken by the projects partners regarding the model of MAG to be used in the CARE4DEM had influence in the results achieved. For instance, the option of having the presence of 2 facilitators, with at least one of them a professional of the social or health sector, may have created the expectations that the group would systematically have an educational and informative dimension, with sessions with defined topics, led by professionals. The purposes of the online MAG model adopted in this project do not meet these expectations, at least

not in the formal sense, since the role defined for the facilitators was to establish the format and functioning of the group and eventually facilitate interaction between the group members. The general objective of the sessions was the exchange of emotions and experiences between the caregivers, in a logic of mutual help. In addition, and already anticipating these expectations, an online forum was also created where participants (including facilitators) could share information material, curiosities, links of interest, and seek support between sessions if necessary. However, the use of the forum has not become widespread, even when stimulated by the facilitators. This project is an effort to boost the use of MAG, to increase its visibility and familiarity with the model, which, despite the benefits found in the literature, is not yet widespread among caregivers. However, participants' reports are unanimous about the importance and perceived benefits of involvement in MAG, and these can be seen in Graphics 18 to 22, table 5, as well as in the comments that we transcribe below (which are only a sample):
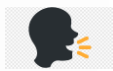
"It was the first time I could talk about my situation with people who could understand... The online performance allowed me to participate in a group even though I was in the home of the person I was assisting. I realized that I'm not the only one in a difficult situation." (Carer, Italy)

"I chose to participate in this group because it is very important for me to share my experiences of life in contact with dementia. I found this experience useful for my growth and I would like to create a self-help group here in Salerno where I live." (Carer, Italy)

"Knowing people who care for their loved ones in the same situation as my loved one or even in worse situations has made me accept my current life better. My group has been very united and we still feel in a WhatsApp group so we can still share our difficulties and joys. Thank you to everyone who organized this meeting." (Carer, Italy)

"I loved it, it was very good, I took very good lessons, spectacular group ... less positive lasted a short time." (Carer, Portugal)
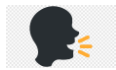
"Being a caregiver for a person with dementia is not an easy task or unique case. Participating in these case sharing sessions has only further enriched my knowledge. I only have to thank you for the opportunity to participate in these sessions." (Carer, Portugal)

"This group helped me a lot, it is the first time I had the opportunity to talk to people tormented by the same anxieties as me, of different ages and from different backgrounds, the common denominator being the fact that we take care of someone dear and sick. I felt like I belonged to a group with similar sufferings. I received encouragement from others, I also noticed different approaches to the issue, I received advice that I will take into account in the future. I looked forward to this meeting every week and after that I always felt more energized, with a reduced emotional burden." (Carer, Romania)

Comparing pre and post test

As stated previoulsy, there were some difficulties in matching the pre-test results with the post-test results, either because not all subjects filled in the pre-test, because of a mistake in filling in the code, or even because of the need not to consider some questionnaires that were inadequately filled in. Thus, in the end it was only possible to match the pre- and post-test questionnaire of 4 participants, and only 1 match between the post-test and follow-up data. Considering that they are very few subjects, we will make an individual analysis of each one of them and eventually draw some more general conclusions. Tables 6 and 7 show the comparative results between the indicators for the context of care, as changes at this level may have an influence on the results of the impact dimensions per GAM participation, which were also analysed.

Table 6. Comparing context of care in pre and post-test moments

| | Subject 1- Italy | | Subject 2- Italy | | Subject 3- Portugal | | Subject 4- Portugal | |
	Pre-test	Pós-test	Pre-test	Pós-test	Pre-test	Pós-test	Pre-test	Pós-test
Co-habitation	Yes	Yes	Yes	Yes	Yes	Yes	No	No
Other carers involved	1	1	0	1	0	1	2	1
Level of contribution to care	41-60%	41-60%	41-60%	41-60%	81-100%	81-100%	21-40%	1-20%
Professional help	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Type of professional help	Psychologist	Psychologist	Formal Carer	Formal Carer	--	--	Psychiatrist	Fisiotheraphy
Hours sleeping	8,5	8,16	8	8	8	8	8,5	8,5
N caregiving tasks	2	2	6	7	7	11	1	4
Time spend in careviging task	8,5	3,16	6	5,5	12	16	2,5	1,5

Table 7. *Comparing subjective dimensions of care in pre and post-test*

	Subject 1- Italy		Subject 2- Italy		Subject 3- Portugal		Subject 4- Portugal	
	Pre-test	Pós-test	Pre-test	Pós-test	Pre-test	Pós-test	Pre-test	Pós-test
GSE 1	3	3	4	4	3	--	3	4
GSE 2	3	3	4	4	2	--	2	3
GSE 3	3	3	4	2	3	--	4	4
GSE 4	3	3	4	3	2	--	3	3
GSE 5	3	3	3	3	3	--	3	3
GSE 6	2	3	3	2	3	--	4	4
GSE 7	3	4	2	3	3	--	4	4
GSE 8	3	3	3	2	3	--	3	3
GSE 9	4	3	3	3	3	--	4	4
GSE 10	3	3	3	3	3	--	3	3
GSE Total Score	30	31	33	29	28	--	33	35
CarerQol-7D a	1	1	2	2	1	--	1	0
CarerQol-7D b	2	1	2	2	1	--	2	2
CarerQol-7D c	0	2	1	1	1	--	2	2
CarerQol-7D d	0	2	0	1	1	--	2	2
CarerQol-7D e	1	2	1	1	1	--	2	2
CarerQol-7D f	1	0	1	0	1	--	0	0
CarerQol-7D g	0	1	1	1	1	--	2	2
CarerQol-7D Total Score	5	9	8	8	7	--	11	10
CarerQol-VAS	5	6	7	5	7	--	9	--

Tables 6 and 7 show that the participants in question changed some of their context of care and subjective dimensions of care. For instance, 3 of the participants diminuished the time they spend in performing caring tasks, although two of them have enhanced the number of taks performed. Also, 2 of them also gained one informal carer to help them with care taks, while another one lost this help. Looking at self-efficacy, it seems that self-efficay has enhanced for two of the participants, and diminuish for one of them. Scores in quality of life and general hapiness have also smoothly changed in both directions for different subjects. It is difficult to make assumptions on the effects of the participating in MAG on the basis on 4 subjects, one of which has not made available data on the subjective aspect of care. However, there is a common denominator among the 3 of the participants (1 of them did not answer the satisfaction questionnaire), that is that all 3 are agree on the positive aspects of participation in MAG and the subjective impact of this experience (assessed through the Experience of MAG questionnaire). All of them report to be tottally satisfied with this participation. They report that being in the MAG had a positive impact in their lives, in the way they see their role as caregivers and in the quality of the care provided and relationship with the person they take care of. It is safe to say, from the results that we obtained that, although it was not possible to confirm the formal impacts in formal measures because of the constraints previously mentioned, theis kind of intervention makes a difference in infromal caregivers life, contributes to their sense of well.being and acceptance of their role, provides coping strategies by the experience of other people in the same situation, and ultimatly contributes to the quality of care and of the relationship between the diad in caregiving.

Contents' Quality Assessment

The piloting of the Online Mutual Aid Groups allowed the partnership to identify the following strengths and weaknesses:

Strengths	Weaknesses
+ Exchange of strategies to help informal carers to deal with the situation and relieve their burden + Getting to informal carers from different regions + Tackle isolation + Sense of belonging between carers + High level of participation and appreciation by participants and facilitators + ICT seen as a plus, rather than an obstacle to communication + No major technical issues registered	− Recruitment of informal carers − The lack of digital skills and resources (tablet, computer) − Low level of support for carers preventing them to participate in different activities (e.g. GAMs) − Relatively low number of participants

During the initial sessions, there was a general concern among facilitators about the challenges they would have had to face because of the use of ICT resources and the same was perceived by facilitators among participants. As the piloting progressed, both facilitators and informal carers realize that it was obvious that, due to the motivation of the informal carers participating in the pilot, the few ICT problems that may arise would be easily overcome.

Attendance was quite constant throughout the piloting, while the participation and level of sharing evolved with the progression of sessions.

Also, it was possible to get feedback from the facilitators:
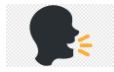
🗣 *"Having started my involvement in a MAG, as a facilitator, I felt, from the first day, very grateful to be able to listen to people sharing their emotions, personal experiences, doubts and knowledge. It was also with great personal satisfaction that I realized, during the sessions, how important the MAG was for its participants who were looking forward to the day of the sessions. It was clear the establishment of social bonds and also the decreasing of isolation. I believe that participating in the MAG had very positive consequences for the well-being of the participants, with direct benefits for the people they care for."* (Facilitator, Portugal)
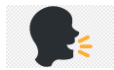
🗣 *"Having the possibility to have a co-facilitator is very important, specially to overcome the technical issues; someone to be right next to the facilitator and who is able to reach participants if they are not able to join."* (Facilitator, Portugal)

🗣 *"ICT was effective, they didn't feel the distance from our interlocutors and everything went smoothly".* (Facilitator, Italy)

🗣 *"For me, it was a unique experience, which made me see the effects of the disease from the perspective of caregivers and not just from the perspective of the professional. The group rules were very useful and led to mutual respect within the group, and the most important aspect was the mutual empathy shown by the informal caregivers. They supported each other to optimize the care activities and efficiently manage the accumulated emotions, especially those of frustration and helplessness. I will definitely use the methods I learned and deepened whenever I feel the need to improve the quality of life of informal caregivers or other persons."* (Facilitator, Romania)

"[...] I wanted to share my experience with other people in similar situations. I hope that no one would have to go through this difficult learning process. I learned that it's very difficult for all caregivers. We all have difficulties, unknown things, fatigue, lack of understanding from those around us. All the meetings and all the materials available in this project proved to be useful for me. I learned a lot of new things: about the support groups, about the interaction in online, and more important how to facilitate a group. In the future I hope we will be able to share our experience with others. I enjoyed sharing and learning in this pilot. It is very pleasant to be a facilitator. I hope the group that I was running will continue the online meetings since we already created a bond." (Facilitator, Romania).

Constraints

The main constraint in implementing the pilot was related to the recruitment of informal carers. Despite all the efforts made by each organization in disseminating the pilot of the MAGs, the number of informal carers involved fell short from what was expected.
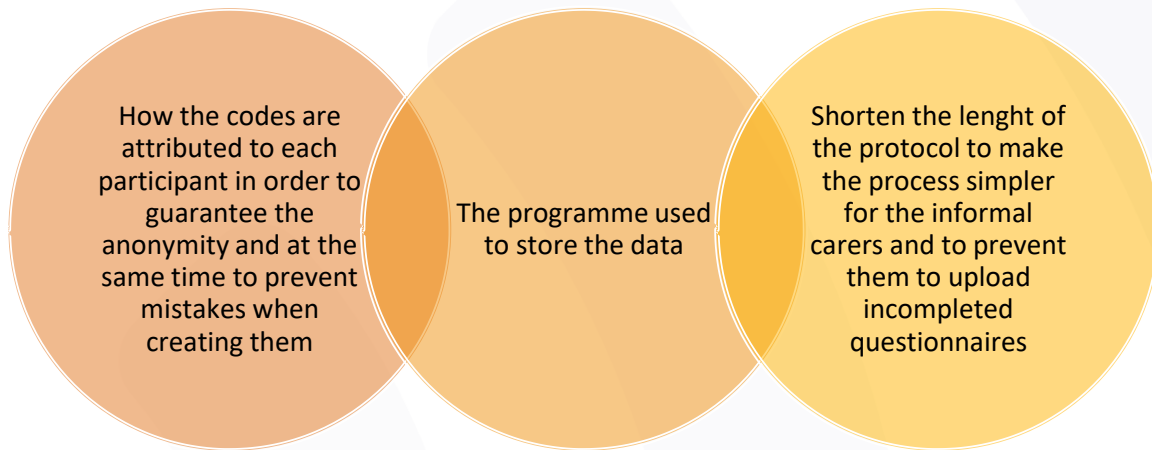
We identified three main reasons that could explain this:

> The lack of tradition of mutual aid groups for informal carers;

> The inclusion criteria set for the piloting, which prevented some potentially interested participants to join because they didn't comply with the criteria;

> The technological barrier that – in spite of the support offered previous to the beginning of the group meetings - could prevent some of the informal carers to feel confident to participate.

Through the experience of implementing the pilot of Online Mutual Aid Groups, the partnership realizes that informal carers, who have such a demanding role, need things to be simple and assertive, so the recruitment and all the phases until the actual implementation need to be simple and easy in order to avoid dropouts during the process. It is also important to make clear that technical support is available and maybe to have a session to explain how to use the devices.

Regarding the evaluation protocol, some aspects need to be considered in order to make the process easy but, at the same time, feasible, namely:

How the codes are attributed to each participant in order to guarantee the anonymity and at the same time to prevent mistakes when creating them

The programme used to store the data

Shorten the lenght of the protocol to make the process simpler for the informal carers and to prevent them to upload incompleted questionnaires

Once the groups started, no major constraints were registered: no major technical disruptions were recorded, attendance was quite constant throughout the piloting, and the participation and level of sharing increased with the progression of sessions. Also, despite the constraints regarding ICT skills, informal carers mentioned that it was a good idea to develop the MAGs online, since it allowed them to save some time, and, at the same time, to be able to supervise the care recipient.

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