RESIL4CARE

RESIL4CARE PR5.A4 Design of the methodologies and confirmation of conclusions and recommendations

Organisation: LAS NAVES

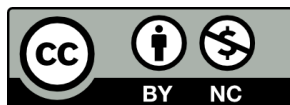Main author(s):
Delmir Giner   LAS NAVES

Other author(s):
Elena Rocher   LAS NAVES
Sara Ceron   ISRAA
Marta Mattarucco   ISRAA

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Executive summary

In previous working documents of PR5 – Adoption and Implementation in Organizations, the Resil4Care partners have delved into the current situation of informal caregivers in Europe, established the basic guidelines for conducting focus groups and systematically organised the information provided by experts in focus groups. Now, this document ends with the compilation of previous information to provide the basic instructions to adopt and implement the Resil4Care methodology in each organization, following a structure similar to that of the development of focus groups.

1.   Introduction

The Erasmus+ funded Resil4Care project aims to improve the resilience of informal caregivers through the use of social media, and involves partners from Patras (Greece), Treviso (Italy), Ljubljana (Slovenia), Nice (France) and Valencia (Spain). The project proposes the creation of Facebook groups that serve as a method of consulting problems, sharing experiences and disseminating practical and useful information for informal caregivers in their daily work. These Facebook groups can be run by social organizations working in the field of care and are in contact with informal caregivers. Precisely, the objective of this guide is to design the way in which social organizations can adopt and implement this methodology, as well as to highlight aspects that must be considered when doing so. To this end, the guide draws on information collected in other parts of the project, such as PR5. A1, which delved into the European political and social contexts related to care and informal care, and also drew in particular on the participative research carried out with experts, established in PR5. A2 and reflected in PR5. A3.

2.   Methodology

The methodology of participative research, on which this guide is based, has already been extensively explained in PR5. A2. However, in a synthetic way and thinking about the possible independent reading of both Project Results, we now proceed to summarize the guidelines established in PR5. A2 – Participative research.

In order to gather opinions and points of view from experts with in-depth knowledge of the field of care and informal care, it was decided to conduct focus groups in four of the project's partner countries: Greece, Italy, Slovenia and Spain. These focus groups were divided into two parts. The first part aims to make a diagnosis of the situation of informal caregivers in each country, with details of the general context, the public policies available regarding this group and the main challenges faced by informal carers. And the second part with the aim of collecting the opinions of the experts on different aspects related to the implementation of the Resil4Care methodology: previous experience, benefits, problems or limitations, essential elements to be able to apply the methodology and final assessment of the toolkit assuming that your own organization implemented the initiative. On the grounds of this division of blocks, this guide is also structured following this logic, so that, after this section, there is a block aimed at analysing the situation of the informal caregiver in each country and, later, it delves into specific aspects of the implementation of the Resil4Care initiative.

As a result, focus groups have been carried out in four different countries with the participation of 55 experts in the field, from different types of organizations: (1) associations of dependent persons / caregivers, (2) private initiatives related to care, (3) NGOs and volunteer organizations for older people or related to care, (4) organizations of prevalent conditions among older people, (5) public organizations related to elderly care and informal care, (6) health centres, residences, day centres, etc. with access to informal caregivers.

3. Diagnosis of the caregiver's current situation

The purpose of this section is to analyse the current situation of informal carers in the pilot site countries of the project (Italy, Slovenia, Greece and Spain). To this end, in the focus groups, experts were asked about (1) the general context regarding economic, political and social issues of informal care, (2) available public policies aimed at them and (3) the main challenges faced by informal caregivers. These three points together will allow us to reach the conclusion of the need to implement the Resil4care methodology, which is addressed in the following section.

3.1. General context

Regarding the general context, all the focus groups agree that, in economic terms, the situation of the informal caregiver is rather precarious. One possible explanation is that they give up part of their working day, that is, they work fewer hours to have more time to be able to carry out care work. This is a phenomenon that occurs in all the countries analysed and, as a result, decreases the income of the caregiver and, ultimately, worsens his or her economic situation. Considering the social and cultural context of the caregivers, it is usually a family member who takes care of a person in need of care, with percentages between 70 and 80%. In addition, in most cases it is women, aged between 50 and 70, who assume this role of caregiver. All the focus groups agreed in pointing out that most of informal care is carried out by women, which allows us to state the feminization of care as a fundamental characteristic of the general context. On the other hand, the fact of placing a family member in a nursing home is socially seen as a stigma, as a symptom of lack of concern for the family. This could be due to the fact that the participating countries share, to some extent, a Mediterranean culture in which family ties are highly important as support networks, especially in terms of care. Another aspect to highlight is the feeling of guilt that many caregivers have in the face of the difficulty of successfully performing their tasks and not providing good care to the person receiving care. This occurs due to the lack of training and specific knowledge about the figure of the caregiver, which results in caregivers feeling overwhelmed. In general, it is widely shared that there is no awareness of the value of care in society, that is, there is a lack of social recognition. In the political sphere, caregivers are not a relevant group in the sense that their viewpoints do not have an impact on public discussion. No matter how much the associations try to lobby for their demands, they do not manage to have enough strength for their voice to set the political agenda.

3.2. Public policies available

In relation to public policies, the participants agree that there is no set of public policies specifically aimed at increasing the resilience of this sector of the population. While there are initiatives and resources aimed at informal caregivers, such as training schools and awareness campaigns, the vast majority come from the NGO sphere, i.e. they are not government actions. In addition to the scarcity of public resources available to caregivers, there is also a lack of knowledge about these public mechanisms aimed at them. In this sense, the bureaucratic burden of applying for aid is a barrier, since many caregivers have neither specific administrative knowledge nor time to inform themselves in detail about it. One of the most highly valued policies among professionals are the "respite programs", which aim to provide time-limited

breaks to caregivers through the organization of collective activities aimed at the receivers of care. In any case, there is a wide gap between the level of need for public actions and the final public resource offered. What is offered is always very small in comparison to what is needed. In conclusion, there is total agreement that there is a gap in public policies specifically aimed at informal caregivers in general and promoting their resilience in particular. In addition, a possible explanation for this is suggested, and that is that public administrations have become accustomed to social entities resolving as far as possible certain problematic situations that should be the responsibility of the administrations, since they aim to achieve social integration and well-being of the population.

3.3.   Main challenges

Finally, the experts were asked about the (3) main challenges faced by caregivers. In this regard, the following stand out:

- The lack of specific training of caregivers, as they have to face complex situations that require specific knowledge (for example, how to act in case the person being cared for refuses to take the prescribed medication). Caregivers have not sought to have that role, but it has fallen to them suddenly; hence, they do not have the necessary previous preparation.
- Caregivers have trouble accessing resources such as respite care, support groups, etc. due to bureaucratic constraints and not quite knowing where to look for accurate, reliable information or helpful guidance.
- Risk of burnout, mental health-related issues such as stress or anxiety. Being a caregiver is a non-stop responsibility, without a fixed schedule, which ends up generating stress and the feeling that there is never time for yourself as you are always dedicating time to others.
- Feelings of loneliness, social isolation, and lack of social recognition and psychological support pose real challenges for informal caregivers. Hence the importance of fostering resilience among this group.
- About health inequalities because of gender, the majority profile of caregivers is that of women between 50 and 70 years old. While they are people who can fend for themselves perfectly, they are also old enough to be cared for, not just cared for. More men need to be involved in informal care work in order to achieve a truly equitable society. In fact, when it is a man who primarily takes on informal caregiving, it is seen as exceptional.
- Strong financial strain, as taking on informal care can lead to reduced working hours and a loss of income and earning potential.

All these valuable contributions from the experts could be intuited in advance. The PR5.A1 – Literature review already pointed out the presence of many of the challenges faced by informal caregivers today. To mention a few, the aforementioned working document highlighted the lack of recognition and the risk of social exclusion, the absence of representation and political voice, the difficulty in reconciling care with work and personal life, the feeling of loneliness, the economic problems derived from low income and the renunciation of part of the working day, low access to community services, limited specific knowledge and skills, mental and emotional

stress and exhaustion, and the negative impact on social relationships. The organization of the focus groups allows us to contrast and confirm the points previously pointed out by the literature review.

In conclusion, the review of the available literature on informal caregivers and the consultation with experts in each country allow us to state without any doubt that there is an unfilled, or insufficiently filled, gap in public policies aimed at addressing the precarious situation of caregivers, particularly to increase their resilience and ability to adapt to their daily challenges. As noted in PR5.A1, the needs of informal caregivers have been studied for a rather short time and no set of public policies have yet been developed to address their situation. In short, there is a market niche that the Resil4Care initiative aims to cover.

4. Adoption and implementation of Resil4Care in organizations

The main objective of the Resil4Care project is to increase the resilience of informal carers in European societies. To this end, it is proposed that social organizations create and manage support groups on Facebook where caregivers can share experiences and knowledge on topics of interest to them. An important issue at this point is to distinguish social organizations on the basis of their characteristics. The size of the organization, its orientation to profit or non-profit or the area in which it provides care (for example, if it is intended for people with Parkinson's, Alzheimer's, etc.) are variables that decisively influence the form and steps to be taken to adopt and implement Resil4Care in the organization. However, the objective of this guide is not to explain in detail all the steps to be taken by each existing organization in the world, but to collect the common aspects to any type of organization and that should be considered when promoting an initiative like this.

To this end, in the focus groups, participants were asked about different issues related to the implementation of Facebook support groups. Thus, the following are the contributions of the participants in relation to the following key aspects for the implementation of Resil4Care: (1) previous experience in online support groups, (2) what elements would be needed to carry out this initiative, (3) benefits and (4) problems or limitations and finally (5) what they would think if their organization implemented this idea.

4.1. Experience in online support groups

In terms of experience in online support groups, all partners report that there is a very low degree of prior involvement in these types of initiatives. Due to the pandemic, there were several more or less successful attempts to promote similar initiatives, since face-to-face contact was very limited, and it was necessary to arrange online alternatives. Those few participants who did promote these initiatives describe them as complex and with a result that was not entirely satisfactory, mainly because of the lack of knowledge of users about social networks. Of course, it was a resource that served to temporarily cover the need caused by the pandemic, although people were already eager to return to face-to-face learning. Some of the risks detected in the different experiences reported are:

- Sometimes written information tends to be misinterpreted, even more so on the internet. It may happen that the group acquires a more destructive atmosphere than a constructive one.
- Sometimes the high volume of information can overwhelm group members and decrease participation and engagement.
- The digital illiteracy of the members complicates the functioning of the group: the simple act of creating a username and password is already complicated for them. Sometimes they do not participate in groups simply because they do not know how to do it. It is necessary to consider the majority profile of informal caregivers: women between 50 and 70 years of age with little digital capacity.

Some interesting ideas discussed from the experience in online groups are to include an initial form when joining the group to ask how they found the group and what they want from it, as well as warning new users that if they post content that has nothing to do with the purpose of the group, they will be expelled from the group.

The limited experience of the participants in online support groups is a clear indication of the innovative nature of the proposed idea. However, far from being a difficult problem to solve, it is an opportunity to experiment with possibilities that, in an innovative way, respond to the problem of the low resilience of informal caregivers in Europe.

4.2. Essential elements for the implementation

What it would take for an organization to implement this idea is an essential issue as participants provide their point of view on the resources needed for the efficient and effective realization of this idea. In this regard, participants highlight two types of resources needed: (A) staff and (B) the digital literacy of group members.

A. A list of characteristics that must be met by the worker of the organization in charge of running the Facebook group is proposed. First of all, it is essential that it is someone who is fully knowledgeable about the functioning of social networks and the field of content creation, who is able to make attractive, relevant publications focused on the group's objective, without overwhelming or saturating with excessive information. Secondly, due to the function of resolving doubts and disseminating rigorous information, the person managing this group must necessarily be someone with technical knowledge about informal care, able to read and understand scientifically-based publications, with experience also in providing care, who can answer questions of a professional nature. Thirdly, it should be a person who monitors the functioning of the group on a regular basis: who pays attention to interactions between participants, who deletes irrelevant, false, or rude comments and posts. Finally, he or she must make sure that the personal and sensitive information of the participants is protected, making the group a safe space.

B. Just as important as the person who manages the group is having people who actively participate in it. Provided the profile of the population, with little skill on Facebook, it would be advisable to train people on the use of Facebook, in order to create an active community of users, as a key piece of the success of the proposal. Otherwise, the group

will never fulfil its function. For this reason, it would be necessary to consider organizing basic training on the functioning of Facebook as a social network.

4.3.   Benefits

Participants consulted have pointed out numerous beneficial impacts that the implementation of Facebook groups could bring:

- The group could become a repository of reliable and rigorous educational resources available to all members, which is not always the case on the internet, as many caregivers tend not to sufficiently contrast the information they receive from the internet. Thanks to the training of the person who manages the group, who publishes rigorous content, the information present in the Facebook group will always be totally reliable.

- The online nature allows members to use the group whenever and wherever they want, quickly, easily and flexibly.

- An advantage of the online group is that it allows certain people to ask questions that they otherwise would not ask elsewhere. Going deeper into this, a relevant contribution of the experts is related to those people who live in environments with a low density of associations and social organisations. An important part of the population lives in this type of municipality, where there are no associations that support many people in need of help. In this context, we must think that in this type of settings, rural in general, the role of Facebook support groups could be very significant, since it would serve to "bring closer" associations that promote social integration to places that they do not currently reach in person.

- Related to the above, a relevant problem when facing a family member's illness by caregivers is social stigma, especially in the first stage of an illness. These types of problems have been reported especially by those participants who work in associations that help people with Parkinson's and Alzheimer's. It is positively valued that the possibility of promoting these groups in an online format would allow informal caregivers to delete the "stigma" they have when they go to these associations in person looking for help.

- A possible consequence of the implementation of Facebook groups would be to involve more demographic groups in caring for other people, specifically young people who do have more digital skills, so that care does not always fall on the same group of people. Young people, unlike older people, do not see the digital world as something strange and alien, but as a space where it is possible to find empathy and closeness and, therefore, the functioning of social networks in general and Facebook in particular would not be strange to them.

- As it is a tool that can be transferred to different regions and countries, experiences can be compared and, consequently, those specific aspects of the functioning of groups in other countries that are considered desirable can be imported.

- While it is true that it is the young population that is more proficient in the use of new technologies, caregivers (usually aged between 50 and 70) have enormous untapped potential to learn from the use of ICTs.

- If the functioning is correct, after a while not only a Facebook group will be created, but a community of people with similar needs and problems, with a feeling of belonging to a group that makes them see that they are not alone and, in this way, combat the feeling of loneliness so widespread among informal caregivers.
- Another beneficial aspect of the implementation of this idea is linked to companies that provide home help services. This help is given for very short periods of time, usually an hour, in which a professional carer comes to the home of the person in need of care. However, the need for care does not disappear when the professional leaves. In the absence of the professional caregiver, informal caregivers have doubts, questions, and uncertainties about different issues related to care, and the implementation of this idea could be an effective contact channel between the home care provider and the group of informal caregivers of people who receive the service of the company.

Sessions with experts in the field of care have revealed some benefits that had not previously been contemplated by the project team, as well as others that could be anticipated. In short, the most positive impact that the implementation of Resil4Care by organizations would bring would be the empowerment of informal caregivers, responding to their main problems on a day-to-day basis.

4.4.   Problems

Obviously, the launch of Facebook groups could also lead to the appearance of some problems for the entity, in addition to certain limitations or related dangers, which should be taken into account. The problems identified by the experts can be classified into three areas: (1) moderator, (2) participants, and (3) the online format. Measures to avoid these problems are included in the recommendations section.

As for the (1) moderator, there is a risk of not having the right person to manage the group, either due to a lack of social media skills or time constraints that do not allow for careful observation to monitor the functioning of the group. Another possible problem is that, after a while, there is a lack of creativity on the part of the administrator that results in the interest of the community slowly fading away and, therefore, the objective of the project would not be met. Finally, an opposite risk to the previous one is publishing too much content and that it has the same result of losing community engagement due to saturation.

A second set of problems to consider is related to (2) the participants. The dynamics of group functioning can lead to undesirable scenarios, such as general passivity and monopolization by one member or a small group of members, or the emergence of disputes or dialectical conflicts between members that create a negative atmosphere. Other participants may make too personal use of the tool, telling experiences and experiences unrelated to the group's objective and irrelevant to the rest of the group, thus moving away from the original purpose of the initiative. Other problems that can be generated from the activity of the participants is the sharing of misleading information, for which the administrator must be very attentive to eliminate it as soon as possible.

Regarding the (3) online format, there are certain limitations or problems to be aware of. Firstly, psychological support depends to a large extent on face-to-face and physical contact, which

could not happen through Facebook, unless it is complemented by face-to-face activities. We are used to using the internet for entertainment, solving specific doubts, etc., but in terms of psychological support, the internet is not the most appropriate tool. And secondly, according to what some experts have indicated in focus groups, although the use of the Internet is widespread in society, people with a lower socioeconomic status are less prone to social networks than the average. Therefore, it should be taken into account that this social class bias does not occur somehow and that no one is excluded from the possibility of participating in the project.

4.5.   Opinion if the organisation implemented Resil4Care

All the participants agree on the current precarious situation of informal carers, with problems in different areas of their activity as carers and the existence of multiple challenges that must be addressed by public administrations, which require an innovative response.

Although the diagnosis of the current situation is widely agreed upon by all, there is more disparity of opinions regarding the implementation of Resil4Care. In any case, the majority opinion is that Resil4Care could be a valuable tool, which could solve – or contribute to some extent to solving– problems that affect all informal caregivers and that would be worth implementing in their organizations. In addition, many participants declare that it would be an initiative that could be perfectly transferred to other European societies.

There are certain reservations regarding the technical implementation, the functioning of the group, moderator, online format and digital literacy of the participants. However, every possible problem is credited with a possible solution. In short, the majority of feedback from the participants in the focus groups is that they would implement the Resil4Care initiative in their organizations if they have the necessary elements to do so.

5.   Conclusions

The review of the academic literature on informal carers in Europe in PR5.A1 and the organisation of focus groups allow us to reach a clear conclusion in the field of informal care: there is a vacuum, a niche, a lack of public policies aimed at improving the situation of this important group in our societies. The outbreak of the pandemic crisis has highlighted the plight of informal caregivers. An in-depth analysis of the problems and challenges faced by this group reveals the need to increase their resilience in order to better adapt to their situation. Within this context Resil4Care methodology emerges, with the aim of promoting the resilience of informal caregivers and, in essence, filling the aforementioned gap.

Obviously, the application of this idea is not immediate, since there are situations that hinder its immediate success. First of all, it is essential to have a person on staff in charge of the administration of the group. It must be a person with a very specific profile, for which a list of characteristics that the worker must meet has been provided. And secondly, in the face of the problem of digital literacy of the typical caregiver population, the Resil4Care team, through the French partner Interactive 4D, has designed a free learning platform on how Facebook works

to ensure that all users, regardless of the initial level of knowledge, can use Facebook without problems.

In conclusion, this project arises from the realization of a need, which is to increase the resilience of informal caregivers. Through an innovative approach, a package of actions is proposed aimed at improving the training resources of the collective of caregivers in Europe, something fully aligned with the general spirit and objectives of the Erasmus+.

6. Recommendations

Once the analysis of the experts' contributions has been carried out, there is enough information to elaborate a list with some recommendations so that organizations can successfully implement the Resil4Care proposal. To do this, the steps to follow are established chronologically, indicating what can be done to accomplish its objective.

1. STEP 1: Identify and motivate potential participants
    Organizations keep regular contact with many informal caregivers and already have more or less established communication channels with them.

    WHAT CAN BE DONE: Seizing this opportunity, the organization should disseminate among the informal carers the future creation of the Facebook group, highlighting the added value that the Facebook group will provide in comparison to the existing established channels, since it will allow the sharing of more attractive content for the community. This is also a good time to ask future members what topics they are most concerned about when carrying out their daily care, as it is relevant information for planning future content.

2. STEP 2: Select a worker specifically to manage the group
    According to the experts' answers, leading a group of this nature would be quite demanding. So, a series of characteristics are required: excellent management of social networks, knowledge about care and informal care, and be attentive to the dynamics of the group to ensure good functioning.

    WHAT CAN BE DONE. It would be advisable to open a selection process to hire someone who meets this profile and who can stay for a while in the organisation linked to the existence of the Facebook group.

3. STEP 3: Find out about methods and techniques to boost the participation in the Facebook groups
    Participation is a key factor for the success and vitality of any online group. This is why specific strategies to engage the facebook members should be applied.

    WHAT CAN BE DONE: There are plenty of guidelines that address the question of how to increase the participation of Facebook participants. In general, the most common methods are (1) the creation of engaging content, with visual posts such as collages or open-ended questions; (2) the active interaction of administrators, who must participate regularly, answer questions, welcome new members, and provide relevant updates; (3) strategic use of surveys and open-ended questions, which not only invite participation, but also provide valuable insights into members' interests and needs; (4) organising streamed events, such

as talks or debates on a specific topic; and (5) offer some kind of rewards for participating, for instance choosing outstanding members, awarding virtual badges, or even hosting online contests on certain topics.

4. STEP 4: Create the Facebook group
    At this point, it is important to carefully choose the name of the group. Simply reproducing the name of the organization can be ineffective in capturing the interest of participants. It is recommended to choose a name that represents the essence of the group. For example, the pilot experiences of these groups within the project have been called "Caring for those who care", "Let's hold hands", among others, which create warmer feelings than just putting the name of the organization. If there are any doubts about the process of creating the Facebook group, the learning platform can be a great support, as it contains a section specifically related to this.

    WHAT CAN BE DONE: An activity to consider with this objective is to organize a joint session with the members of the group and collectively decide on the name of the group, so that it is representative of the group and, in this way, begin to generate the sense of belonging to a community. This day may be also used to carry out more activities within the context of these recommendations, which will be detailed later.

5. STEP 5: Train caregivers about Facebook
    As important as having a worker specifically in charge of the Facebook group is to have an active community that participates in the publications, comments, contributions, questions, shares experiences... experts stated. For this reason and taking into account the common profile of informal caregivers (women aged from 50 to 70 with little social media skills), it is crucial to train caregivers about how to use Facebook.

    WHAT CAN BE DONE: Organize a joint training session for members based on the platform developed by Interactive 4D with the aim of making it easier for users to learn how to use Facebook. There are several fields on the learning platform aimed at people who are new to Facebook, such as (1) What is Facebook, (2) Create a new account, (3) Connect with friends, (4) Post a message, (5) React to a post, and (6) Join a Facebook group. In addition, each of these fields has its own final questionnaire, so we can make sure to assess how much users have learned and correct their mistakes. This training session can take place the same day as the activity recommended in Step 4 to choose the group name.

6. STEP 6: Periodical assessment of the results
    It is important to receive feedback from members on the functioning of the group in order to assess the impact of the Facebook group and to improve its results. Considering the profile of potential users, it would be advisable to avoid long questionnaires with lots of questions with rating scales that could make it difficult to capture important information about user opinions.

    WHAT CAN BE DONE: Organize a collective evaluation session in an open format, where everyone gives their opinion about the functioning and what changes they would make to improve it. It would be advisable to gamify the session to achieve the maximum involvement of the participants. Some crucial issues that should be assessed are the

interest of the contents, the real impact on their well-being or topics unaddressed in the group that should be addressed.

7. STEP 7: Analyse the evaluation and take corrective actions
Once the opinions of the participants on the functioning of the groups are received, it is time to analyse their contributions and assess which aspects could be implemented and reject those that do not have a place or that can hardly be adopted.

WHAT CAN BE DONE: Examine what inputs can or cannot be adopted, either in a meeting with the organization's management team or individually the person in charge of leading the Facebook group and communicate the decision in the group to involve the community.

8. STEP 8: Communicate the results
The idea of an online support group may seem strange to outsiders, and as a result, people who could potentially be members do not join it. For this reason, communicating the results is important, because it conveys to people who are not yet in the group the positive impact that the group members are having.

WHAT CAN BE DONE: A brief report with statistics and infographics can be published through the organization's social networks detailing for instance how many participants the group has, the number of questions asked and solved, and topics that have been covered in their publications. This can be done once every six months. It is important to disseminate this report on the organization's social networks and not only in the Facebook group itself, so that the information reaches users who have not yet joined the group.