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CARE4DEM

WEB-BASED MUTUAL AID GROUPS FOR INFORMAL CARERS OF PEOPLE WITH DEMENTIA: AN EVIDENCE REVIEW

**Executive Summary of the baseline study prepared in the
framework of the Erasmus+ project CARE4DEM**

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ABSTRACT

This report gives an insight of the state of play regarding web-based peer support groups for informal carers of people with dementia in the EU.

It provides a baseline for the Erasmus+ project CARE4DEM, aimed to support the development of web-based support groups for informal caregivers of people with dementia, through the design and the piloting of an innovative model of web-based support group, as well as a competence profile and a blended training for facilitators of such groups.

The report is based on research including a literature review, a survey, as well as interviews. The report identifies the added value of web-based support groups for carers, as well as the lack of such supporting initiatives. It describes a series of relevant initiatives at local, regional, national and international levels.

The report confirms the relevance of the objectives and method of the project and points out the learnings of existing initiatives as well as the challenges to be addressed.

1. INTRODUCTION

Background: the issues linked to informal caring in the case of dementia

Dementia is the common name for many different brain disorders which are degenerative, causing a decrease in functional capacity and human interaction. Dementia has become a high priority in the 21st century as Organisation for Economic Co-operation and Development (OECD) estimates 9.6 million people live with some type of dementia in EU countries and World Health Organization (WHO) reports the economic cost of dementia to be higher than the expenditure in cancer, heart diseases or depression.

Obviously, carers are **an inherent as well as an indispensable part of the provision, organisation and sustainability of health and social care systems**. They will become even more important in view of the changing health and care needs, due to the ageing of society and the increasing prevalence of frailty, dementia and chronic disease.

Caring can be a highly demanding task, even more when the caretaker is a person with dementia. Whereas taking care of a loved one can bring some personal satisfaction, it can also impact negatively on the caregiver's physical, mental and social well-being. For carers of working age, these difficulties can compromise their inclusion in the labour market. Several projects and initiatives have been undertaken to address these issues, aimed at supporting informal carers of a person with dementia, as well as recognising and increasing the skills acquired through caring experience. Ultimately, these initiatives aim at:

- Preventing physical and mental health problems among informal carers;
- Supporting carers towards high quality care, respectful of Human Rights provisions;
- Avoiding cases of maltreatment and supporting the development of community-based care;
- Fostering caregiver's inclusion in the labour market and social inclusion.



The CARE4DEM project: developing an innovative web-based model of mutual aid group for informal carers.

The European Commission (EC) has highlighted the advantages of supporting family 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, Portugal, Romania and Spain and a European umbrella organisation. 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.

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.

Purpose and scope of the baseline report

The use of mutual aid groups is being developed across Europe with several programs using this type of intervention to help dementia caregivers. There is evidence of the added-value of using ICT to promote social inclusion of caregivers who, otherwise, would be left out of these initiatives. Nevertheless, there is few information regarding the practices implemented, the methodologies applied or the most suitable competences and profile of the volunteers or professionals who facilitate these groups. This is the gap that the present report aims to address.

However, the objective of this report is not to provide readers with an exhaustive and detailed description of all the relevant best practices, but rather to give an insight of the state of play regarding this particular type of support. As such, this publication aims to emphasise a series of **useful pointers for the development of an innovative model of web-based group support for dementia carers as part of the CARE4DEM project.**

The methodology implemented included desk research, the dissemination of a survey and interviews with relevant stakeholders. It focuses mainly on initiatives developed in the projects countries, though referring also to projects developed in other EU countries.

An extensive version of the baseline report is available in English. This summary is available in Italian, Spanish, Portuguese and Romanian.



2. METHODOLOGY

The methodology implemented included a literature search (in PubMed, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Cochrane Library, Embase and PsycINFO as well as Google Scholar), a search in a database of practices created through the European project [CarICT](#), interviews, and a collection of good practices through an ad hoc survey.

3. FINDINGS

3.1. KEY POINTS FROM THE LITERATURE SEARCH

The literature search allowed to build a bibliography of 16 relevant references. Essentially, research brings evidence of the positive impact that participation in peer-support groups can have on the well-being of informal carers of people with dementia, and the potentialities of ICT to overcome accessibility issues. It also sheds light on the challenges attached to this type of support, even web-based, notably the difficulty from the side of informal carers to take part regularly in the group, without dropping after a short period due to lack of time, caring commitments and economic issues.

3.2. KEY POINTS FROM THE INTERVIEWS

In addition to sign posting some relevant practices currently developed, interviews with experts gave additional insights on the current state of play regarding online support for informal carers. They confirmed the findings from the literature review, notably with regards to the lack of available supports for informal carers of people with dementia and the relevance of developing web-based peer-support groups. They also highlighted a series of challenges to be addressed, notably the difficulties with regards to writing expressed by a number of carers, as well as the lack of ICT literacy, and the difficulty to engage with male carers.

3.3. COLLECTION OF GOOD POLICIES/PRACTICES

There are a total of **39** practices and policies collected through Lime Survey. After selected those which answered YES to the question “Does the intervention/practice/policy belong to the field of web-based support for caregivers”) only have **22**. Among these, only **14** answers YES to the question “Is the intervention documented, in a peer reviewed journal or grey literature. The other **8** have not been selected because:

- **6** do not have online documentation, and there very was few information related other question.

- **2** do not have online documentation and have not include any information in any other question.

For the **14** practices previously selected, **5** of them have not been take into consideration due to the lack of information, it is impossible to create a list with them.

Therefore, the total number of selected practices and policies included in this report is 9.

Only 9 practices and policies have been selected, that met all the criteria set, including detailed documentation online. It should be underlined that this 'documentation' criteria ruled out some extremely relevant practices, some of them implemented at a large scale. Though, the learnings from three of them were included in the overall analysis and the partnership will remain in contact with stakeholders who implement them. These include notably CarersUK Online and Forum (UK), and the online peer-support group of carers of people with dementia organized by the Association Novilunio (Italy).

The 9 documented practices/ policies selected are related to the following types of intervention:

(Online) peer support groups for informal carers (4)

- Gruppa Ama online, Online peer support for informal carers, Italy
- The carers' company /La Compagnie des Aidants, France
<https://lacompaniedesaidants.org/>
- A good place (En Bra Plats), Sweden: <https://www.enbraplats.se/>

Training opportunities for carers and professionals (3)

- ELMI Project, Romania, www.elmiproject.eu
- Educa&care, Portugal (<http://educacare.web.ua.pt/>)

- Cuidem Project: Mutual Help Groups For Informal Carers, Portugal (www.cuidem.pt)

Strategic interventions (3)

- Law for the recognition of the informal carer (Emilia Romagna Region) Italy, <https://bit.ly/2HmxhRc>
- Bread and internet (Pane I internet), Italy, <https://www.paneeinternet.it/public/pei-en>
- TV-ASSISTDEM, Spain, Italy, Switzerland, Romania, <http://www.tvassistdem-aal.eu/>

The main aims of these practices can be synthesized as follows.

Emotional support:

Caregivers experience emotional, physical, functional, psychological discomfort and isolation as a consequence of the continuous attention that must be made to his family member suffering from dementia. The interventions are therefore aimed to:

- Increase **personal skills to deal with emotional aspects**, feelings and behaviours that continuous attention can produce in caregivers.
- Creating a space for **listening and sharing** based on the principles of mutuality, respect and confidentiality

Skills development:

To improve the lives of unpaid carers it is important to provide them with new knowledge, expert information and advice that's tailored to their own personnel situation, to support them in finding new ways to manage their situation. The interventions are therefore aimed to:

- Share of **information** between caregivers, to help them with the difficulties of daily activities.
- Improve the **capacity** of the caregiver to manage the care of one or more older people and reduce the intensity or burden that this causes on caregivers.
- Improve the **quality of care** in the accompaniment and care of the disabled patient by learning the skills needed by those relatives and volunteers with



responsibility for direct care of patients and people in a situation of dependence, attending to their needs.

Foster social inclusion through ICT:

In this context, technologies can be of help by

- Giving the **possibility to participate** to the group to people that, for various reasons, cannot access groups organized by local associations or structures.

The technologies piloted in the various ICT-based interventions are:

- Zoom (similar to Skype, that has a very clear interface and that guarantees a more stable connection).
- Blog, video for training, Apps for smartphones, Facebook, Twitter, Google+, Tumblr and Pinterest
- Online forum, including the possibility of private messaging using phpBB platform.

4. CONCLUSIONS & KEY RECOMMENDATIONS

The data gathered through the literature review, interviews and good practices review lead the partnership to **some general conclusions**.

- The difficulties encountered when trying to identify good practices in relation to web-based support groups for informal carers illustrate the fact that such support is **very seldom implemented**, despite being valued by experts and practitioners. This is an acute illustration of the lack of recognition of the needs of informal carers, and of the lack of development of relevant supporting services.
- More initiatives were identified that relate to **training for informal carers of people with dementia**, which content could be usefully used in the development of training for facilitators of web-based support groups for informal carers, as well as signed posted to carers likely to be interested. However, guarantees regarding the positive evaluation, the regular update and the accessibility in the long term of the training material are often lacking.
- A series of relevant initiatives were identified, though not selected because of a **lack of documentation**, that made them difficult to transfer. Indeed, a number of relevant initiatives are developed within a tight budget, and face sustainability issues. Such financial limitations prevent these initiatives to benefit from robust evaluation and extensive dissemination. This illustrates also the lack of transnational research on how to better support carers, likely to focus on these promising initiatives.
- This is all the more regrettable that, as shown in this study, initiatives developing web-based support groups for carers share a series of common challenges, and **the development of this promising tool would benefit from evaluation and cross-country analysis**.

Though, based on the outcomes of our research, we can identify some **key-recommendations** that could inform the next steps of the Care4Dem project:

Digital skills are a precondition for the success of ICT-based programs, but they shouldn't be given for granted: it is clear that no ICT-based intervention can be effective if the target users do not have the necessary skills to access and use them. Therefore, while adopting ICT tools can be an inclusive practice towards carers who have reconciliation issues or who live isolated, it can on the other hand contribute to exclude those who are not familiar with new technologies or who do not have the necessary devices. In order to avoid this risk, some precautions should be taken:

1. **Make sure that target users can access ICT training opportunities:** these could either be embedded in the project or make use of opportunities offered at local level by other organizations. In this latter case, available courses should be mapped and synergies seek with “local intermediaries” such as associations, unions, municipalities, local communities or others. High school students can be involved in delivering smartphone digital literacy to citizens through School internships.
2. **Promote the “Bring your own device approach”:** in either cases, it is a good practice to allow trainees to attend the training using their own devices. Indeed, if people are able to use their devices it is more likely that they will continue learning activities and internet usage after the course.
3. **Build on applications and software that are largely used:** it seems wise to implement interventions using tools which the public is likely to know, such as for example Whatsapp/ Messenger – Facebook – Skype etc. Users might be more encouraged to use something they already know instead of a new tool that they have to learn from scratch.

Peer-support groups are proven to be effective for informal carers, but the participation should be fostered in different ways and from different points of view: there are evidences that peer-support groups are an effective tool to support informal carers and relieve their burden. However, it is important to take into consideration some issues, concerning the recruitment and retention of participants:

1. **Participation to the group should not be perceived as an extra-task for the carer:** although ICT should help to control this risk, it is important to recognize

the difficulties of the informal caregiver to participate in the mutual aid group and to acknowledge that there might be drop-outs or inconstant participation.

2. **Recruitment strategies should take into account the specificities of informal carers:** special attention should be taken to reach the target population living in more isolated/not urban areas. For this target population it would be important to identify dedicated promotion channels, in order to make sure that information reach also those people.
3. **Virtual vs. Physical:** although ICT is meant to overcome geographical distances, this might not necessarily mean that the all process should be virtual. For example, it could be envisaged that while the process will primarily be delivered online, some meetings are foreseen. Indeed, being all together in the same room might contribute to create a sense of belonging and of being “a group” for participants. Also, in case participants come from different geographical areas it might be advisable for the facilitators to make sure he/she knows to whom the carer can be referred at local level, and which services he/she can access locally in case of need.
4. Web-based support groups should be embedded in **an integrated set of supporting services for informal carers**, offering recognition, information, respite care, counselling ...

Moderation: experience and soft skills are highly recommended

1. In most of the practices analysed, the moderation of online discussion is relatively light, contributions do not need to be approved before publication, and the priority is put on facilitating the participation of all.
2. For four practices, facilitators are required to have followed a training (either a generic training or an ad hoc training regarding this particular support group): **providing a training to facilitators is not a common pattern.**
3. Some practices require that **the facilitator is a professional** (care or social worker, psychologist...) and value to a certain degree of knowledge about the issues (from a medical and administrative point of view). **However, experience (in caring and in participating to support groups), motivation, and soft skills**

(communication, empathy, sensitivity) seem to be of paramount importance in most of the cases.

Local policies recognizing carers and their needs constitute the necessary background for an effective intervention: interventions are never delivered in a vacuum. The local context makes the difference in terms of potential impact of the intervention:

1. **Raise awareness:** Promote the increasing awareness of the issues faced by informal carers in the context of the demographic change within public opinion and public authorities at local level. This will have positive consequences on the capacity of reaching out carers and in creating synergies between the Care4Dem and other interventions offered at local level.
2. **Foster commitment:** the commitment of public authorities towards informal carers should be fostered, for example by lobbying for the explicit inclusion of informal carers as target group of interventions dealing with ICT-literacy, or build partnerships with the promoters of initiatives at local level, allowing them to scale-up and reach a wider group of informal carers;
3. **Introduce web-based support groups:** local policies aimed at developing dementia friendly societies and community care for people with dementia should, building on existing initiatives, introduce web-based support groups within the set of tools implemented.

Policy background at national level

Main competencies in relation to health and long-term care lay at national level; governments should ensure the sustainability of long-term care for people with dementia through an adequate combination of appropriate quality care services and support for their carers. Such a national framework is needed to back the development of relevant support at local and regional level.

1. Informal carers should be granted **legal recognition**, to which specific rights in relation to work-life balance, and financial support should be attached.

2. The provision across the whole territory of **adequate integrated long-term and social care services** should ensure that the long-term care of people with dementia is not left to the sole responsibility of informal carers, that they can rely on services on general interest to alleviate the most intensive aspect of care, and concentrate on contributing to the well-being and quality of life of people with dementia, and preserve their own health status.
3. **Adequate funding** should be devoted to the development of initiatives supporting informal carers at national level, in cooperation with organisations representing informal carers.

Finally, the **European Union should play a decisive role** in supporting and steering the efforts made by member states for supporting informal carers, notably through:

1. **Implementing the Pillar of Social Rights**, including for informal carers (including adopting and implementing the 'Work-Life Balance Directive currently discussed, which allows specific rights to carers.
2. **Ensure European funding is available** for initiatives that support informal carers.
3. **Support transnational research and mutual learning** on how to best support informal care.