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ORIGINAL RESEARCH

Peer Support Workers as an Innovative Force in Advocacy in Dementia Care: A Transnational Project Delivered in Norway, Greece, Italy, and Romania

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Aim: Peer Support Workers (PSW) as an Innovative Force in Advocacy in Dementia Care (PIA) project aimed to create sustainable and competency-enhancing services for people with dementia by finding new ways to involve former as well as current caregivers in dementia services and, therefore, provide their valuable perspective in dementia care and daily practice.

Participants and Methods: In order to achieve the aforementioned goals, the first step consisted in mapping the situation existing in the partners' countries, respectively, Norway, Greece, Italy, and Romania. Subsequently, specific and well-structured training material was created with the purpose of recruiting and engaging PSW, in order to contribute to dementia services. The training material was then transferred to a digital platform addressed to PSW, people living with dementia (PwD), caregivers, and health professionals.

Results: The PIA project proposed the introduction of PSW in dementia care, establishing a close collaboration across the contributing countries, and trained a total of fifty potential PSW. Each country identified a specific role and function of PSW in dementia practice, according to their national particulars. The training seminars and videos proposed by the PIA project are presented in the current study and therefore helped to the distribution of significant information about the contribution of (potential) PSW in dementia care. All the results were uploaded on the platform designed to increase communication and collaboration across health professionals as well as caregivers.

Conclusion: The PIA project developed and designed training materials and methodologies for establishing PSW in dementia care in Norway, Greece, Italy, and Romania. PIA aims at introducing PSW in the healthcare system of the aforementioned countries, whereas future studies will elaborate on novel ways to measure the efficacy of being a PSW, as well as the benefits to stakeholders.

Keywords: dementia care, dementia caregivers, peer support workers, training material

Introduction

Among older people worldwide, dementia is the leading cause of dependency and disability, and according to the available data, dementia is estimated to affect approximately 14 million people in Europe by 2030, and this number will reach 18 million by 2050.[1] It is noteworthy that the number of people who live with dementia (PwD) approximately doubles every five years.[2] Moreover, it places a burden on regional economies, with estimated costs of US$312 billion per year in the United Nations by more developed regions and US$110 billion in less-developed regions.[3] Additionally, the World Health Organization report in 2023[4] states that 80% of older people will be living with dementia in low- and middle-income countries (LMICs) by 2050. It is worth mentioning that Lian et al[5] highlight that the diagnosis in LMICs is 5–10%, compared to the existing rate in higher-income countries.

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Stigmatisation and stereotypes are the usual barriers to early diagnosis and treatment.[6] To address this, countries must recognize dementia as a public health priority and improve the care of PwD through early diagnosis, comprehensive treatment, and support for caregivers. Additionally, countries must scale up public awareness and advocacy to reduce stigmatisation and discrimination and improve the quality of life for people living with or affected by dementia. Although it is not at all an easy task to change public opinion's views on dementia, the damaging impact can only be alleviated by significant campaigns that will reduce the discrimination of such a minority.[6,7] In this context, caregivers are regarded as valuable members in dementia care, because they know better the needs of PwD and, hence, can provide sufficient care and support to their peers, health professionals, and PwD.

Peer Support in Mental Health Care

According to Riessman,[8] the term of peer support is associated with the concept through which people with shared experiences or problems come together in order to exchange support, practical knowledge, and effective strategies. Therefore, Peer Support Workers (PSW) are people who use their lived experience of mental health problems to support people affected by this kind of disorder as well as their families. It is noteworthy that PSW is a new role being developed by means of the Government's commitment in countries like the US, Canada, the UK, and Australia[9] to increasing mental health and wellbeing support. Peer support can also be assumed as a type of strategy for providing empathy and compassion, which are basic human skills when responding to shared difficulties.[10] Providing peer support arose as a type of self-help skill and therefore is a non-hierarchical approach and has been primarily implemented for people with psychiatric diseases, and chronic diseases having a strong impact on their emotional and social life.[10]

To sum up, the concept of peer support includes interpersonal interaction by means of the communality of the experience, reciprocal needs, emotional and social support as well as the learning process by means of various challenges arising in the context of care. Therefore, the focus is transferred from identifying medical symptoms and various negative aspects of chronic situations to a social feature aspect of offering and getting support from others in order to overcome the disease's barriers. The World Health Organization and Alzheimer's Disease International published the following report under the title of Dementia: A Public Health Priority (2012),[11] in Geneva, which encouraged every country to launch a national Alzheimer and Dementia Plan to respond to PwD as well as their carers' needs. Among other needs, support provided by a peer who has similar experiences and, therefore, can be engaged in empathetic relationships[12] providing increased levels of sustenance and practical help according to PwD's and their carers' needs and priorities via online or onsite. Precisely, there are two possible types of PSW: people who are in an early stage of developing dementia and former or current caregivers of PwD.

PSW in Dementia

In recent years, in health and welfare services, PSW have been employed as a resource to promote the significant role of caregivers in dementia care. This will better tailor the services to the needs of PwD and give more emphasis on alternative thinking in dementia practice. According to the National Dementia Strategy for England,[13] «one clear message we have received from people with dementia and their carers is that they draw significant benefit from being able to talk to other people with dementia and their carers, to exchange practical advice and emotional support» (p. 41). Hence, PSW can provide significant help to those who struggle with similar problems having the additional benefit of feeling valued. Sabir et al[14] state that the role of peer support is assumed as a type of intervention aiming to reduce social isolation and its subsequent consequences usually observed in carers. Additionally, in the aforementioned study, it was found that sharing stressful and rewarding experiences can enhance peer support relationships, as only caregiving experience can be a strengthening factor.

Clare et al[15] state that the impact of peer support on PwD can be very positive by means of giving a sense of belonging, realising the reciprocal effect of support, and increasing feelings of friendship. Subsequent benefits deriving from the role of PSW were the feeling of being an active person and not a neglected and passive patient, finding new roles and values in life, boosting self-identity, and learning to use new strategies to regain a sense of control. Ward et al[16] highlight the importance of reducing social isolation among PwD through sharing common experiences. Increased social networks[17] and improved quality of life indexes[18] are also observed in PwD who had the experience of PSW. Moreover, the benefits of providing peer support to carers are also prevalent in various studies, such as reducing isolation, joy from engaging in peer support activities, learning new ways to cope with various circumstances, and understanding their own caregiving experience through a different perspective. These peer narratives allow experiences to be normalised, reduce uncertainty, and promote effective coping strategies.[19,20] Carter et al[20] highlight that providing peer support can be a multi-component intervention, which can be delivered in various ways either online or onsite, sharing the information among the non-healthcare professionals as common components of support.

PSW in the Countries Participating in PIA Project

The role of PSW has not yet been tested in Greece, Italy, and Romania, however in Norway, similarly to the UK,[21] PSW are included in dementia services. The "Peer Support Workers as an Innovative force in Advocacy in dementia care" (PIA) project will meet the needs of our partnership through the sharing of competence and capacity building in education and training for PSW and through a focus on recovery orientation in service. The project will meet the needs of PwD by introducing PSW in dementia care, which means increasing caregiver's knowledge and support delivered, whereas caregivers' stresses and challenges of care for a PwD will be strengthened. Therefore, empowering caregivers, relatives, and PwD will most likely result in developing services that are more adapted to their needs.

All participating countries have the same challenges, concerning the growing number of PwD and the subsequent need for supporting caregivers. Although all four participating countries have different human and economic resources available, they still have to meet the needs of their caregivers and PwD from a humane perspective. By contributing to knowledge sharing, and developing better strategies and policies, new pathways towards a synchronised approach in the Introduction of PSW in dementia care may arise. Additionally, it is also of great importance to see how PSW function in different contexts and the effect they will have on meeting the needs for an increased volume of care. PSW can also be an important element in implementing a recovery approach. Wright and O`Connor[22] illustrated that there is a need to develop strategies to cope with the increased number of PwD.

To conclude, the positive impact of peer support on caregivers has been demonstrated in research and is routinely advocated in national strategies and policies as a post-diagnostic intervention.[20,23] Nonetheless, with the increasing prevalence of dementia and the high demand for informal carers, it is time to undertake a knowledge synthesis to determine what exactly is known about peer support services for dementia carers. Overall, this will help to inform ongoing research, policies, and practices in the matter.

Study's Aims and Objectives

The scope of the current study is to address the following domains regarding the role of PSW in dementia services across the contributing countries of PIA project:

1) Developing a strategy to involve informal caregivers in dementia care providing training material as well as motivational and reflective exercises (sub themes: Creating guidelines for recruiting and qualifying PSW; Creating a training course as well as an evaluation questionnaire, which the participant must complete after the course; Developing a digital platform for collaboration and networking between partners, participants, and stakeholders).
2) Strategies for development and implementation – Urging the engagement with broader frames of reference (eg collaborating with dementia care centers etc), as a potential for enabling bolder and better dementia care models.

Materials and Methods

Step 1. Developing a strategy to involve informal caregivers in dementia care providing training material as well as motivational and reflective exercises

The training material and guidelines were produced on the basis of the competence of the various partners in the field (Greek Association of Alzheimer's Disease and Related Disorders; Association AFECT from Iasi; Kompetansesenter for brukererfaring og tjenesteutvikling-KBT; Anziani e non solo soc. coop. soc. and Asociatia Habilitas - Centru de Resurse si Formare Profesionala) as well as through dialogue and responses from family caregivers of PwD. Through this approach, a co-creation method was followed in order to outline the material using a combination of user experiences and good professional insight into dementia. At this step, PIA project developed training courses for PSW, which included topics like general knowledge on dementia, symptoms, causes, treatments, and how it affects the individual in daily life, skills such as education and training for different communication techniques such as role playing. The presentation materials also focused on autonomy and meeting the needs of PwD in various dementia services of the participating countries.

Except from the theoretical background, various activities took also place to increase participants' active enrolment as well as interaction with others. Therefore, training material also included role-playing activities as well as raising empathy techniques in which future PSW will have the opportunity to interact effectively with dementia caregivers, dementia care services and mainly with PwD. Specifically, each PSW group comprised approximately among eight to ten people to ensure immediate communication, direct contact, and constant interaction. Participants had access to the training material either via their active participation in training awareness seminars, or activities in the platform, so they were able to interact and exchange possible experiences given by their lived experience with PwD. The delivery methods included PowerPoint presentations, videos, auditory documents, chat, open discussions in the forum, and group discussion via the PIA platform. The meeting of these groups took place on partners' premises and the training sessions were delivered under the guidance of the researchers of the PIA project. During each session, participants were encouraged to actively contribute, proposing various ideas or providing comments about the training material. At the end of each gathering, they were asked to write down their feedback and/or ideas for improvement. Additionally, they were encouraged to participate in the digital groups that were delivered for this purpose through social media like Facebook and LinkedIn.

After the training courses' implementation, evaluation forms were administered to evaluate the following domains: Satisfaction, which is measured by Usefulness (The training course was useful for me/my role) and Clarity (The training course has clarified the role; What did you like most?; What did you like least?) and Improvements, measured by the subsequent questions (Was the allocated time and location conducive for learning?; Have I acquired necessary and sufficient knowledge of dementia during the course?). Additionally, facilitators involved in the training sessions provided their feedback and evaluation. Partners shared the results of their national pilot experiences via SWOT analysis. This kind of analysis is a method used to evaluate the "strengths", "weaknesses", "opportunities", and "threats" involved in a project or activity. It is the most common method for analysing qualitative data, and thus it was crucial to be used in the pilot of the PIA project. It is a qualitative and descriptive study in which firstly the position of SWOT analysis in the strategic management process is explained and secondly the components of SWOT analysis are examined.[24]

Step 1.1 Developing a digital platform for collaboration and networking between partners, participants, and stakeholders

After the implementation of the training modules, the learning material was uploaded on the web portal of PIA project. This way, people can digitally participate, and the course can also be implemented in a hybrid format and the lectures can be performed again, at any time, via the portal.

Step 2. Strategies for development and implementation

The main goal of the PIA project was to increase advocacy and promote the user perspective in the development and delivery of services. To achieve this goal, it was important to develop strategies and policies that meet the needs of all stakeholders. In order to develop better strategies and policies for the development of PSW within the field of dementia, it was necessary to involve partners, participants, and stakeholders in a strategic process. The particular situation of each country and society as a whole was taken into account. A description of the situation in each country regarding PwD care, the overview of user involvement, and strategic analysis were included.

In order to complete this step, a strategic process was conducted in each country:

1) Mapping the existing strategies and policies;
2) Recording the actual level of advocacy;
3) Charting accessibility of services and welfare for persons with dementia;
4) Dialog meetings and conferences;
5) Sharing findings offered by the partners;
6) Formulating and presenting new strategies and policies.

All partners approached a common strategy, yet different adaptations based on the context, culture, and resources of each country were noticed. The main goal of all four partners was to formulate acceptable strategies and policies.

This study was approved by the Scientific and Ethics Committee of GAADRD (Scientific Committee Approved Meeting Number: 75/23-2-2022) and complies with the Declaration of Helsinki.

Results

Based on the aims and objective described in Steps 1 and 2, the project's results are presented below.

Step 1. Developing a strategy to involve informal caregivers in dementia care providing training material as well as motivational and reflective exercises

Creating Guidelines for Recruiting and Qualifying PSW

The criteria for the recruitment of PSW were:

a) The PSW meets the DSM V criteria for the absence of major neurodegenerative disorders or any psychiatric disorder;
b) The PSW provides a written consent in caregiver's presence;
c) The PSW do not present prominent behavioural and psychological disturbances to ensure their safety during the training courses.

Creating a Work Program the Participant Must Complete During the Course

Training courses that have been developed for PSW and caregivers in terms of PIA project have the following modules (Table 1):

Table 1 Training Material Content

Modules	Learning Material	Learning Outcomes
Module 1	• Basic information about dementia • Recognizing different dementia subtypes • Early symptoms of dementia • Risk factors • Progression to dementia and dementia stages	• Comprehending how dementia can impact the person with dementia, their life and relationship with family members and carers.
Module 2	• Introduction in Dementia Friends program • 5 key messages about Dementia Friends program • Activities concerning Dementia Friends	• To learn how to interact with PwD and create dementia friendly communities. • To raise awareness about dementia and recognize possible ways to respond to PwD needs in the community.
Module 3	• The description of PSWs' characteristics • Their roles • Aiming to induce the drive to become a PSW • Stating the specific issues of the participating countries concerning the presence of PSW	• To know the figure of the PSW in general, and in each participated country separately, and in the context of dementia care. • Clarifications with regard to the benefits of the PSW figure for caregivers and community awareness. • Awareness of the contexts in which an Expert by Experience can operate and what actions he/she can perform.
Module 4	• Legal issues • Human rights, and, • Practical activities (reflective techniques, active listening, empathy techniques, experiential exercises, communication skills, and role playing). All learning material from the last module is represented by descriptions upon: • Dementia Services in each country • Various definitions of Dementia Friendly communities.	• Knowing how to approach, communicate and help a career of a person with dementia • Being able to raise awareness and support through storytelling and experience; • Being able to communicate with a carer and a decision-maker for change and awareness-raising.

1) Introduction in dementia (general definition and prevalence);
2) Five keys to have in mind about dementia (Dementia Friends program);
3) The role of PSW in dementia care – Countries specific issues;
4) Significant issues for people living with dementia, eg legal matters, human rights, and practical activities (reflective techniques, active listening, role playing, motivation, empowerment, self-management, stories of PSW).

The material was digitised and has been uploaded in the web portal of the PIA project. The course and training were primarily face to face, but the participants were able to participate digitally by a hybrid solution and repeat the lectures in the portal. In order to produce the aforementioned material, the following strategies have been applied:

1) Create guidelines and methodology for the recruitment and training of PSW;
2) Create a work program the participants had to complete during the course;
3) Make a description for coaching the participants;
4) Digitalization of the learning material;
5) Develop a completion test for the end of the course.

After the accomplishment and implementation of the training material, each country prepared a national pilot report described above.

Pilot Analysis Content for Each of the Participating Countries

The analysis is a description of the results of training materials testing in all four participating countries. The course was based on extensive research of the national dementia plans of the partners, for those countries that have completed national dementia plans, whereas need analysis was also implemented to clarify the triggering motivational factors of being a PSW. Literature review[20] was also applied to enrich the PIA project material with current knowledge from countries as well as research groups who have worked with PSW. Moreover, Dementia Friends material created from Alzheimer's Society, UK, was used to deliver the message of Dementia Friendly communities in current and future PSW across the participating countries of the PIA project.

The material was initially developed in English in order to be free and available on the PIA platform for the public and is available for free download at this link (https://piaproject.eu/). The training material has been then translated and adapted to the national context of each project partner, according to the needs, priorities, and dementia services of each country. In Appendix, national adaptations of the originally created material are presented so that the reader can identify cross-cultural differences and needs existing between Norway, Italy, Romania, and Greece.

The sessions were supplemented with a series of printed documents such as "World Alzheimer Report 2022" delivered by Alzheimer's Disease International, "Dementia in Europe – Yearbook 2021" issued by Alzheimer Europe, "The National Action Plan for Dementia – Alzheimer's Disease" issued by Alzheimer Athens, Greece, "Global Peer Support Celebration Day (GPSCD)" released by National Association of Peer Supporters, 2018, SUA, "Peer Support for People with Dementia – Resource Pack", HIN 2015, the UK. All the materials were translated into local languages and presented to the participants in a progressive manner.

Pilot Training Courses

After the translation and the adaptation of the developed training material, all five project partners conducted the pilot between October and December 2022 to test the training with the target groups. Participants' recruitment had different profiles according to the national needs, detailed in the country-by-country pilot reports. Criteria have been mentioned in Methods.

Additionally, the duration and subdivision of the training course were decided by each participating country onsite either online, again according to the common framework of activity, but taking into account the specific training needs and availability of the participants. This made it possible to ensure a training offer is adapted to the specific contexts. No statistical analysis to identify any differences between the in-person and digital groups was implemented. Detailed information about the structure of the training courses in each country are placed in Table 2.

Table 2 Training Course Description Across the Participating Countries

	Duration	Instructor	Number of Participants
Norway	1 day, 8 hours	1 Trainer (nursing specialist)	8 participants including PSWs, home care nursing staff, managers and volunteers from 2 municipalities (4 PSW, 2 managers from homecare units, and 2 members from the memory unit team).
Greece	2 days, 8 hours	A trainer (a psychologist experienced in Alzheimer's care)	8 former caregiver participants and 2 psychotherapists from various municipalities in North Greece.
Italy	4 days, 16 hours (12 were face to face and 4 autonomous)	2 trainers (1 social worker and 1 psychologist) and involved 2 key experts for targeted interventions (1 local social worker and 1 expert in narrative medicine)	6 current and former informal caregivers were involved.
Romania- Iasi	4 days, 16 hours, 12 of which were face-to-face and 4 of which were independent work	2 trainers	9 participants were involved (5 informal caregivers and 4 volunteers)
Romania- Bucharest	2 days, 12 hours		12 participants with different professional backgrounds, as well as students and pensioners

Participants' Evaluation

The course was evaluated very positively by all participants who considered useful to learn more about dementia and issues of care. The evaluation questionnaires administered at the end of the training, aimed towards the investigation of various aspects concerning the satisfaction and validity of the course. Overall, and with reference to all pilots of the PIA project, the following feedback items were given (Table 3) above.

Free comments were also provided via the questionnaire, which allowed for a more concrete analysis of the PIA training course and the collection of final recommendations (Appendix). In general, the pilot participants in the various partner countries particularly appreciated the content and the project as a whole. They considered it very balanced in theory and practice, although some would have preferred it to be more dynamic and concrete. In this respect, the interactive activities and exercises, as well as the real-life examples and cases, were particularly appreciated. They considered it very useful to be able to have real references in order to assimilate the knowledge provided and would have liked more examples for this purpose. However, some reported feeling somewhat discouraged by the fact that they feel little trust in governments and authorities that are distant in the matter and do not simplify things. Among the aspects that were most appreciated was the fact that a lot of information, useful both professionally and personally, was conveyed in a simple and clear manner. It was emphasised, however, that it would be important to consider that some people often lack time and that it might be necessary to offer short meetings. The experience was very positively received for its

Table 3 Participants' Evaluation Mean Scores

	6.3/7
The training was clarifying to understand the aspects and tasks of the PSW	6.3/7
The duration time and the environment in which the training took place were considered particularly appropriate	6.8/7
The training was very helpful in developing the skills and abilities to perform the role of PSW in dementia care settings	6.5/7
The dementia knowledge provided in the course was considered sufficient and adequate	6.4/7

innovativeness and for the open, welcoming and friendly environment that was created, which left ample space and freedom to express without the fear of stigma in order to share knowledge and experiences.

These results confirmed the hypothesis that was at the basis of the project and the training courses, that communication and sharing among peers represent a great benefit in supporting people experiencing a similar condition. The course can therefore be considered a success, although it is important to adapt it to specific contexts and target groups. It is also important to provide the right support to prevent unpleasant feelings on the part of the participants. The results of this evaluation will be the basis for the finalisation and will be an integral part of the next project results.

Digital Platform for the Network for Collaboration and Knowledge Exchange Webinars and Training Videos

The initial goal was to develop a web portal and a knowledge database that can facilitate cooperation, sharing of knowledge and experience and networking. The digital platform (https://www.pia-dementia.digital/) was constructed on the basis of a clear specification of requirements with regard to functionality, content, and security. It is important to communicate with users of the portals and combine design and dialogue through an eclectic approach.

The portal was created in different languages and some special adaptations to meet each partner's requirements. In this process, the following steps were followed: 1) Construction of the web portal; 2) Testing of functionality and user friendliness; 3) Content development and file structure (texts, videos, dialog forums); 4) Knowledge database; 5) System of security (GDPR, Accessibility); 6) Service and development (KBT had the necessary competence for developing the web portal and database and give support and maintenance). The digital platform aimed to increase the network for collaboration and knowledge through webinars and training videos, as well as to provide a knowledge base for PSW in dementia care.

Step 2: Providing knowledge base for PSW in dementia care; Strategies' development and implementation

The main goal of the project was to increase advocacy and promote the user perspective in the development and delivery of services. To achieve this goal it is important to develop strategies and policies that meet the needs of all stakeholders. In order to develop better strategies and policies for the development of PSW within the field of dementia, it is necessary to involve partners, participants, and stakeholders in a strategic process. The situation in which each individual country and society as a whole should therefore be taken into account. Therefore, a description of the situation in each country regarding care for PwD, how user involvement is introduced, and a strategic analysis are required.

Discussion

Up to now, informal caregivers constitute the major source of support for PwD, while according to research,[25] they cover approximately the 85%–90% of total societal costs. It is noteworthy that, despite that PSW are widely used in mental health, child care, social services, and drug treatment, this role is new in the field of dementia. Therefore, the introduction of PSW in dementia care and relevant services will help dementia services across countries to find out how PSW can be useful for the development of cooperation/co-production between those who deliver and those who receive dementia services.

The innovation in this project consisted in developing a model for the introduction of PSW as a recognized service provider for people with dementia. The project approach included:

- collaboration between PSW with health professionals;
- techniques to recruit PSW;
- types of tasks that can be assigned to PSW;
- designing the role of a potential PSW with regard to expectations and norms/rules;
- follow-up of a PSW, related to guidance and termination of employment.

Given that except from Norway, the other partner countries, respectively, Greece, Italy, and Romania, do not involve PSW in national dementia settings, this project, aiming to introduce the intervention of peer support in dementia care, can enrich the help and support provided by health professionals in this field. To our knowledge, except Norway,[26] no previous studies have been conducted on this field in the participated countries. However, Austria, Czech Republic, Finland, the United Kingdom, and Malta[27] have incorporated peer support in their national policy. Therefore, introducing the peer support model by determining various ways to recruit and introduce PSW in the formal health care national system, can be assumed as a positive approach to address psychosocial challenges in dementia care.

To conclude, the current project aims at highlighting the role of PSW in dementia care to help caregivers and health professionals to manage difficult situations, implement innovative coping strategies and share helpful advice, which are assumed as added value for peer support.[28,29] By means of these goals, the training modules as well as the whole strategy of describing and figuring out the role of PSW were described to be assumed as a role model for the near future of dementia services, as PSW can provide specific help and support, which is different compared to this provided by health professionals.[30,31]

What makes this need even more crucial, is that the term of peer support is targeted in exchanging both practical and emotional support through reciprocity and shared experience. Peer support services provide to caregivers the possibility to have free time, handle with daily challenges, as well as feeling a sense of joy and satisfaction, with subsequent benefits in reducing burnout,[26,32] whereas according to Clare, Rowlands, and Quin[15] peer support process can be an anchor through which a PwD can be connected with other people, feeling a sense of belonging while struggling with loneliness and isolation. Additionally, this new perspective can impact national dementia policies by involving PwD in national dementia plan.[33,34] PSW can also inform PwD and their caregivers about their rights and allowances being an intermediate link between them and dementia services or any other funding sources,[35] whereas, peer support initiatives unite their efforts towards stigma and discrimination providing inclusion, priorities setting, and action.[36]

Finally, peer support can be assumed as a multifactorial intervention incorporated in dementia care delivered by former caregivers as well as PwD in early stages to respond to PwD and their caregivers' individual needs. Our project highlighted that providing a detailed program and further dissemination strategies, the role of PSW can be an innovation in dementia services, which can be adopted by the beneficiaries mentioned above. Future studies should shed light on the efficacy of peer support in beneficiaries' mental health, their levels of satisfaction from dementia services as well as identifying successful types of peer support using both qualitative and quantitative measures.

Limitations

The study is implemented in four European countries; therefore, future studies should elaborate on the role of PSW across Europe. Moreover, this study did not recruit PSW, because the sample of the PIA project constituted former and current caregivers who participated in the training courses. Therefore, the effectiveness of the PSW in dementia care cannot be evaluated by the current study. Finally, the generalization of the project's outcome should be interpreted considering the current limitations.

Conclusion

This protocol presents the PIA project, which aimed at inserting the figure of PSW in dementia care by creating and disseminating training material designed for this purpose. Hence, this study can be assumed as a stepping stone for adopting PSW in dementia services of Greece, Italy, and Romania compared to the Norwegian experience of peer support in this field. In this context, well-designed training material and reflective techniques were presented in the study's participants, whereas self-reported evaluation was also conducted after the training courses. Additionally, a digital platform including the training material, as well as facilitating digital conversation between former and current caregivers, PwD and health professionals was also created to promote PSW. Finally, dissemination strategies were also developed to boost the current project's results.

To conclude, the protocol of this study could reinforce health professionals and caregivers to establish the role of PSW in dementia care having a large variety of benefits as mentioned previously. Due to the fact that dementia is a chronic condition that affects various populations, except from those living with dementia, it is crucial to promote these kinds of interventions to boost the function of the already existing dementia services, especially for those beneficiaries living in remote areas of the European countries.

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Disclosure

The authors report no conflicts of interest in this work.

References

1. Wortmann M. Dementia: a global health priority-highlights from an ADI and World Health Organization report. *Alzheimer's Res Ther*. 2012;4(5):40. doi:10.1186/alzrt143
2. Cao Q, Tan CC, Xu W, et al. The prevalence of dementia: a systematic review and meta-analysis. *J Alzheimers Dis*. 2020;73(3):1157–1166. doi:10.3233/JAD-191092
3. Wimo A, Jönsson L, Bond J, Prince M, Winblad B, International AD. The worldwide economic impact of dementia 2010. *Alzheimer's Dementia*. 2013;9(1):1–11. doi:10.1016/j.jalz.2012.11.006
4. World Health Organization. *Ageing and health*. (2023). Available from: https://www.who.int/news-room/fact-sheets/detail/ageing-and-health. Accessed July 03, 2024.
5. Lian Y, Xiao LD, Zeng F, Wu X, Wang Z, Ren H. The experiences of people with dementia and their caregivers in dementia diagnosis. *J Alzheimers Dis*. 2017;59(4):1203–1211. doi:10.3233/JAD-170370
6. Bacsu JD, Kortzman A, Fraser S, Chasteen AL, MacDonald J, O'Connell ME. Understanding intersectional ageism and stigma of dementia: protocol for a scoping review. *JMIR Res Protoc*. 2023;12(1):e46093. doi:10.2196/46093
7. Devlin E, MacAskill S, Stead M. "We're still the same people": developing a mass media campaign to raise awareness and challenge the stigma of dementia. *Int J Nonprofit Volunt Sect Mark*. 2007;12(1):47–58. doi:10.1002/nvsm.273
8. Riessman F. A school-change paradigm. *Educ Dig*. 1989;54(9):10.
9. Mirbahaeddin E, Chreim S. A narrative review of factors influencing peer support role implementation in mental health systems: implications for research, policy and practice. *Adm Policy Ment Health*. 2022;49(4):596–612. doi:10.1007/s10488-021-01186-8
10. Darby Penney MLS. *Defining "Peer Support": Implications for Policy, Practice, and Research*. Advocates for human potential, inc; 2018:1–11.
11. World Health Organization. *Dementia: A Public Health Priority*. World Health Organization; 2012.
12. Allicock M, Kaye L, Johnson LS, et al. The use of motivational interviewing to pro-mote peer-to-peer support for cancer survivors. *Clinical Journal of Oncology Nursing*. 2012;16(5):156–163/. doi:10.1188/12.CJON.E156-E163
13. Burns A, Robert P. The national dementia strategy in England. *BMJ*. 2009;338(mar10 1):b931–b931. doi:10.1136/bmj.b931
14. Sabir M, Pillemer K, Suitor J, Patterson M. Predictors of successful relationships in a peer support program for Alzheimer's caregivers. *Am J Alzheimers Dis Other Demen*. 2003;18(2):115–122. doi:10.1177/153331750301800211
15. Clare L, Rowlands JM, Quin R. Collective strength: the impact of developing a shared social identity in early-stage dementia. *Dementia*. 2008;7(1):9–30. doi:10.1177/1471301207085365
16. Ward R, Howorth M, Wilkinson H, Campbell S, Keady J. Supporting the friendships of people with dementia. *Dementia*. 2011;11(3):287–303. doi:10.1177/1471301211421064
17. Fung WY, Chien WT. The effectiveness of a mutual support group for family caregivers of a relative with dementia. *Arch Psychiatr Nurs*. 2002;16(3):134–144. doi:10.1053/apnu.2002.32951
18. Wang L, Chein W, Ym Lee I. An experimental study on the effectiveness of a mutual support group for family caregivers of a relative with dementia in mainland China. *Contemp Nurse*. 2012;40(2):210–224. doi:10.5172/conu.2012.40.2.210
19. Kreuter MW, Green MC, Cappella JN, et al. Narrative communication in cancer prevention and control: a framework to guide research and application. *Ann Behav Med*. 2007;33(3):221–235. doi:10.1007/BF02879904
20. Carter G, Monaghan C, Santin O. What is known from the existing literature about peer support interventions for carers of individuals living with dementia: a scoping review. *Health Soc Care Community*. 2020;28(4):1134–1151. doi:10.1111/hsc.12944
21. Stott J, Sweeney JM, Koschalka L, O'Connor L, Mwale A. People with dementia as peer workers, challenges, and benefits: a thematic analysis and nominal groups study. *Int Psychogeriatr*. 2017;29(7):1185–1192. doi:10.1017/S1041610216002519
22. Wright T, O'Connor S. Reviewing challenges and gaps in European and global dementia policy. *J Public Mental Health*. 2018;17(4):157–167. doi:10.1108/JPMH-02-2018-0012
23. Graham JT, Rutherford K (2016). The Power of Peer Support. London: Nesta. Available From: *https://www.nesta.org.uk/sites/default/files/cfsaif_power_of_peer_support.pdf*. Accessed November 1, 2017.
24. Gurl E SWOT analysis: a theoretical review; 2017.
25. Prince M, Comas-Herrera A, Knapp M, Guerchet M, Karagiannidou M. *World Alzheimer Report 2016. Improving healthcare for people living with dementia: Coverage, Quality and costs now and in the future* [Doctoral dissertation].Alzheimer's Disease International; 2016.

26. Halvorsrud L, Bye A, Brekke LA, Bergland A. Being a trained volunteer Peer Supporter for carers of people living with dementia in Norway: reciprocal benefits and challenges. *Health Soc Care Community*. 2020;28(6):2150–2159. doi:10.1111/hsc.13026
27. Tokovska M, Nour MM, Sørensen A, Småland Goth U. Informal caregivers and psychosocial support: analysis of European Dementia Policy documents. *J Public Health Res*. 2022;11(1):jphr–2021. doi:10.4081/jphr.2021.2416
28. Boisvert RA, Martin LM, Grosek M, Clarie AJ. Effectiveness of a peer-support community in addiction recovery: participation as intervention. *Occup Ther Int*. 2008;15(4):205–220. doi:10.1002/oti.257
29. Thomson G, Balaam MC. International insights into peer support in a neonatal context: a mixed-methods study. *PLoS One*. 2019;14(7):e0219743. doi:10.1371/journal.pone.0219743
30. Dam AE, de Vugt ME, Klinkenberg IP, Verhey FR, van Boxtel MP. A systematic review of social support interventions for caregivers of people with dementia: are they doing what they promise? *Maturitas*. 2016;85:117–130. doi:10.1016/j.maturitas.2015.12.008
31. Pillemer K, Suitor JJ. Peer support for Alzheimer's caregivers: is it enough to make a difference? *Research on Aging*. 2002;24(2):171–192. doi:10.1177/0164027502242001
32. Smith R, Drennan V, Mackenzie A, Greenwood N. Volunteer peer support and befriending for carers of people living with dementia: an exploration of volunteers' experiences. *Health Soc Care Community*. 2018;26(2):158–166. doi:10.1111/hsc.12477
33. Dupuis SL, Gillies J, Carson J, et al. Moving beyond patient and client approaches: mobilizing 'authentic partnerships' in dementia care, support and services. *Dementia*. 2012;11(4):427–452. doi:10.1177/1471301211421063
34. Keyes SE, Clarke CL, Wilkinson H, et al. "We're all thrown in the same boat…": a qualitative analysis of peer support in dementia care. *Dementia*. 2016;15(4):560–577. doi:10.1177/1471301214529575
35. Chappell M, Zdanowska J, Cashmore J, Oliver G, Cooper J. Peer support for carers of people with dementia. *Ment Health Soc Incl*. 2018;21(2):110–118. doi:10.1108/MHSI-12-2016-0038
36. Keyes SE, Brandon T. Mutual support: a model of participatory support by and for people with learning difficulties. *Br J Learn Disabil*. 2012;40(3):222–228. doi:10.1111/j.1468-3156.2011.00698.x