PILOT REPORT

PROMOTING BREAST CANCER PREVENTION
BETWEEN INFORMAL CAREGIVERS

GA n° 2019-1-CY01-KA204-058266

Co-funded by the
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of the European Union

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Erasmus+ Programme
of the European Union

This report was developed in the framework of the Erasmus+ Prolepsis[1] partnership, under the leadership of Cyprus University of Technology.

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[1] To learn more: https://prolepsis.eu/

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Introduction

European guidelines are in place for the provision of mammography screening for the early detection of breast cancer. Although women, for various reasons (e.g. lack of knowledge, limited health literacy) do not attend these screenings as expected despite their awareness on the availability of preventive cancer screening tests.

Women who assume the role of the informal carer face additional challenges in engaging in health promotion practices such as BC screening. Explicitly, studies on caregivers' health behaviours stress the presence of impaired health behaviours, such as neglecting health care appointments, eating a poor-quality diet, limited exercise time and forgetting to take prescribed medications, compared to non-caregivers.

The project aims to develop a mobile phone-based health intervention, as a means to enhance preventive health care behaviour among informal caregivers' population with tailored individual messages.

The specific objectives of the project are:

1. to create a methodology and relevant contents extending informal caregivers' knowledge regarding the impact of their prevention avoidance behaviour on BC development
2. to educate and enhancing them, through training modules, to assume control over this disease through adopting and maintaining changes in their lifestyle and living practices. These include modifications of their lifestyle habits, self-monitoring, self-assessment and reinforcement of positive behaviours as well as encouragement of use of preventive BC services.
3. to develop a personalized mobile application (i.e. personal characteristics, needs and preferences), which will support informal caregivers to better manage self-care and behaviour change in illness prevention.

The aim of this document is to report the results of the piloting of the Prolepsis training programme, which saw the implementation of blended training through the use of the Prolepsis App and face-to-face sessions in Cyprus, Italy and Portugal.

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Prolepsis training programme overview

Aim of the Prolepsis training is to build an e-health educational programme which enables participants to increase their knowledge of breast cancer and the importance of prevention, and provides them with the skills to self-manage their own health monitoring. The educational materials have been provided in accordance with the HBM model, mostly to increase female caregivers' awareness on Brest Cancer symptoms, on screening exams as mammography and to cultivate and improve their practices on preventive behaviours of BC including physical activity, healthy diet and stress management techniques. The principle guiding all training modules is to increase perceived sensitivity and perceived seriousness about the threat of this malignancy and their understanding to the barriers in performing BC preventive behaviours. These constructs, in turn, could help women to strengthen their ability and impart positive beliefs towards preventive behaviours including Breast Self-Examination, Clinical Breast Examination and mammography. The production of the material followed several stages, of creation, peer-revision and translation, and took about 8 months. In the first instance, the training modules were constructed by searching for authoritative and reliable sources with which to build the material. The pedagogical material covers different areas of intervention, which are:

1. Information on Breast Cancer: what is Breast Cancer, which are the risk factors, epidemiology and prevention methods.
2. Preventive lifestyle: how to prevent BC by implementing modifications of lifestyle habits (e.g. physical wellbeing through healthy nutrition and exercise, psychological wellbeing through stress management techniques and meditation), self-assessment of their own habits
3. Self-monitoring: how to manage the self-monitoring of their own health, benefits of regular mammography
4. Self-efficacy: how to alleviate feelings of tension prior to mammography screening/strengthening positive beliefs about mammography and reduced anxiety about screening methods. To increase self–efficacy, the mobile app will provide information about practical steps that can be taken to maintain regular/ monthly BSE and it is envisioned to include a reminder system (based on user's personalized preferences) whereby the app will remind women (e.g. on-screen notifications) about their next scheduled screening test.

Subsequently, a peer-review process between the partners began, aimed at achieving an optimised product. Finally, once the reviews were completed and the material agreed upon, the translations began. In parallel, a video was developed on how to perform the breast self-examination, explaining various steps and showing with an avatar how to do them. This video was then published on the Prolepsis Youtube channel and subtitled in all partner languages. The developed material, exported as video presentations, was uploaded to the Prolepsis app, so that participants in the pilot could use it at any time. The model has been tested in Cyprus, Italy and Portugal, respectively with the participation of 17 women caregivers in Cyprus, 10 in Italy and 10 in Portugal, for a total of 37 women involved, of which 28 completed the entire course. Below is a table summarising the planned training sessions and the learning outcomes of each.

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Module	Sessions	Learning outcomes
Module 1 Information on Breast Cancer	3 hours online	• Increased knowledge about breast cancer, what it is, where it affects and how it affects the European population and worlds. • Greater awareness of the risk factors that have an impact on breast cancer contraction, including those that can be controlled by the individual. • Increased knowledge of breast cancer prevention and screening practices.
Module 2 Preventive Habits	1h30 in face to face 1h30 in face to face	• Learning simple guidelines for healthy nutrition • Learning how to keep physically active, also independently and in a short time • Approaching meditation as a practice for self-awareness and well-being • Knowing tools through which monitoring progresses
Module 3 Self-monitoring	3 hours online	• Increased awareness about the importance of self-monitoring • Increased knowledge on how to perform breast self-examination • Greater awareness about the importance of mammography
Module 4 Self-efficacy	1h30 in face to face 1h30 in face to face	• Understanding of management strategy to alleviate feelings of tension prior to mammography screening • Strengthened positive beliefs about mammography and reduced anxiety about screening methods • Increased self-recognition as a carer • Learning time management methods to reconcile the role of carer with prevention

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ITALY

Chapter 1: Organisation and structure of the pilot

Anziani e Non Solo (ANS) is an NGO working since 2004 in the field of social innovation with specific reference to the design and implementation of interventions, products and services in the field of welfare and social inclusion. As a partner within the Prolepsis project, ANS implemented in September 2021 the pilot course addressed to informal caregivers. The cooperative has in fact a long experience in working with this target group, having promoted and implemented projects addressed to family members of people with chronic diseases, disabilities or elderly since its inception. The activities carried out by Anziani e Non Solo concern different social fields, such as training and support to family caregivers, informal and formal, adults and young people; active ageing, intergenerational activities and support to frail and non-self-sufficient elderly; social inclusion of vulnerable groups. The implementation of the project pilot therefore involves activities in which the co-operative has developed experience and professional skills.

1.1 Organisation of the training course

A central part of the Prolepsis project was dedicated to developing training materials on breast health promotion and breast cancer prevention for women caregivers. Women who take on the role of caregiver may have difficulties in adopting health promotion practices, such as mammography screening for breast cancer. Studies on health behaviours point to a higher occurrence of altered health behaviours among caregivers, compared to the non-caregiver population. Examples of altered health behaviours are neglecting health care appointments, adopting a poor-quality diet, limited exercise time and incorrect or failure to take prescribed medication.
The training material, built through the collaboration of the different partners, i.e. university professors, nutritionists, psychologists and nurses, aims at stimulating the adoption of positive behaviours for the health of caregivers. In detail, the training focused on the following topics:

- **Module 1- General knowledge about breast cancer:** information about the types of breast cancer, risk factors, epidemiology, diagnosis and treatment.
- **Module 2 - Prevention through physical and psychological wellbeing:** information and advice on how to maintain a healthy diet and adequate exercise. Introduction to mindfulness as a practice to become more aware of oneself, one's needs and well-being.
- **Module 3 - Prevention through early diagnosis:** information and advice on preventive screening tests, such as mammography, and breast self-examination.
- **Module 4 - Self-efficacy and management of the role of caregiver:** reconciling self-care and care of the family member for a common well-being.

These training modules were implemented partly through the Prolepsis APP, in self-education, and partly in presence, through 4 dedicated meetings. In detail:

- Module 1 - Completely in self-education through the prolepsis APP
- Module 2 - Developed in presence with trainers
- Module 3 - Completely in self-education through the prolepsis APP

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- Module 4 - Developed in presence with trainers

The choice of which modules to implement in presence and which to implement in self-education was determined by the contents of the modules themselves: the more theoretical parts were left to the autonomous consultation of the participants, to be then taken up in presence through exercises and practical activities as well as question and answer sessions.

Participants were recruited through three main channels, described below.

Newsletter on the Prolepsis website and main social channels

The first communication tool used to disseminate the execution of the Prolepsis Project pilot was a Project Newsletter. This Newsletter briefly described the objectives of the project, the stage of execution the project was in and the next steps for its implementation, i.e. the piloting of the training material. The main contents of it were then described. The Newsletter was drafted by ANS in English and then translated by each partner into their mother tongue, with each national version adding the necessary adaptations and details for their audience. The newsletter was published on the Prolepsis website at this link and disseminated through the ANS social networks.

Networking between users of ANS services

As described above, Anziani e non solo has extensive experience in organising training opportunities and support services for caregivers. This allowed over the years to create a network of caregivers who use different services of the cooperative and are connected to it. Therefore, the main recruitment strategy was to disseminate the pilot to direct contacts the team already had.
To do this, a poster was created solely for this direct contact (therefore not promotional for social networks or the website), indicating the dates, times and place of the trainings as well as contacts for information and registration.

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ANS social media campaign

Numerous publications followed before the start of the pilot and throughout its implementation. For the recruitment of the participants specifically, a card was made with some basic information and a QR code linking to the project website and contacts for information and registration. This post was sponsored on Facebook for about 10 days and allowed to reach people from outside the seniors' network and beyond.

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The training took place in Carpi, at the Fondazione Casa del Volontariato; this place was chosen in order to have a room large enough to accommodate all participants in compliance with the Covid-19 regulations in force. The pilot was divided into 5 different sessions, listed below:

- 24 August 2021: Online session via Zoom introducing the project and the Prolepsis APP
- 31 August 2021: Module 2 - health and psychological wellbeing
- 7 September 2021: Module 2 - physical health and well-being
- 14 September 2021: Module 4 - self-efficacy in health prevention
- 21 September 2021: Module 4 - self-efficacy and the role of caregiver

It was decided to separate the meetings by one week so that the participants could also watch the contents of the APP modules each time. The two training modes, face to face and self-education online, were therefore continued in parallel, thus integrating the materials.

1.2 Profile of participants

The participants are 10 women caregivers, who take care of a loved one with a disability, a chronic disease or an elderly person. Specifically, the person they take care of for some of them an elderly parent or a parent with specific pathologies, for others a child with a disability.
The age range of the participants is between 45 and 65 years and they have different family and work situations. From the care point of view, some of them have a family unit to support them, e.g. husband, other children, brothers or sisters, others have a care role alone. Most of them are employed, but some of them do not work because of the caring commitment, and some are retired.

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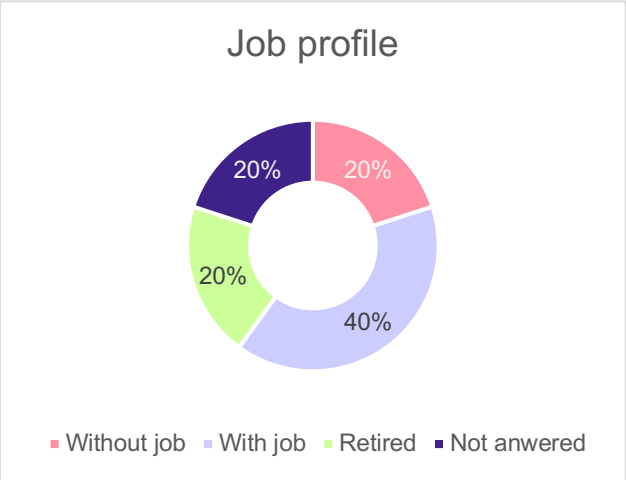

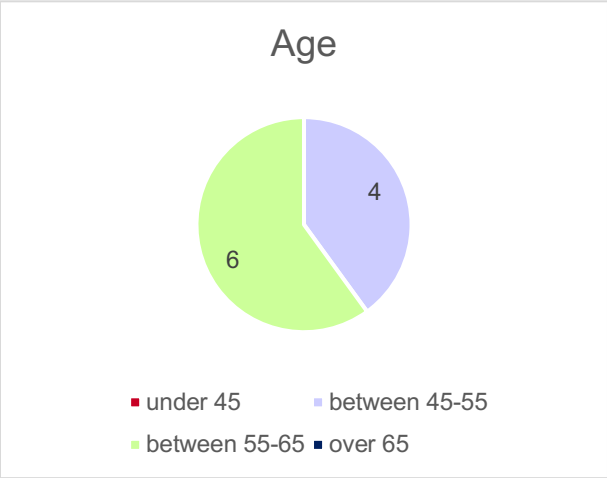

1.3 Structure of the training course

The pilot course was led by the trainers Alessia Palermo, psychologist, and Sara Beccati, sociologist. During its implementation, three experts from outside the partnership were involved:

- Dr. Alessandra Manattini, psychologist specialised in neuroscience and mindfulness techniques
- Dr. Andrea Salami, doctor of physical sciences and personal trainer
- Dr. Martina Toschi, nutritionist biologist

The course was organised in 4 face-to-face sessions of 1h30 each and a pre-session online, as foreseen in the programme. In order to facilitate the caregivers' participation, it was decided to keep only one meeting per week, on Tuesdays from 18:30 to 20:00 CET. This time schedule allowed the participation of those who are busy during the day, and the presence, only once a week, was manageable for most of them. However, two of the participants were only able to attend one meeting due to their caregiving commitments. One of them, however, continued to follow the development of the training through the application and updates provided by the trainers; the other, on the other hand, could not continue the course in any way.

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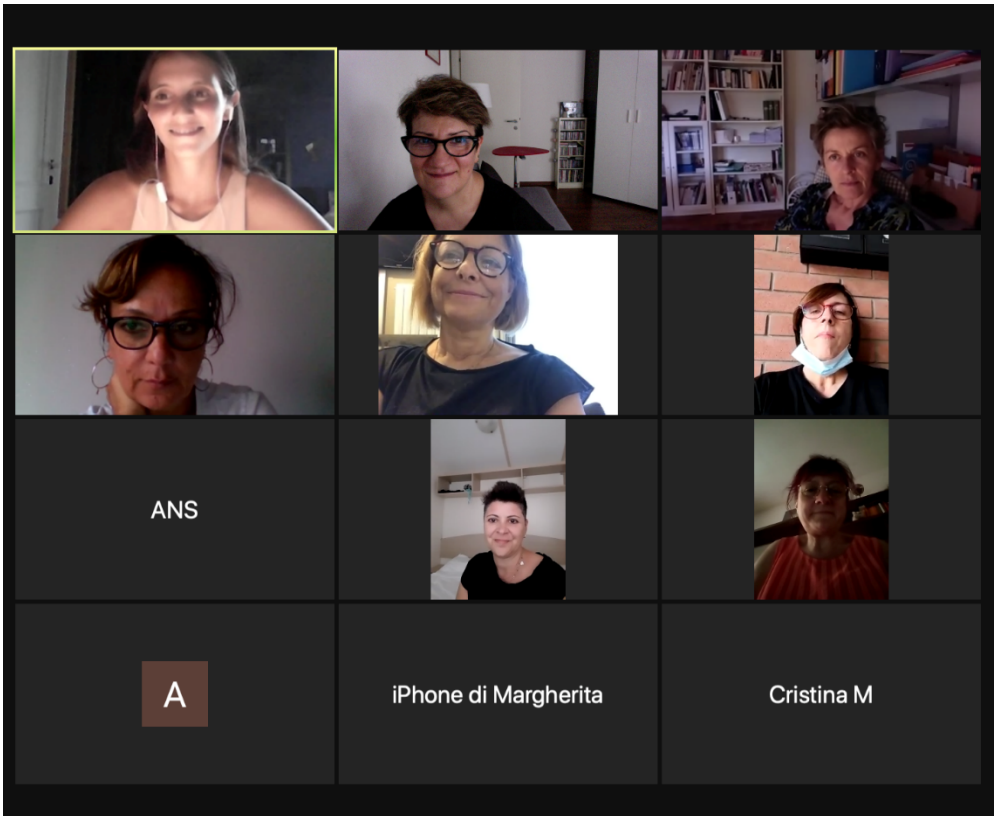
Pre-session

The first meeting took place online and coincided with a pre-session of about one hour aimed at introducing the participants to the objectives of the Prolepsis project and the training path they were about to undertake. Part of the meeting was devoted to showing the participants the application and describing its use; the trainer then shared the screen of his phone and allowed the participants to see its functionality. The delay in the approval of the application by the main app stores, however, did not allow the participants to download it in real time, but only a few days later. At the end of the meeting, participants were invited to view the first module on the app as soon as it was available.



First session: Module 2 - Psychological well-being

As suggested by the programme in relation to some specific activities, professionals from outside the partnership were involved in the in-presence training in order to deepen in a specialised way some topics of Module 2, concerning a preventive lifestyle. Specifically, the professionals involved were a psychologist, a nutritionist and a personal trainer[2]. The time availability of the different professionals led to the reversal of the two main parts of Module 2, namely *physical well-being* through nutrition and exercise, which was scheduled first, and *psychological well-being*, which

[2] Questi ultimi presenti al secondo incontro

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was scheduled second. However, this inversion proved to be irrelevant overall, as both parts of the same module were self-contained.

During the first meeting, dedicated to psychological well-being, the participation of an external psychologist led to the modification of one of the two planned exercises on her advice. In detail, the following schedule was followed in the execution of the session:

- *Welcome and introduction*: Presentation of the PROLEPSIS project, its objectives and how they will be achieved.
- *Ice-breaker*: the trainers introduced themselves through 3 words describing them. The participants had a few minutes to think and then shared their words. This exercise was aimed at creating interconnection between the participants, getting to know each other and finding any similarities or differences between them.
- *Q&A session:* the trainers deepened questions and curiosities arising from the previous module, which they had viewed independently.
- *Presentation of the learning material:* the trainers presented introductory material, prepared together with the Prolepsis partnership, exploring the topics of psychological well-being and mindfulness as a technique for dealing with moments of stress.
- *Mindfulness exercise on breath:* as a first exercise, the participants were offered a brief moment of meditation centred on breathing, a simple mindfulness exercise aimed at introducing the women to deep reflection and this practice. The aim was to offer them an activity that they could repeat independently and that could help them to manage anxiety and critical moments.
- *Mindfulness imaginative exercise*: an imaginative and figurative exercise was then proposed, focusing on intrusive thoughts. Participants were asked to imagine themselves at the bank of a stream, with a tree beside it. They were asked to deposit any thoughts that arose during meditation on a leaf falling from the tree and then let it go with the flow of the stream. This exercise was not included in the training programme, but the psychologist found it useful to offer it as it allowed them to explore different types of mindfulness exercises. The compassionate letter exercise, planned for this session, was postponed to the last training session.
- *Conclusion*: the meeting was concluded with a short question and answer session, referring back to the application for additional materials.

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Second session: Module 2 – physical well-being

As mentioned, the second meeting saw the participation of two professionals from outside the partnership, namely a nutritionist biologist and a personal trainer with a degree in physical education. Their involvement was considered useful for the development of the training activities in order to make them less theoretical and to address in a more specialised and applied way the topics of the module. In detail, the following programme was followed in the execution of the session:

- *Welcome and Q&A session*: the trainer welcomed the participants and asked if any doubts or curiosities had arisen from the previous meeting and the material on the App.
- *Presentation of the learning material:* the nutritionist presented introductory material, prepared by the Prolepsis partnership, exploring the issues of physical well-being from a nutritional perspective.
- *"PROLEPSIS* cookbook*" activity:* after explaining to the participants the 10 tips to follow in order to have a healthier and more balanced diet, the trainers asked them to think of one of the recipes that they make most often and that they like (possibly a recipe that is quite simple and quick, and that is within the reach of even those who are not experts in cooking). The nutritionist then asked them to share them and where the recipes did not follow the guidelines, she opened a small discussion with the participants on how they could be improved. The improved recipes were then collected to create the Prolepsis cookbook.
- *Presentation of the learning material:* the personal trainer resumed the presentation of the training material by deepening the topics of physical well-being from the point of view of physical activity.
- *Conclusion*: the meeting was concluded with a short question and answer session, referring back to the application for additional materials.

In this session the participants were particularly engaged by the presence of the two professionals, and some recommended that in future this session be split into two parts so that more time could be devoted to each aspect of physical well-being.

Third session: Module 4 – self-efficacy in health prevention

The third meeting was devoted to addressing issues related to self-monitoring and self-efficacy in managing emotions and fears that may arise in relation to breast cancer screening procedures. In fact, the seriousness of this disease and its general association with death often leads many women to want to avoid even preventive examinations, despite the fact that they are necessary to anticipate (and not cure) the disease. Due to time constraints, only some of the exercises

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suggested in the training plan were implemented, so we suggest that in the light of this experience the other exercises be kept as possible alternative options. In detail, the following programme was followed in the execution of the session:

- *Welcome and Q&A session*: the trainer welcomed the participants and asked if any doubts or curiosities had arisen from the previous meeting and the material on the App.
- *Exercise "false myths about mammography":* The trainer asked each member of the group to take out a sheet of paper from a box; each sheet contained a sentence concerning breast cancer and its prevention. The participants were asked to read what was written and to take turns in starting a dialogue about that sentence (how true or false they thought it was, for what reason, etc.). The aim of this activity was to work on beliefs and to give information about breast cancer screening and to deconstruct false myths.
- *BSE video:* The trainer then presented a video, created by the project coordinator CUT, on how to perform breast self-examination. He then explored with the participants their self-perceptions of the main obstacles and facilitators in undergoing regular self-examination and mammography.
- *Record your exams on the Prolepsis App*: The trainer then outlined to the participants how often breast self-examination should be done and showed them how to mark on the Prolepsis App calendar one day per month until the end of the year. He also informed the participants about the possibility of creating a chat room on the App with friends who could help them keep their screening appointments and support them.
- *"Fear in the box" exercise:* Each participant wrote down on a sheet of paper her main fear or emotion related to mammography or breast self-examination. The trainer collected the sheets in a box and took them out one at a time and read them aloud. A group discussion was opened on how to overcome fears and obstacles, often linked to one's role as a caregiver. The main aspect that emerged was the importance of a network to lean on, to rely on.
- *Exercise "the rules of emotions":* Finally, the trainer asked the participants to reflect on some statements concerning emotions and how to express them. Specifically, for each of these statements, the participants had to comment on how much they agreed from 1 to 10 and what following these rules implied. Participants generally agreed with statements such as "*You are not guilty of your emotions, but you are responsible for the behaviours you choose to carry out in the presence of them*" or "*Emotions when shared with important people strengthen the relationship*" although they sometimes found it difficult to implement them. Some of them talked about time as a barrier in being able to take care of themselves and

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manage their commitments, others about how their history influences them, because of the relationship they have with the loved one they care for or the network of social relations. However, they all recognised the importance of managing their feelings constructively, not by avoiding situations of fear or worry but by recognising them and finding a strategy to deal with them.

- *Conclusion*: the meeting was concluded with a short question and answer session, referring back to the application for additional materials.

This session proved to be particularly emotionally intense for the participants, especially with reference to the exercise "*Fear in the box*"; we therefore suggest that one of the trainers could be a psychologist or another professional figure with experience in helping caregivers (such as a facilitator of self-mutual help groups), as narratives about the commitment to care may emerge and need to be managed and regulated. Moreover, as expressed in the incipit, talking about breast cancer makes salient the fear of death that participants may encounter: this fear must be managed and resized during the training, not letting participants leave the meeting overly emotionally activated.

Fourth session: Module 4 - Self-efficacy in the caregiving role

This meeting was the most complex for the trainers as only 3 caregivers were present. The other caregivers registered had different commitments, so their presence was not possible. This inconvenience must be considered in possible future repetitions of the programme. It is common that in a one-month programme with 4 meetings, some participants are unable to attend at least one meeting. For this reason, the trainers decided not to implement the exercises in the programme, as they were designed for a larger group, but to conduct an open discussion around the core issues of the module. The main areas covered were:

- time management in relation to their caring role
- managing guilt feelings related to doing activities for themselves and not for their loved one
- the activation of a social support network, formed for example by friends, family, other caregivers etc.
- the need to delegate, where possible, the activity to other secondary caregivers (siblings, partners, children etc.)
- training in accepting that they cannot be the only ones to take care of their loved one and that they need help
- finding out about all the services that can help them (respite services, social worker services, care workers...)

The participants were particularly involved in the discussion, so the session was effective despite the change of schedule. The sharing of thoughts and emotions also motivated them to exchange their personal contacts in order to stay in touch with each other. This result is particularly important

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in view of the fact that the Prolepsis training course not only generates knowledge, but also a new social network.

The training pilot plan for Italy stands as shown in

Table 2.

Table 1. Pilot action configuration in Italy

Format of the training (face-to-face, blended, etc)	Blended mode (partly performed on the APP and partly in presence)
Duration of the training	6 hours in total, divided into 4 meetings of 1h30
Contents covered	The programme proposed within the Training Plan was fully covered with the following sessions: • Online session via Zoom introducing the project and the Prolepsis APP • Module 2 - psychological health and well-being • Module 2 - physical health and well-being • Module 3 - self-monitoring of health • Module 4 - self-efficacy and the role of caregiver
Total nr. of registered learners	10
Total nr. of learners who completed the course	8
Training methods used	• Guided discussion • Brainstorming • Experiential learning
Use of learning materials from IO2 (use of multimedia, use of all worksheets or partially, adaptations needed, etc)	All materials in the manual were used. Some changes have been made in terms of the order of the exercises and alternative exercises have been used where necessary, which are provided in the manual as possible choices.

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Chapter 2: Results and evaluation

Despite some challenges to overcome, especially with regard to the functioning of the app and the loading of content, the training course developed without any major issues. The participants were enthusiastic about the proposal and happy to meet other caregivers in their country. Generally, their knowledge improved after the piloting of the training programme, and their level of satisfaction seems high. This was also remarked orally to the trainers during the last face-to-face meetings.

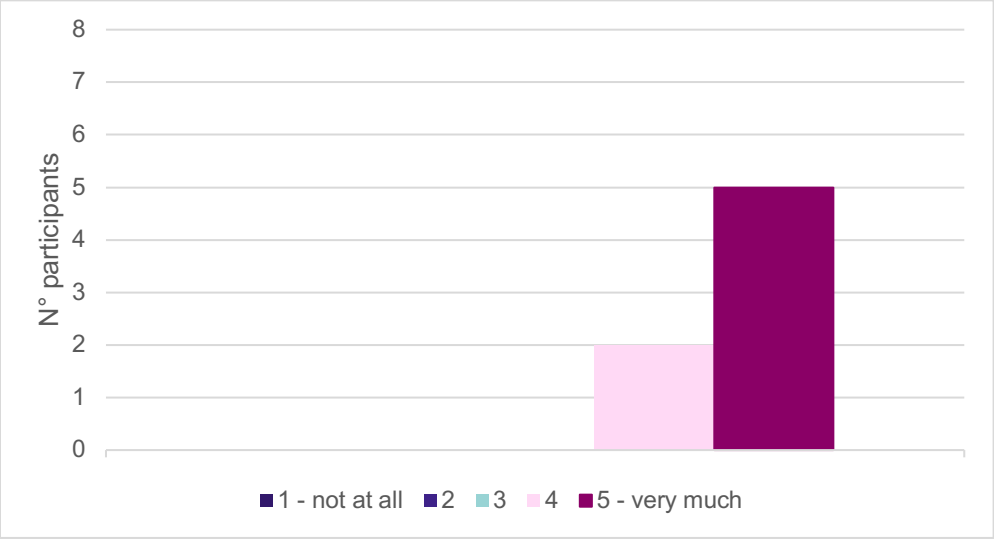
2.1 Satisfaction with the training and the app

The survey aimed at assessing the satisfaction with training program carried out in the framework of Prolepsis project and the app, we submitted an online questionnaire to the participants who were willing to answer. Interviewees were invited to answer to an anonymous series of closed and open question in Italian. Only 7 participants out of 8 which participate to the whole training decided to respond to the questionnaire; the other one gave simply verbal feedbacks during the face-to-face session.

1st question: Place (City, town)

Most of the respondents were from Carpi, while the remaining interviewees answered from Novellara and Reggio Emilia. All respondents came from Emilia Romagna region.

2nd question: Are you satisfied with your participation in this training?



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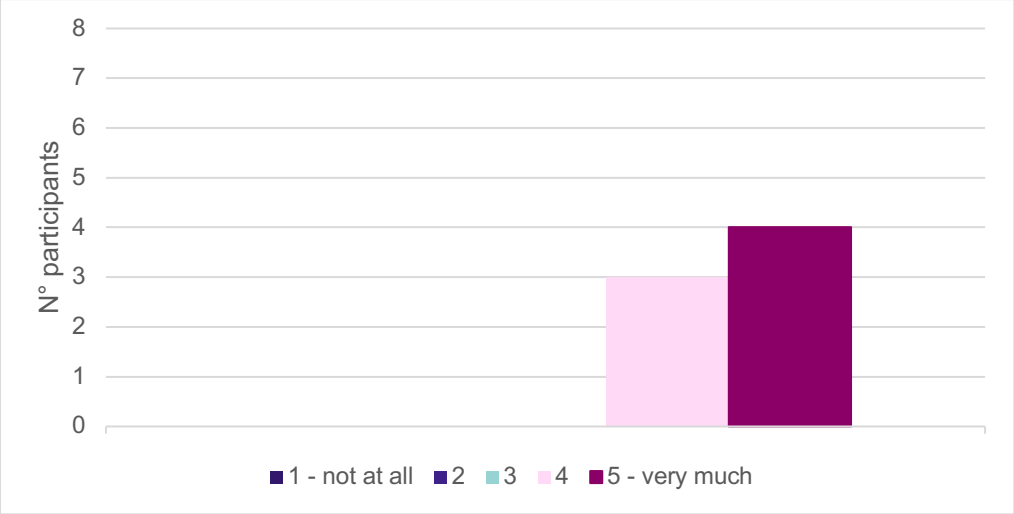
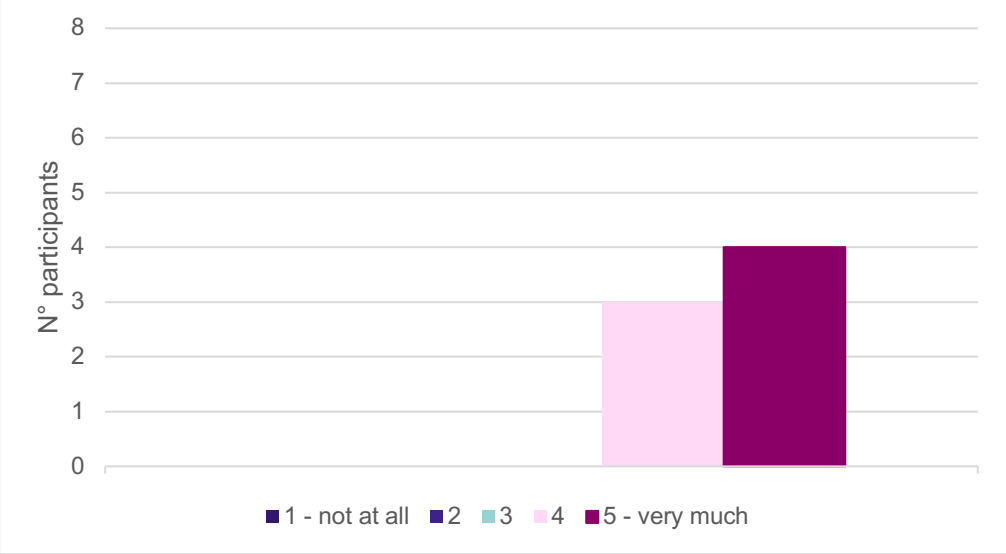
On a scale of 1 to 5, 71.4% of respondents gave a score of *5* and 28,6% of them gave a score of *4*. Overall, the respondents were satisfied or very satisfied with the training programme.

3rd question: Were the objectives of the training similar to or different from your expectations?



On a scale of 1 to 5, 57,1% of the interviewees answered that the objectives of the training were **very similar** to their expectations. The remaining 42,9% believed that the objectives were **similar** to their expectations. None of them felt that the objectives were different from their expectations.

4th question: Do you think you learned something from participating in this training?



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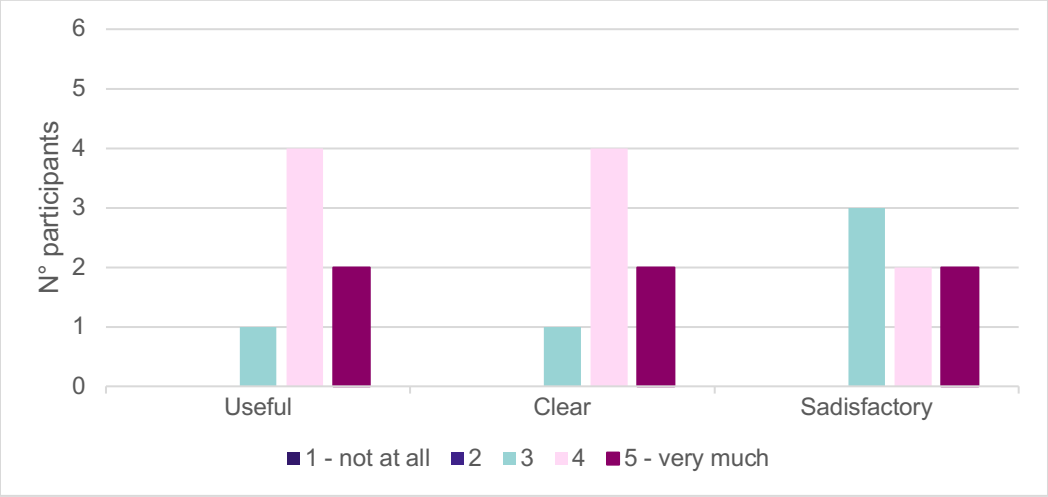
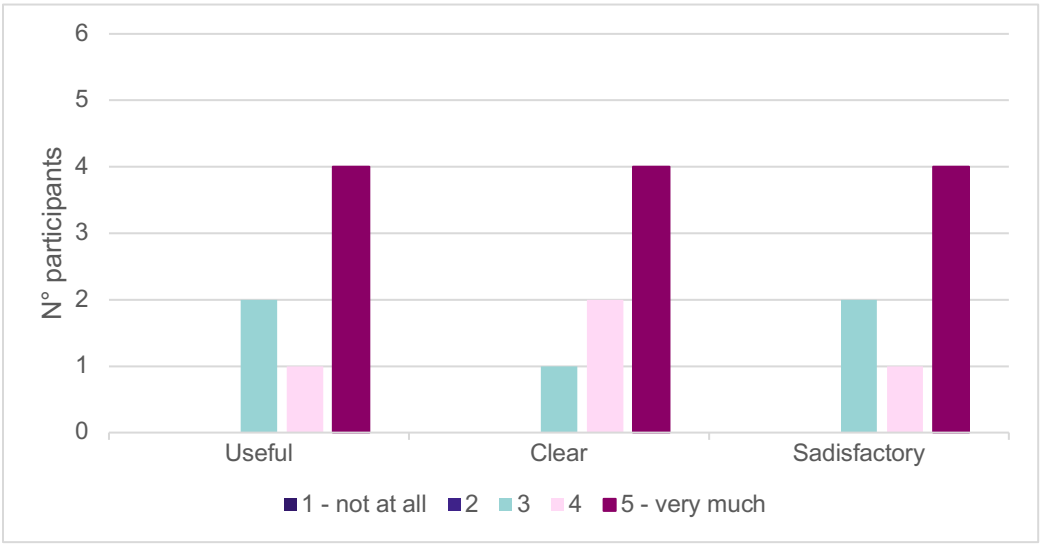
On a scale of 1 to 5 (not entirely/ definitely), 42,9% of participants gave a score of *4*. The other 57,1% of the interviewees gave a score of *5*. Overall, participants of the training program received a good level of learning, according to their answers.

5th question: The contents of the video modules in the app were… (useful, clear, stimulating)



On a scale of 1 to 5 (not at all/very significantly), the participant gave a score to the contents of the video, indicating how **useful, clear and satisfactory** they had been. 4 participants gave a score of *4* in the *useful* and *clear* boxes. Instead, 3 interviewees rated the stimulating box as *3*, 2 of them gave a score of *4* and the remaining voted *5*.

6th question: The contents of the in-person sessions were: … (useful, clear, stimulating)



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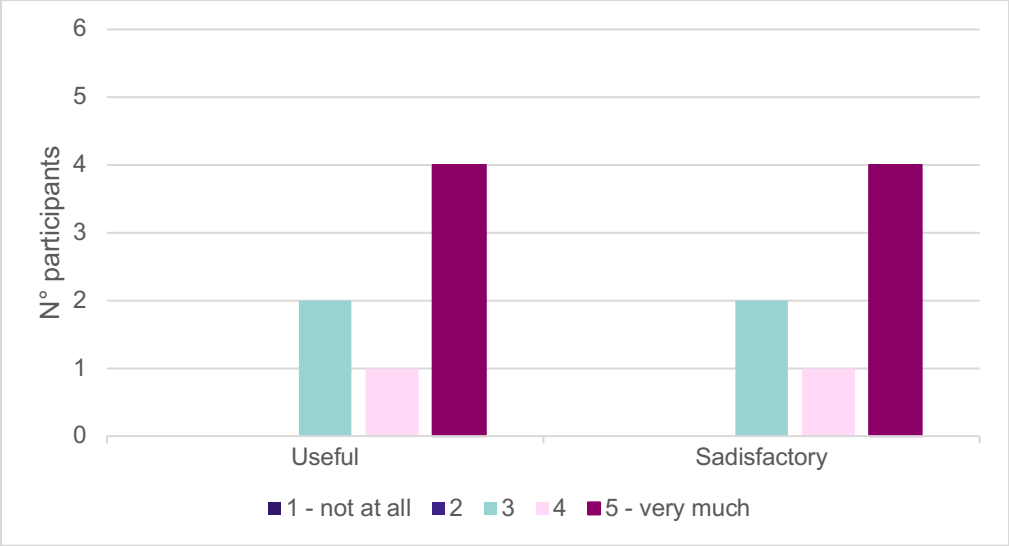
On a scale of 1 to 5 (not at all/very significantly), 4 participants indicated that the contents were **very useful**, while 2 of them gave a vote of *3* and one of them voted with a *4*. In addition, 4 interviewees believed that the contents were **very clear** giving a vote of *5*, while 2 of them gave a score of *4* and one of them gave a *3*. 4 participants also considered the contents **very stimulating** and two of them gave a score of *3*. In general, the contents of the in-person sessions were appreciated by the interviewees.

7th question: The participation of experts (external professionals) on the topic was… (useful, stimulating)



On a scale of 1 to 5 (not at all, very significantly), 4 respondents believed that the participation of experts on the topic was **very useful** and very **stimulating**. The remaining interviewees gave a score of *3* or *4*. Overall, participants were satisfied with the participation of experts in the field.

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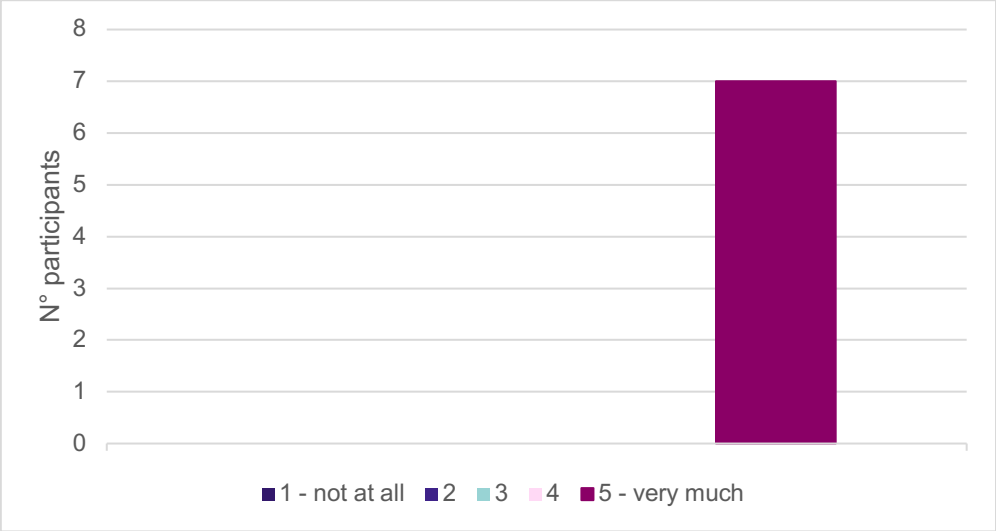
8th question: How would you rate the performance of the internal trainers (i.e., Alessia Palermo and Sara Beccati)?



On a scale of 1 to 5 (not effective/very effective), all participants rated the performance of the internal trainers as **very effective**.

9th question: Please describe in more details your thoughts on the performance of trainers

The attendees described the performance of trainers as "*emphatic*", "*kind*" and "*competent*". One of them appreciated the trainer's capacity to listen and welcome people

"The trainers were able to capture the essence of the deepest feelings that affect caregivers and provided with willing and interactive tools. They carried out their work with an uncommon human charge."

"Gentle and empathetic, good listening and very welcoming."

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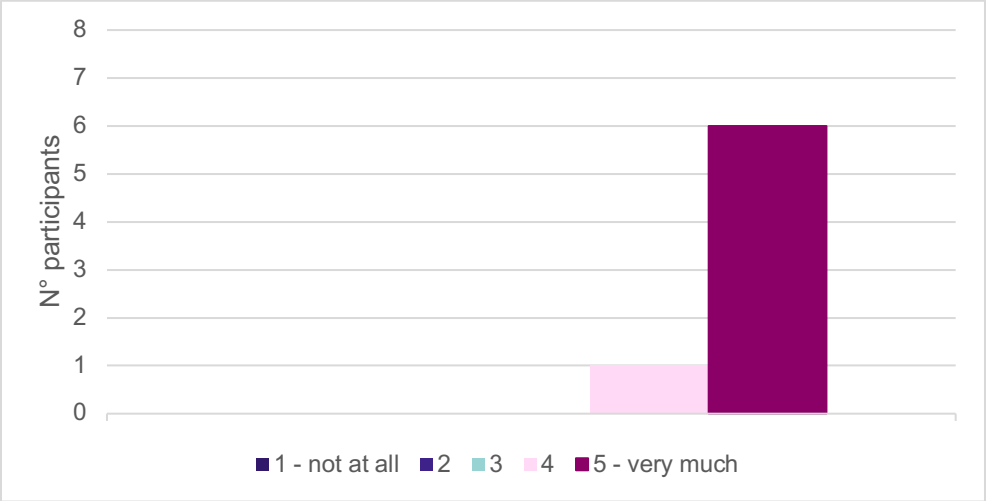
10th question: How would you rate the training overall?



85,7% of participants gave a score of *5* to the training, on a scale of 1 to 5 (negatively/positively).

In general, the attendees believed that the whole training was very positive.

11th question: Please describe in more details your thoughts on the training in general terms

The participants described the training using terms as "*very good*", "*satisfying*" and "*interesting*". In particular, one of them affirmed that the trainers were competent and appreciated the contents used during the training program.

"[…] It was interesting to see the difficulties and solutions proposed by the participants, the other caregivers, emerge. Certainly, the training offers support, and meeting other people with the same problems offers a different and stimulating view of the same..."

"The training provided a very broad picture of the world of the caregiver and gave non-obvious insights into possible strategies to make this role coexist with self-love."

"Competent people and useful content bringing people together at a delicate time"

Two participants also mentioned the importance of meeting people with common problems and experiences.

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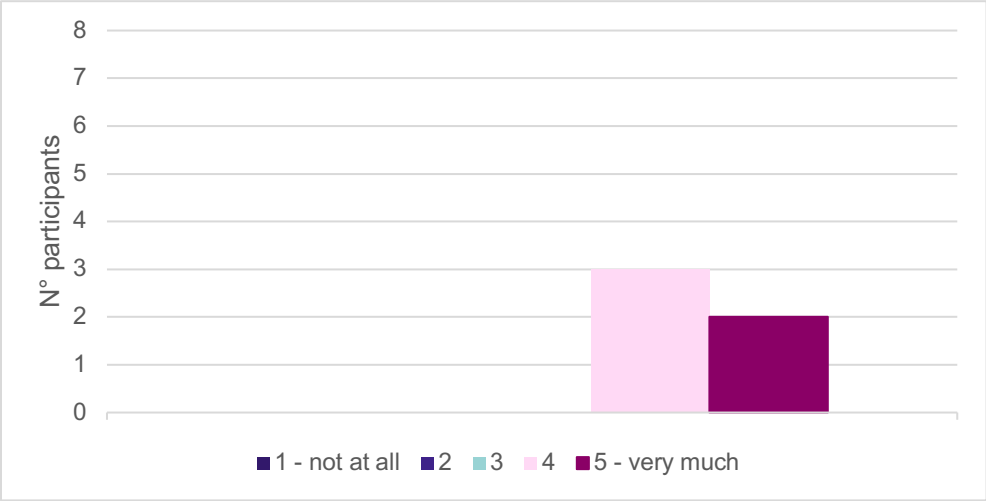
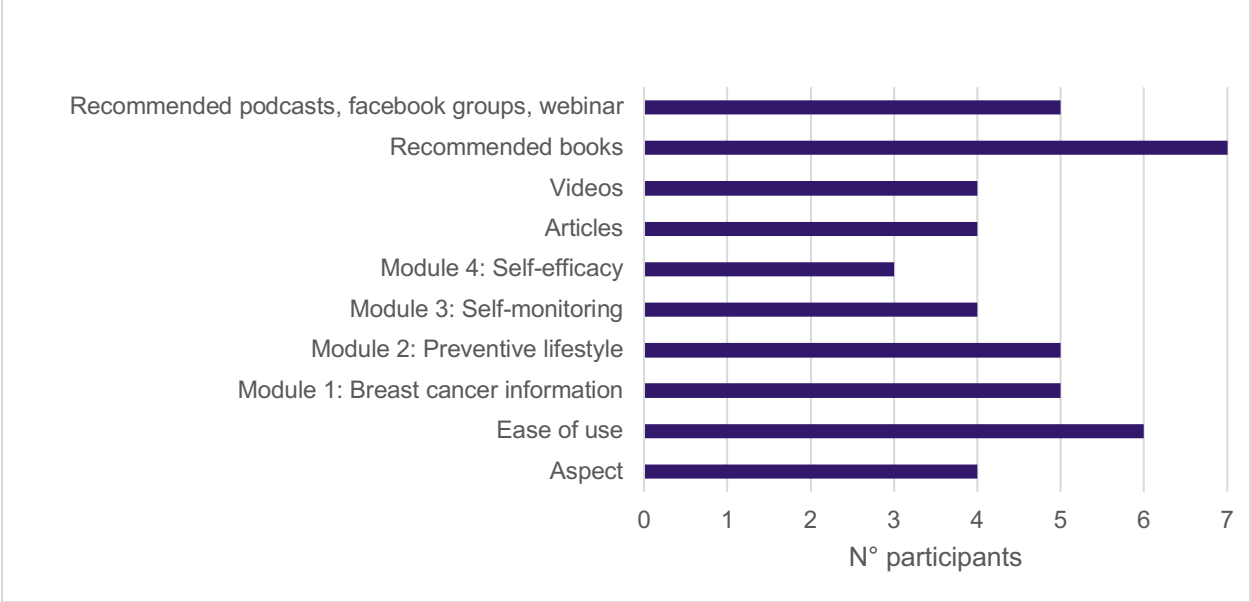
12th question: How satisfied are you with the app?



On a scale of 1 to 5 (not at all/ very significantly), 71.4% of interviewees gave a score of *4*, while the other 28,6% gave a score of *5*. Overall, the performance of the App was considered satisfying by the participants to the training program.

13th question: Which of the aspects listed below is most satisfactory to you? You can select more than one answer



The most appreciated aspects of the App were user-friendliness (*ease of use*) and recommended books with the 85,7% and 100% of votes. Other popular aspects were: the content of the app such as the various modules (1,2,3), videos and podcasts, WhatsApp groups and webinars. Instead, the least voted aspect was self-efficacy module (4).

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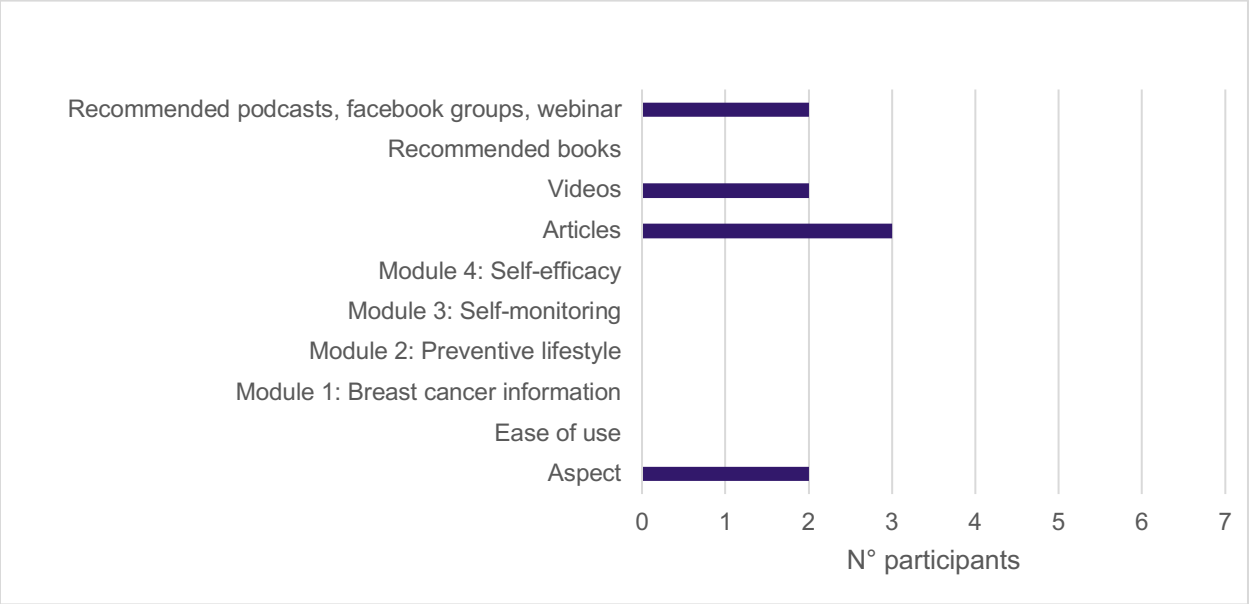
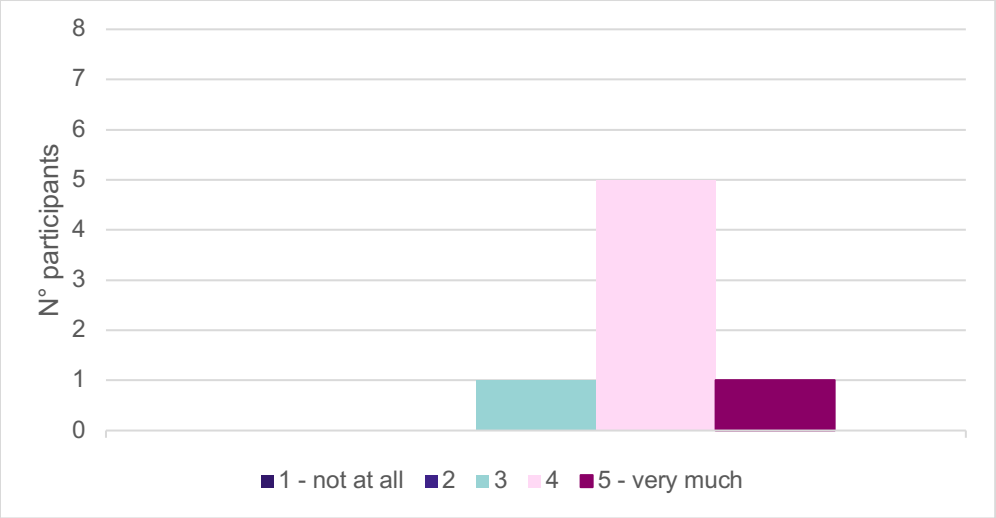
14th question: Which of the aspects listed below are least satisfactory to you? You can select more than one answer



The least satisfactory aspects of the App were: the aspect, articles, videos and podcast, Facebook groups and webinar with 2 or 3 of votes respectively.

15th question: How helpful do you think the app can be in self-management of your health?



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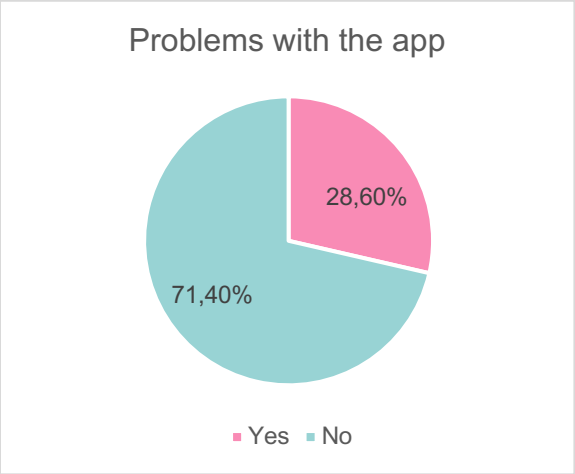
On a scale of 1 to 5 (not at all/very significantly), 71.4% of participants gave a score of *4* and 14,3% of *5*. Overall, most participants felt that the app can be generally helpful in self-management of their health.

16th question: Did you have any problems with the app? (Yes/no) If yes, please tell us which one

One respondent reported that sometimes the app does not upload notifications. Another participant, on the other hand, stated that "empty" notifications were received.



17th question: Please describe how you think we could improve this app

The participants provided the following suggestions:

"I am not very familiar with the day-to-day use of apps, so I really enjoyed the face-to-face meetings for which the app was only a partial substitute."

"Dedicating time to it and monitoring visits and frequency of use"

"This works for me"

2.2 Upskilling of Participants' Competences

Anziani e non solo, as the organization responsible for the quality assessment of the project as well as the partner in charge of Output 2, elaborated a self-assessment questionnaire to be submitted to the participants before and after the training. The questionnaire includes 11 questions relevant to content covered during the training. It is therefore expected that after the training, on average, participants' answers will be more precise and accurate than before the training. The pre-test was sent to the participants at the end of the introductory pre-session on the project, thus before the training started. The post-test was sent one week after the end of the training, so that the participants had the opportunity to see the latest content uploaded on the app. In the pre-test questionnaire 10 participants answered, in the post-test questionnaire only 8, due to drop-outs. An analysis of the answers by question follows.

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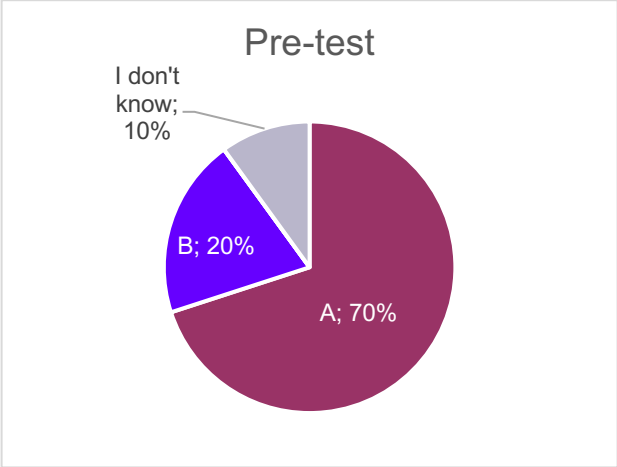
Question 1: What is breast cancer?

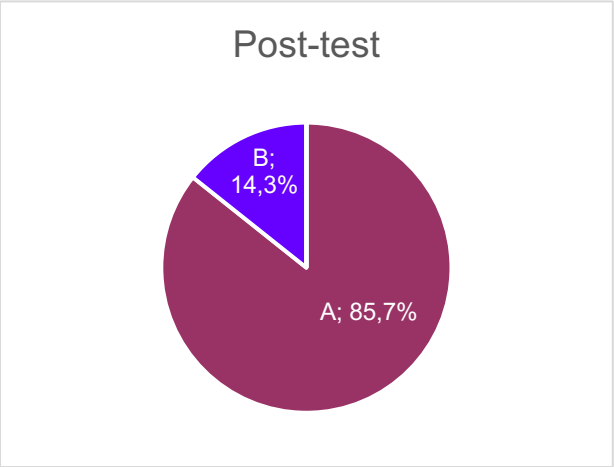
This question was aimed at investigating the knowledge base of the phenomenon on which the training focused, breast cancer. The answers below reflect the content communicated during the first training module, in which the anatomy of breast cancer is also briefly discussed.

Answers:

A. Breast cancer is a disease in which breast cells grow out of control. There are different types of breast cancer. The type of breast cancer depends on which cells in the breast become cancerous.
B. Breast cancer is a disease in which breast cells grow out of control. There is only one type of breast cancer, also called mammary cancer.
C. Breast cancer is a disease in which breast cells block in their growth, thus causing a lack of cell renewal. There are different types of breast cancer. The type of breast cancer depends on which breast cells become cancerous.
D. Breast cancer is a disease in which breast cells block in their growth, thus causing a lack of cell renewal. There is only one type of breast cancer, also called mammary cancer.
E. I don't know.

Answer A is correct, while the other answers are incorrect - although they may to the untrained eye appear correct.





It can be observed that most of the participants improved their knowledge of what breast cancer is, as only one of them chose the wrong answer in the post-test. Furthermore, while in the pre-test one participant stated that she did not know the answer, this did not happen in the post-test. Correct answers rose from 70% to 85.7%, indicating a significant improvement in the response rate.

Question 2: Which of these are risk factors for breast cancer?

The first training module also looked at the factors that expose people most to the risk of breast cancer, describing which ones may be under the person's control. This question listed some of

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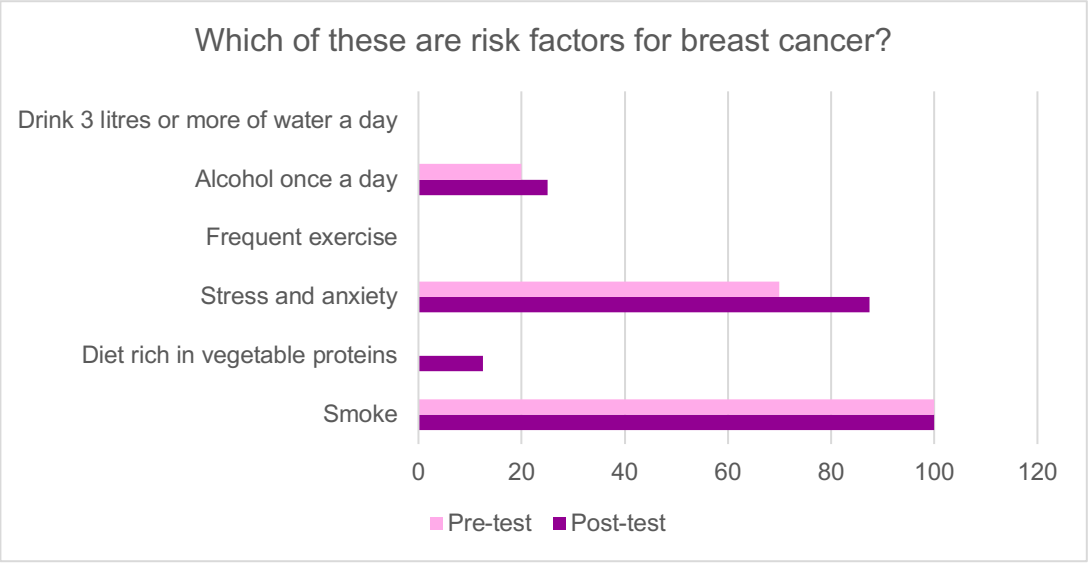
these, to see if the knowledge of the participants had improved since the training. The correct answers to this question are:

- Alcohol once a day
- Stress and anxiety
- Smoking

The other answers represent preventive factors, or elements that are irrelevant to breast cancer risk. Participants were informed that they could select more than one answer.



As can be seen, most of the participants knew these main risk factors even before the training. Nevertheless, an increase of correct answers can be observed after the test. In fact, some participants gave only one correct answer in the pre-test, which was generally *smoke*, while in the post-test many of them added other correct answers. As can be seen in the post-test also the other two answers increased the percentage, indicating that this knowledge was learnt by more participants. The only outlier was the response of one participant in the post-test of *diet rich in vegetable proteins*. As this topic was discussed extensively with the expert nutritionist in the in-person session, it is assumed that this participant did not attend that session and did not carefully review the material on the app.

Question 3: To date, what is the survival rate for women diagnosed with breast cancer in Europe - 5 years after diagnosis?

This question was aimed both at surveying women's perceptions and at assessing their use of the app, as this data is provided in the material on the app. The answers to the question are:

A. 52.9%
B. 92.4%
C. 83.7%
D. 39.5%

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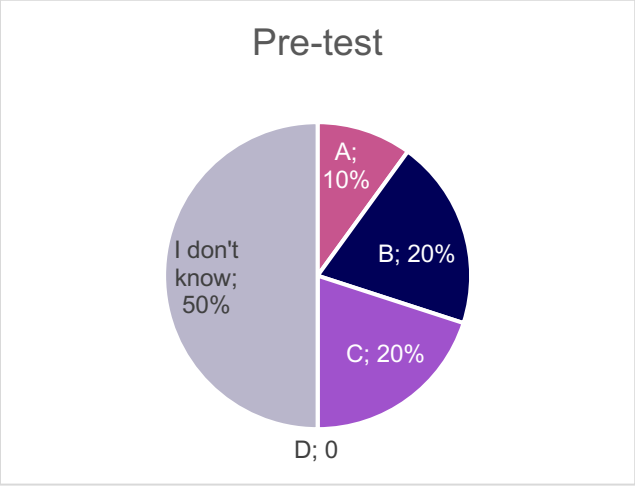
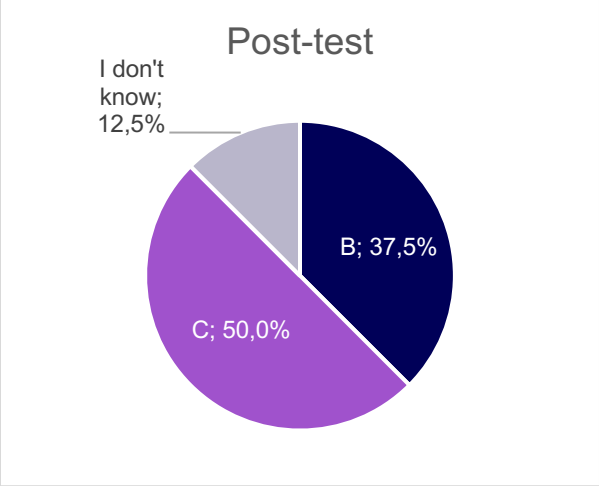
E. I don't know

The correct answer is C, 83.7%.





A significant change in the responses can be seen in the post-test. In fact, the correct answers went from 20% of the participants to 50%. The number of participants who overestimated, rather than underestimated, the risk also increased. This could be an effect of the training itself, which having made the topic salient for the participants could have generated this reaction. Only one participant, compared to 5 in the pre-test, stated that she did not know the data yet.

Question 4: Do you know how perform a Breast Self-Examination? If yes, which is the correct position?

This question was aimed at investigating another important chapter of training, the self-monitoring of one's own breasts. The question enabled us to assess whether the participants already knew how to carry out breast self-examination and whether they had learned it through the training. The answers to the question are:

- No
- Yes, but I am not sure of the correct position
- Yes, it must be carried out in a standing position in front of a mirror
- Yes, it must be carried out lying down
- Yes, in both positions (standing and lying down)

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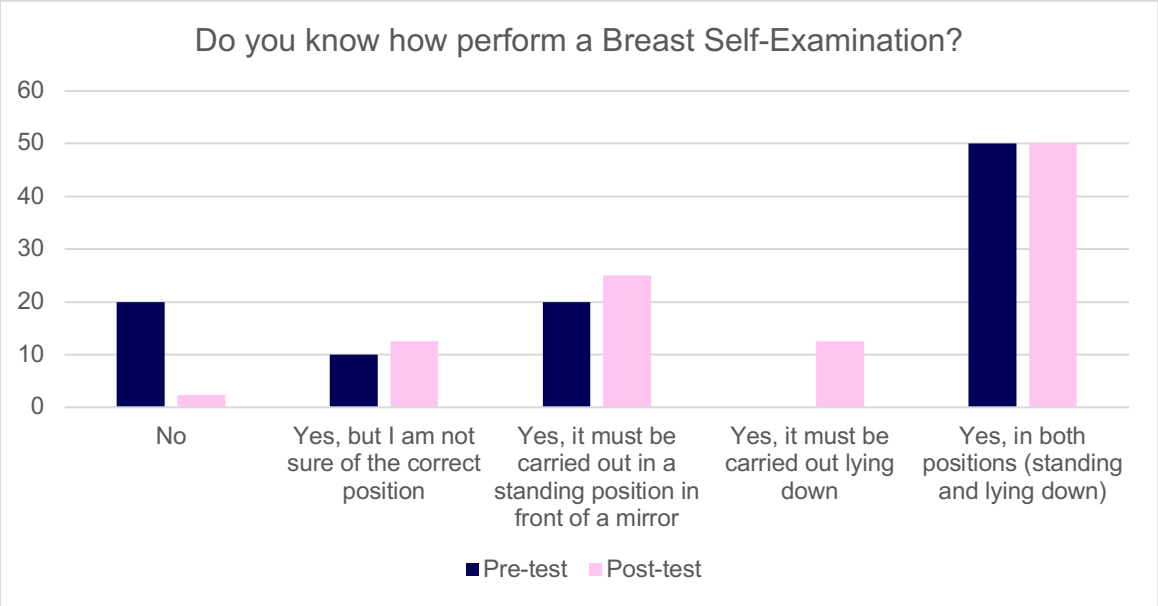
The correct answer is *Yes, in both positions (standing and lying down)*.



In this question, the data return a degree of uncertainty of some participants. In fact, the correct answer is chosen both in the pre-test and in the post-test by 50% of them. However, although the number of "*No*" answers decreased significantly, some participants did not completely understand how to perform it. Indeed 2 of them choose the *only in a standing position* option, and one of them choose the *only lying down* option. There is a possibility that this question was posed in a complex or ambiguous way and the participants did not consider the last answer, the correct one. In fact, the other two answers given are not wrong, but rather incomplete.

Question 5: How often should breast self-examination be done?

This question compared to the previous one is about the frequency of BSE. The answers to the question are:

A. Every 3 months
B. Depends on age: under 50 every 6 months, over 50 every 3 months.
C. Once a month. If you still have your menstrual cycle, it is recommended week after the end of your period.
D. Every 6 months.
E. I don't know.

The correct answer is C, *once a month*.

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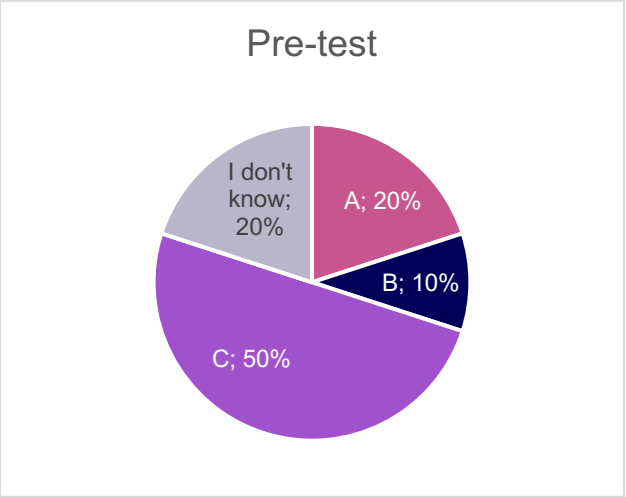
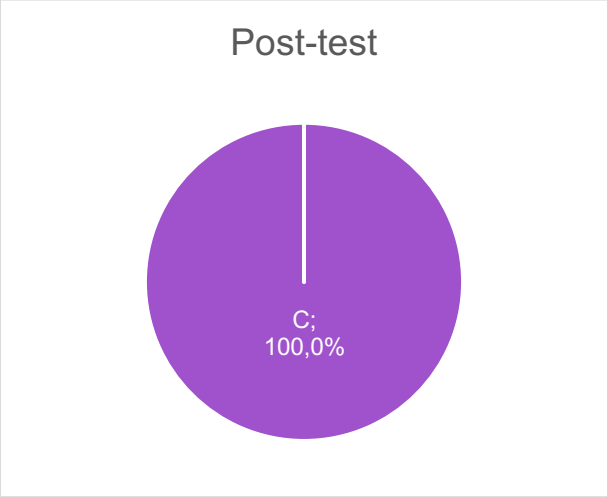




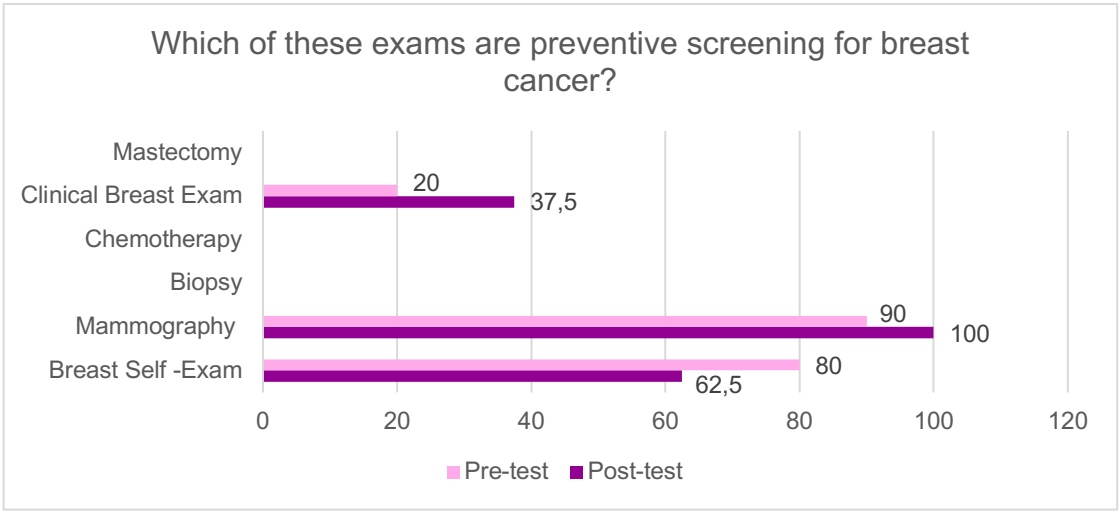
The comparison of pre-test and post-test offers a clear insight into the participants' understanding of how often to conduct breast self-examination. It is therefore assumed that this information is conveyed very clearly.

Question 6: Which of these exams are preventive screening for breast cancer?

Question 6 investigates the participants' knowledge of screening examinations, as well as their ability to distinguish them from diagnostic examinations. The correct answers were:

- Breast Self -Exam
- Mammography
- Clinical Breast Exam

Participants were informed that they could select more than one answer.



A first observation of the results can immediately give a positive view: both in pre-test and post-test participants identified the right exams. However, the change in the data leads us to imagine

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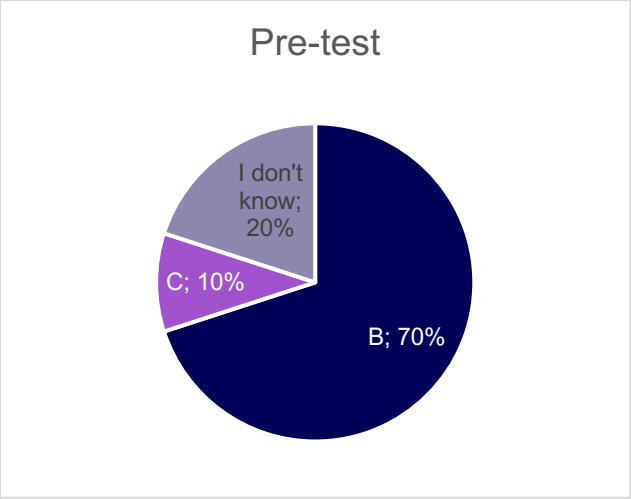
that the question was either ill-posed or not well understood. In fact, although all participants in the post-test identify mammography as a preventive examination, thus giving evidence of having understood its importance, compared to the BSE and CBE the percentage of response decreases from the pre-test. We interpret that the participants might have misunderstood what was meant by a preventive screening exam, associating it only with a specialist check-up.

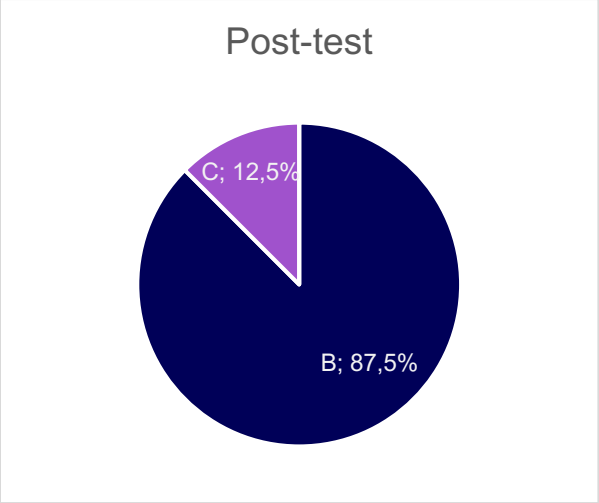
Question 7: What is a mammography screening?

This question aimed to investigate women's knowledge of mammography screening and awareness of the type of examination. Although the question is very specific, it is covered in detail in the course and should therefore be learnt by the participants after attendance. The answers to this question are:

A. Is the collection of breast tissue material from the area of the breast where an abnormality or suspected neoplasm has been detected.
B. Is X-ray imaging of your breasts designed to detect cancer and other abnormalities. It is used to detect breast changes in women who have no signs or symptoms or new breast abnormalities.
C. Is an exam performed with a high magnetic field machine and is a non-invasive examination that does not use ionising radiation or radioactive substances.
D. I don't know.

The correct answer is B, an *X-ray imaging of your breasts*.





Although the question was technical, only one respondent confused the type of examination, while the others identified the correct description. The percentage of correct answers increased from 70% to 87.5% and none of the participants answered "don't know" in the post-test.

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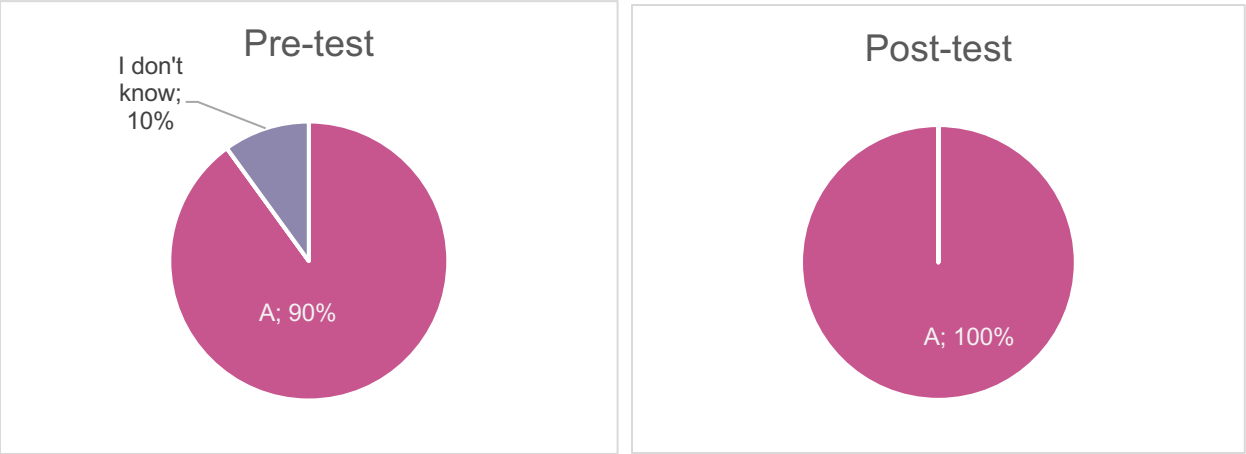
Question 8: How often is it recommended to have a mammogram for women aged between 50 and 69?

This question aims to investigate whether the participants know how often mammography should be done. The answers are:

A. Annually or every 2 years
B. Every 2-3 years
C. Every 3 years
D. I don't know.

The correct answer is A, *Annually or every 2 years*.



The majority of participants even in the pre-test phase knew the frequency of the test, probably because they themselves are part of the national health service's regular screening recall system. However, the shift from 90% correct answers to 100% is still significant, suggesting that the training intervention also contributed in part to providing this information correctly.

Question 9: Which of these are alert signs when performing a breast self-examination?

Question 9 goes into detail about the warning signs that a woman should be aware of in order to prevent cancer, and should visit her doctor immediately if they appear. This aspect was addressed not in presence, but through the uploaded material of the app; so the answers are also indicators of having seen the material itself. The answers to the question are:

- Skin rushes
- Fluid coming out of the nipple
- Smooth breast feel
- Change in shape or size
- Nipple extended outwards

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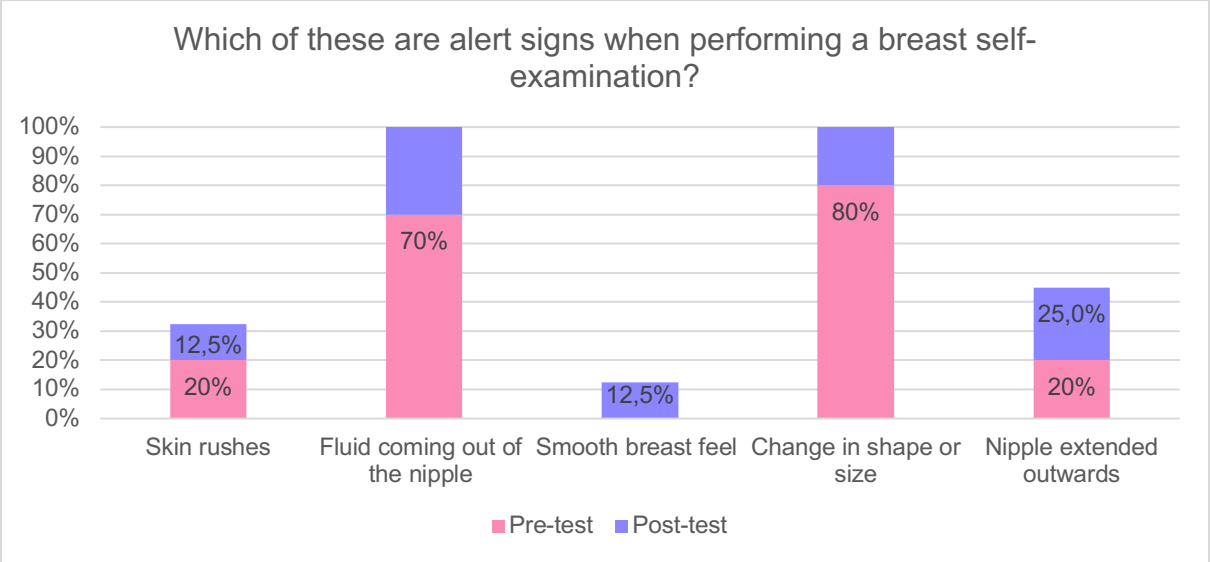
Of these, the correct ones are *skin rushes*, *fluid coming out of the nipple* and *change in shape or size*. Participants were informed that they could select more than one answer.



The results of the responses show some confusion with regard to the alarm signals. Although almost all participants recognised two of them, namely *change in breast shape* and *secretion of fluids*, there appears to be over-recognition even where some signs are not associated with a breast disorder. This result could also be an indication of the special attention given to breast care by virtue of attending the training. In fact, the over-estimation of the signals could be due to the salience that the "breast cancer" discourse has for the participants at the end of the course. However, the clarity of this part of the course will need to be optimised.

Question 10: Which of these negative health impacts are often experienced by a carer?

The last two questions of the questionnaire were devoted to Module 4, specific to caregiver self-efficacy and caregiver health and well-being. These aspects have also been dealt with in detail on the app, so the results will also show whether the participants consulted the material. The answers to the question are:

- Difficulty in sleeping
- Development of addictions
- Articular/back pain
- Stress and anxiety
- Cardiovascular problems
- Loss of eyesight
- Frequent feeling of fatigue and tiredness

Of these, the correct ones are *difficulty in sleeping*, *articular/back pain, stress and anxiety* and *frequent feeling of fatigue and tiredness*. Participants were informed that they could select more than one answer.

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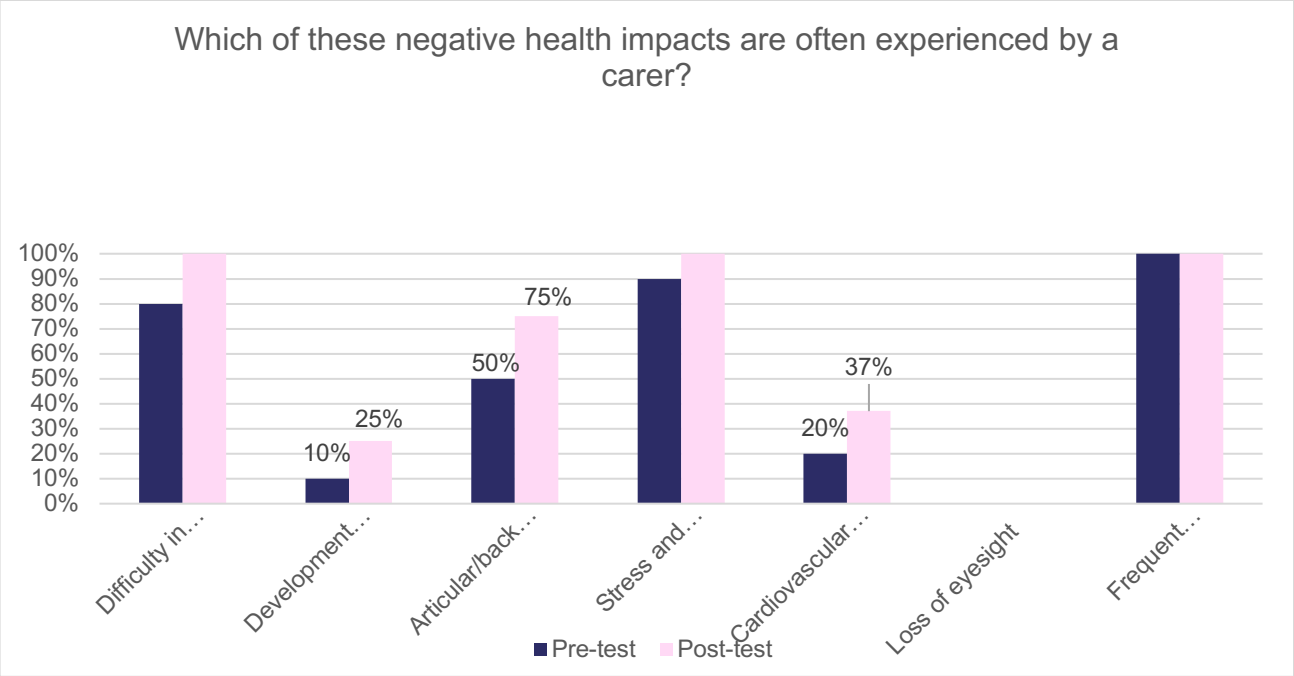

The graph returns a positive figure, as all the correct answer factors received an increase in responses, 3 of which scored 100%. This is an important finding as it implies that the caregivers involved are able to recognise signs, due to their caring burden, that may affect their health. Recognition of such negative impacts is fundamental to understanding whether one needs to seek help. Nevertheless, other signs, not related to caregiving, such as the *development of a dependency* were indicated. This aspect should be further investigated in order to understand the origin of this perception on the part of the participants.

Question 11: Which of these are time management strategies?

The last question was devoted to investigate which time management strategies the participants were familiar with that could help them in their caregiving activities. The answers to the question are:

- Reducing sleep time
- Writing priority lists
- Reducing social activities
- Planning frequent short breaks
- Not taking breaks until tasks are finished
- Using online services

Of these, the correct ones are *writing priority lists*, *planning frequent short breaks, using online services*. Participants were informed that they could select more than one answer.

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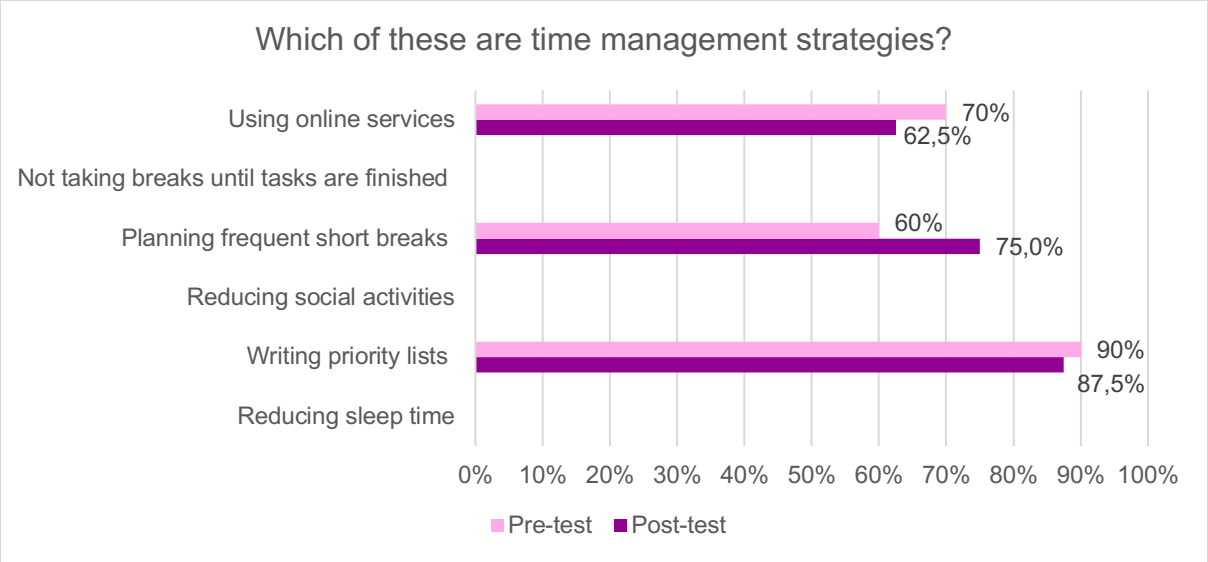

Also in this last question, the answers of the caregivers do not go in one direction, plausibly because each caring experience is unique and the strategies, although useful, are not applicable to every case. Generally, however, the data is positive, since neither in pre-test nor in post-test were identified time management strategies detrimental to their physical health (such as *reducing sleep time*) or psycho-social (such as *reducing social activities*).

2.3 Outcomes

Summarising the above, two types of conclusions can be drawn about the evaluations carried out:

- The participants are generally satisfied with the training, although they appreciated more the content developed in person than the self-study through the application. Despite this, they all appreciated its content and found it generally useful and clear.
- What was stated in terms of satisfaction is also confirmed in terms of knowledge acquired after training. It can be seen from the graphs in the previous paragraph that in almost all questions, a clear improvement occurred between pre-test and post-test. This indicates an achievement of the proposed training objectives as well as a confirmation of the effectiveness of the programme.

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Chapter 3: Challenges and final remarks

The piloting experience in Italy was positive, welcomed by the participants and generally completed as planned. The challenges faced are of two types of order:

- *Prolepsis APP*: the application was not fully finalised during the pilot implementation period. This meant that not all participants were able to download it or use it in the best possible way. There were several obstacles, but they all contributed to improving the app by modifying it according to the users' needs. For future adoptions it would be possible to follow the whole programme, as the application is now finalised.
- *Course length*: splitting the course into 4 meetings had both pros and cons. On the one hand, it was possible to involve the participants for a short time at each meeting, not colluding with their care or work commitments. Also the chosen time slot, from 6.30 p.m. to 8 p.m., was appreciated by them, as it gave them the possibility to participate at a time when they are generally more free. However, the duration of the whole cycle, one month, meant that not all the participants were ever present, as each session had at least one of them engaged in other activities. The last session only had three participants. Therefore, in view of this experience, in future adoption it would be more effective to condense the course into two meetings of three hours each, strategically chosen together with the participants, perhaps at the weekend. This would allow them to be present for the whole course, despite the increased load at the moment.

In conclusion, the piloting experience was rich in input and possible ideas for the next possible applications of the programme, which proved to be valid and effective in its training objective

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CYPRUS

Chapter 1: Organisation and structure of the pilot

Executive summary

The Department of Nursing of CUT provides undergraduate and post-graduate courses in the field of nursing. In relation to the pilot course, the learning materials and the mobile app that have been produced, these will be used as a valid tool to facilitate the training process to the informal caregivers, in collaboration with the Ministry of Health. It is expected that, this will enhance informal caregivers' engagement in health promotion and self- awareness activities. Furthermore, the knowledge and skills acquired will empower and increase the confidence of informal caregivers to actively introduce health promotion habits in their daily living and finally to become more aware of their health.

The pilot testing took place in Cyprus on the 23th of August – 11th of September 2021 (3 weeks). The training was offered face-to-face (three meetings of 3 hours), with self-directed learning by using the mobile application in each face-to-face meeting. The modules piloted face-to-face were the:

1. Information about breast cancer
2. Preventive habits
3. Self – Examination
4. Self - Efficacy

Participants had online access during the first meeting and they were guided by the educators on how to download the application on their mobile phones.

Seventeen informal caregivers were participated in the pilot testing. The participants were invited to participate in the testing by the Cyprus University of Technology (CUT) team, through a press release (which was published in various social media platforms).

All participants were excited to the use of the new mobile app and seemed to accept and integrate it well within their daily life. This was highly reflected in their active engagement during the pilot testing and they expressed intention to make full use of the app in their daily life. Additionally, all participants were satisfied with the presentations and the knowledge they gained through the training. The Satisfaction Questionnaire, showed an overall satisfaction of the participants with the participation in this pilot training.

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1.1 Organisation of the training course

Participants were invited through a Press Release and an invitation for the pilot testing in August 2021. Registrations ended on the 22th of August and the training was delivered on the 23th of August - 11th of September 2021 (3 weeks).
The first meeting with the participants was scheduled on the 23th of August, in order to orientate participants about the course procedure and inform them about the Prolepsis program (Video ppt

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and leaflets); furthermore, the first meeting aimed to evaluate their needs (skills and knowledge to download and use mobile app). Afterward, the CUT team piloted the four modules of the program in three meetings.

The training took place in a classroom at the Primary School in Pelendri village (participants preeminent residence), from the CUT research team (3 educators).

In the first meeting with the participants, an attempt was made to download the application. We found out that the majority of the participants had mobile digital phones but some of them (3 participants) did not have emails. The next step was to create their emails, usernames and passwords. Also, two participants did not have a smartphone. For this reason, during the training the content of the application was displayed on a screen projector so they could have an opinion of the content of the application, further more they cooperated with their others participants who had smartphone and the educators provided also their own smartphone for training purposes during the pilot.

During the first face-to-face meeting, the educators guided them all to download the mobile app and gave them usernames and passwords in order to have full access to the application. The educators guided them to watch the videos and to complete the quiz. Identified difficulties due to the network itself. The signal was very weak as a result connection was unable. The whole training procedure was provided through 4G connection and hotspot. In addition to the difficulties of the network, difficulties were identified due to the application itself. Specifically, the questionnaire regarding personal data was not saved, and the mobile app asks the user each time to fill it, indicating that the available time was expired. Also, participants were unable the completion of Quiz in both section 1 and section 3 respectively. Direct telephone communication was established from Singular Logic for support and solving difficulties. The CUT team during the piloting education program tried educated them in the themes of the four modules and parallel to encouraged and guided trainees to involve the mobile app in daily routine.

1.2 Profile of participants

At the first meeting, participated 17 participants permanent residence on Pelendri village. At the second meeting participated 16 participants and the third meeting attended 11 participants. Everyone informal cares for people with cancer or other chronic diseases.

The participants were all women who assume the role of the informal carer, with the age ranging from 39 years – 68 years, most of them were between 50 yrs - 60yrs as show in Chart: 1 below.

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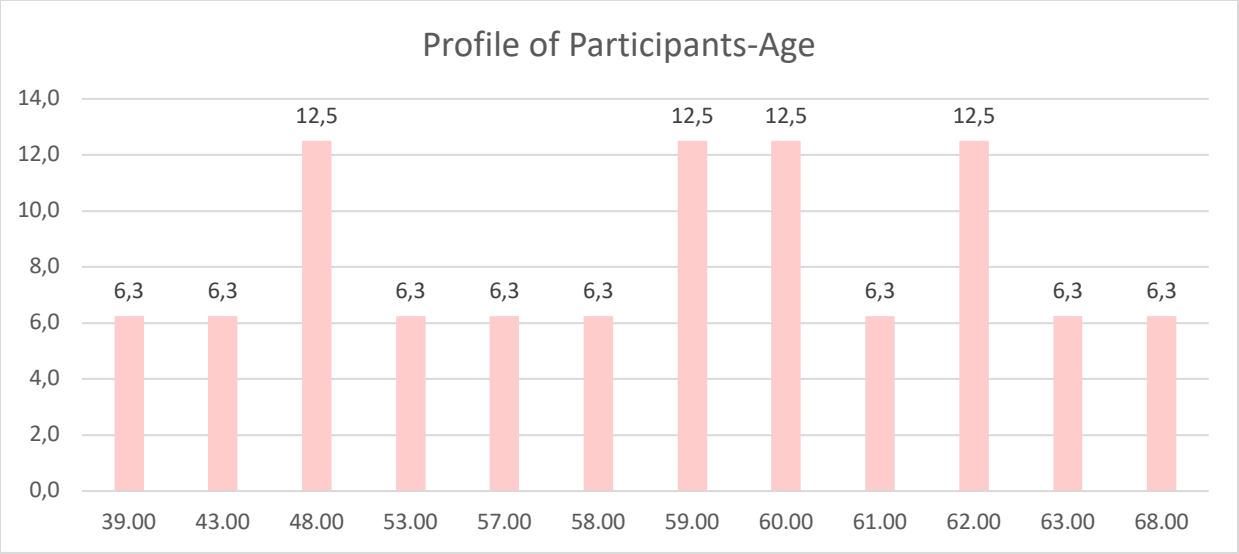

Chart 1: Age of participants

1.3 Structure of the training course

The introduction and the orientation of the piloting was delivered by Dr Theologia Tsitsi, Dr Maria Christodoulou -Fella and Andri Christou who are the research team. The oversight of the pilot testing was made by Dr Andreas Charalambous, PI of the Prolepsis Project. Dr Tsitsi and Dr Christou are Special Teaching Staffs in the department of nursing with background on Oncology nursing with research experience on the area of care and informal caregivers of patients with cancer and other chronic diseases. Dr Christodoulou Fella is postdoctoral coorperator of the Nursing Department, with research and clinical experience in the field of psychiatric nursing.

The research team met the participants and introduced them to the Prolepsis project, the pilot training and the application. They explained to the participants that the training will be partly delivered through the application and partly in person, developing in 4 modules. Finally, most of the time spent downloading the application together and trying out its use. The educators paid special attention in addressing all the questions made by the participants.

The training pilot plan for Cyprus stands as shown in

Table 2.

Table 2. Pilot action configuration in Cyprus

Format of the training (face-to-face, blended, etc)	3 face-to-face training
Duration of the training	3 hours each Module
Contents covered	Module 1 – Information on BC Module 2 – Preventive Habits

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	Module 3 – Self-monitoring Module 4 – Self-efficacy
Total nr. of registered learners	17 registered learners
Total nr. of learners who completed the course	11 learners completed the course
Training methods used	We encouraged trainees to use the APP of Prolepsis, to watch videos for each module and make the quiz during their free time, to go through the other modules
Use of learning materials from IO2 (use of multimedia, use of all worksheets or partially, adaptations needed, etc)	We use the multimedia and a part of worksheets. Specifically, Module 1– Information on BC: multimedia + Quiz 1.1 Module 2 – Preventive Habits: multimedia + Worksheets 2.1,.2.2, 2.4, 2.5. Module 3 – Self-monitoring: multimedia and Module 4 – Self-efficacy: multimedia +. Worksheets 4.1,4.2,4.3,.4.4,4.5.

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Chapter 2: Results and evaluation

Although educators faced many difficulties at the beginning of the training (i.e. no smartphones, no emails), with the good collaboration of the participants the difficulties were overcome and the overall goal was achieved.

All participants were excited with the training and they were satisfied with the new skills and knowledge they gained. Eleven participants out of 16 filled in the questionnaire about the evaluation and satisfaction of the training.

2.1 Satisfaction with the training and the app

Most of the participants were satisfied with all domains. Specifically, 81.3% of the participants in the pre-test evaluation were very satisfied with their participations in the training and all participants (100%) at the post-test evaluation were strongly satisfied with their participation. All participants mentioned that the training was similar to their expectations (very similar 100%), as it shows in Table 1. Most of the participants reported that, they definitely learned from this participation (90.9). Ten out of 11 participants mentioned that they agree with the statement that 'the contents of the e-learning modules were useful, clear, very stimulating (90.9) as it shows in table 2. Similarly, ten out of 11 participants referred to the face to face session and they evaluated it very effective and evaluated positively the trainers' performance and the training overall as it shows in Table 3.

Are you satisfied with your participation in this training?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very satisfied	11	**100.0**	100.0	100.0
Have the aims of the training been similar or different to your expectations?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very similar	11	**100.0**	100.0	100.0
Do you think you have learnt something from participating to this training?					

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		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	1	9.1	9.1	9.1
	Yes, definitely	10	**90.9**	90.9	100.0
	Total	11	100.0	100.0	

Table 1

Do you think you have learnt something from participating to this training?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Yes	1	9.1	9.1	9.1
	Yes, definitely	10	**90.9**	90.9	100.0
	Total	11	100.0	100.0	

The contents of the e-learning modules have been/useful

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Useful	1	9.1	9.1	9.1
	Very useful	10	**90.9**	90.9	100.0
	Total	11	100.0	100.0	

The contents of the e-learning modules have been/clear

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very useful	10	**90.9**	100.0	100.0
Missing	System	1	9.1		

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Total		11	100.0		
The contents of the e-learning modules have been/stimulating					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very stimulating	10	**90.9**	100.0	100.0
Missing	System	1	9.1		
Total		11	100.0		

Table 2

The contents of the face to face sessions have been/stimulating					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Stimulating	2	18.2	20.0	20.0
	Very stimulating	8	**72.7**	80.0	100.0
	Total	10	90.9	100.0	
Missing	System	1	9.1		
Total		11	100.0		
The participation of experts has been/useful					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very useful	10	**90.9**	100.0	100.0
Missing	System	1	9.1		
Total		11	100.0		

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The participation of experts has been/stimulating					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Clear	1	**9.1**	10.0	10.0
	Very clear	9	**81.8**	90.0	100.0
	Total	10	90.9	100.0	
Missing	System	1	9.1		
Total		11	100.0		

How would you evaluate the trainer's performance?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very effective	10	**90.9**	100.0	100.0
Missing	System	1	9.1		
Total		11	100.0		

How would you rate the training overall?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	8.4	1	9.1	10.0	10.0
	Positively	9	**81.8**	90.0	100.0
	Total	10	90.9	100.0	
Missing	System	1	9.1		
Total		11	100.0		

Table 3:

Although at the beginning the team experienced a few problems with the mobile app, these were solved in collaboration with the technicians (during face-to-face meeting, and post-meeting via

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email and phone). The educators with constant guidance and supervision of the participants we managed to solve any problems that occurred in order to achieve the objectives of the pilot program.

81.3% of the participants in the pre-evaluation questionnaire were satisfied with the App (table 4). At the post-evaluation questionnaire the percentage increased to 90.9%, that refers to participants who were very much satisfied from the App as it shows in Table 5.

How satisfied are you with the APP?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	9.4	3	18.8	18.8	18.8
	Very much	13	**81.3**	81.3	100.0
	Total	16	100.0	100.0	

Table 4: satisfaction (pre- evaluation)

How satisfied are you with the APP?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very much	10	**90.9**	100.0	100.0
Missing	System	1	9.1		
Total		11	100.0		

Table 5: satisfaction (post- evaluation)

2.2 Upskilling of Participants' Competences

Sixteen participants completed the pre-assessment questionnaire and eleven participants completed the post assessment questionnaire.

The data in the figure below, show an overall increase in the participants' knowledge and skills after the training (Chart 2). Specifically, we can see that their knowledge about the risk factors for breast cancer (i.e. smoking, stress and anxiety, alcohol) increased in double in the post-assessment, compared with the pre-assessment because more participants.

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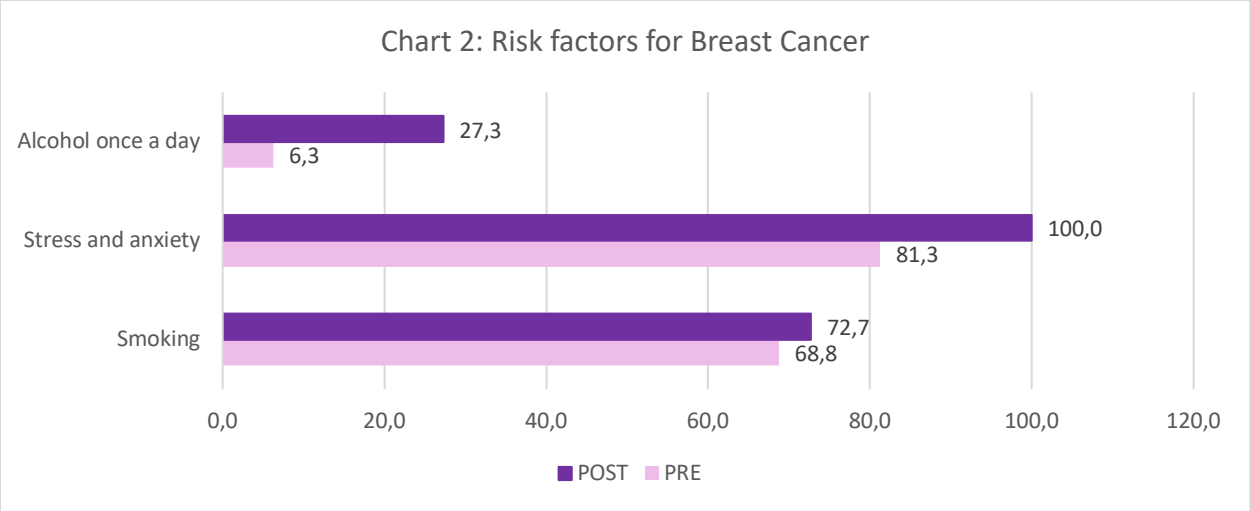

Chart 2: Risk Factors for breast cancer.

Furthermore, during the post assessment all the participants knew which are the preventing screening exams for breast cancer as shown in chart 2. In contrast, with the pre- assessment that it shows that the women underestimated the Clinical Breast examination (45.2%) and Breast self-examination (58.8%).

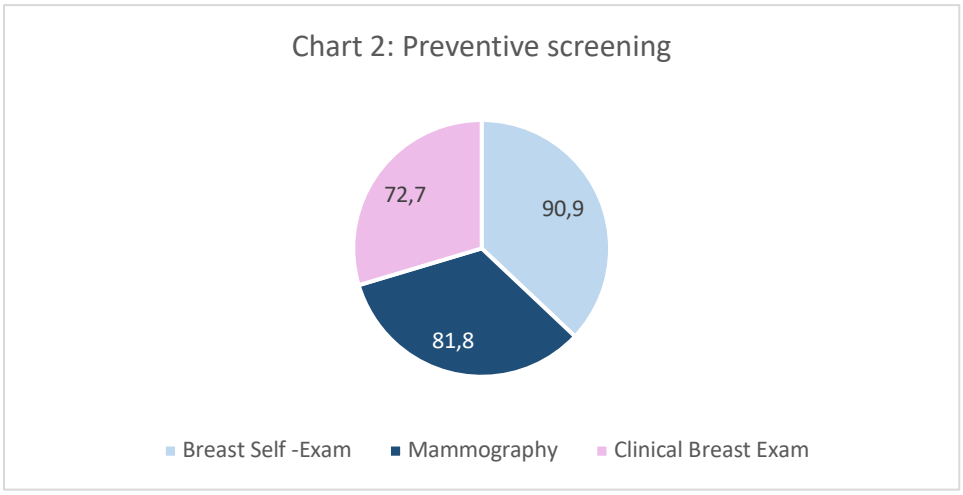

Chart 2: Preventing screening for cancer

As it shows in table 6 only 43.8 % of participants during the pre-assessment questioner mentioned that they knew what is the mammography screening. After the piloting, all participants (100%) knew what is the mammography screening as it shows in Table 7.

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What is a mammography screening?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Is the collection of breast	5	31.3	33.3	33.3
	Is X-ray imaging of your breasts	7	43.8	46.7	80.0
	Is an exam performed	3	18.8	20.0	100.0
	Total	15	93.8	100.0	
Missing	System	1	6.3		
Total		16	100.0		

Table 6: Mammography screening (pre- evaluation)

What is a mammography screening?						
		Frequency	Percent	Valid Perc	Cumulative Percent	
Valid	Is X-ray im	11	100	100	100	

Table 7: Mammography screening (post- evaluation)

Additionally, participants supported that they learned how often it is recommended to have a mammography, as shows in Table 8 and in Table 9 only 87. 5% of participants during the pre-assessment questionnaire they replied annually or every 2 years, while during post-assessment turned out 90.9%.

How often is it recommended to have a mammogram					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Annually or every 2 years	14	87.5	87.5	87.5
	Every 2-3 years	2	12.5	12.5	100.0
	Total	16	100.0	100.0	

Table 8: How often recommended mammography (pre- evaluation)

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How often is it recommended to have a mammogram for women aged between 50 and 69?					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Annually or every 2 years	10	90.9	90.9	90.9
	4.00	1	9.1	9.1	100.0
	Total	11	100.0	100.0	

Table 9: How often is it recommended to have a mammogram for women aged between 50 and 69? (post- evaluation)

2.3 Outcomes

Sixteen participants completed the pre- assessment questionnaire and eleven participants completed the post assessment questionnaire. The analysis showed an overall increase in the participants' knowledge and skills after the training (Chart 2). Specifically, the knowledge about the breast cancer risk factors (smoking, stress and anxiety, alcohol) was doubled in the post-assessment, compared with the pre-assessment. All participants (100%) knew what the mammography screening is after the training (table 2). These results demonstrated that the participants' knowledge has been increased after the pilot training program.

Despite some problems with the application arising during the pilot training, 81.3% of the participants were satisfied with the App (table 4) in the pre-evaluation questionnaire but at the post-evaluation questionnaire 90.9% of the participants answered that they were very much satisfied from the App as it shows in Table 5. This can be explained by the fact that during the training the content of the application was displayed on a large screen via the computer so all participants could have an opinion on the content of the application. Furthermore, the trainers provided also their own smartphone for training purposes during the pilot. All participants were excited with the training and they were satisfied with the new skills and knowledge they gained. However, due to the small sample size (the results has a little chance of being statistically significant), the findings of the study should be interpreted with caution.

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Chapter 3: Challenges and final remarks

The commitment of CUT research team to deliver a training program of the highest quality led to the decision for face-to-face training. The team considered that the value and opportunities to personally engage with the participants during the face-to-face focus group facilitate the maximization of the outcomes. It was considered a good opportunity to have feedback on their involvement in the research process but in addition it was considered that the presentation would help participants to be better familiarized with the mobile application. It also provided the opportunity to witness the use of the mobile application by the participants in real-life. This provided the team with valuable information for any potential challenges that future users might face so that anticipatory measures can be assumed for resolving these. All participants were excited with the training, they were satisfied with their participation (Table 1) and were very much satisfied from the App (Table 5). Most importantly the participants felt that the training they received as part of the program, helped them in better understanding breast cancer as well as the value of adopting healthier behaviors and integrating the breast self-examination in their daily living. Furthermore, the view that the feeling of familiarity with the use of the mobile application increases the possibility of its utilization in the daily routine was another factor that led to the decision to conduct face-to-face training.

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PORTUGAL

Chapter 1: Organisation and structure of the pilot

Portincarers - Associação Cuidadores de Portugal is an NGO working in consulting and developing support services for the promotion of health and quality of life regardless of their age, or the health needs of the person they care for. Promoting inclusion, social innovation, the development of new technologies and financial instrument so that caregivers have solutions and alternatives for their day-to-day activities, are also aims of this Association.

As a partner within the Prolepsis project, Portincarers - Associação Cuidadores de Portugal implemented in September 2021 the pilot course addressed to informal caregivers. The training was offered face-to-face with self-directed learning aiming to enhance engagement in self-awareness activities as well in health promotion.

1.1 Organisation of the training course

The mobile app and the contents were tested. The training focused on the following topics:

- **Module 1 - Information about breast cancer;**
- **Module 2 - Preventive habits;**
- **Module 3 - Self-monitoring;**
- **Module 4 - Self-efficacy.**

These training modules were implemented partly through the Prolepsis APP, in self-education, and partly in presence, through 3 dedicated meetings. In detail:

- Module 1 and Module 2- Blended learning through the prolepsis APP and later with trainers
- Module 3 - Blended learning through the prolepsis APP and later with trainers
- Module 4 - Blended learning through the prolepsis APP and later with trainers

In the beginning each new module in face to face sessions participants were motivated to do questions and share what they have learned. Participants in the end of these sessions were guided and orientated to what to do in self-education.

It was presented to participants 4 days: 23rd September, 24th September and 27th September and for those who couldn't be present, day 27th September was suggested as alternative day 25th September. The complete pilot was defined to be in total 3 sessions.

Participants were recruited through the main channel, described below.

Networking between users and collaborators of Portincarers-Associação Cuidadores de Portugal
The main recruitment strategy was to disseminate the pilot to direct contacts the team already had. Also was done a Press Release.

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Portincarers-Associação Cuidadores de Portugal campaign

Instituto PIAGET

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The training took place in Vila Nova de Gaia, at the Jean Piaget Institute. The choice of this place was also related because is well known in the region, by the trainers and better compliance with the Covid-19 safety measures. The pilot was divided into 3 different sessions, listed below:

- 23rd September: Introducing the project and the Prolepsis APP; Module 1 and Module 2
- 24th September: Module 3
- 25th September: Module 4

  Participants who couldn´t attend day 25th September had the chance to participate day 27st September
- 27th September 2021: Module 4.

It was decided to do an intensive course giving the users the option of an additional day in order to enhance their participation and minimizing the possible dropouts. It was also given a complete pilot for those caregivers with only 2 days' participation - the trainers decided with these specific caregivers to meet one hour before in the last day, in order to update them and do training session. Moreover, one of those caregivers who was not able to be present one hour before was compensated with a virtual online meeting in order to update her as well.

All users were given specific instructions about Self-education online and the use of the APP.

Communication with users and trainers were potentiated by the use of the WhatsApp. This facilitated continuous feedback (during the pilot), larger follow-up after face to face training sessions (during 3 weeks) as well promoted APP´s features final tuning with Singular Logic Partner (responsible for the technological development).

1.2 Profile of participants

The participants are 10 women caregivers with the age ranging from 40 and 66 years with residence in Vila Nova de Gaia. They care people with disability, dementia and other chronic diseases. The majority of the participants are unemployed or retired.

1.3 Structure of the training course

The course was originally organised in 3 face-to-face sessions of 1h30 each, however due to the number of activities developed there was an extension of the time - an average 1h per session. Because of that, the sessions lasted from 18h00 to 20h30 CET; this time schedule allowed the participation of those who are more time limited during the day due to their caring activities.
It was decided to do an intensive course, giving the users the option of an additional day in order to enhance their participation and minimizing the possible dropouts. It was also given a complete pilot for 3 caregivers with the only possibility to do 2 days' participation - the trainers decided to invite these specific caregivers to meet in presence one hour before in the last day, in order to

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update them and do training session. One of those caregivers who was not able to be present one hour before was compensated with a virtual online meeting in order to update her as well. However, one of the participants was only able to attend one meeting due to the caring commitments.
Communication with trainers continued in the following 2 weeks after in face to face training sessions using WhatsApp.

The training pilot requested 4G connection, hotspot and users should have smartphone for training purposes during the pilot.

The training pilot plan for Portugal stands as shown in

Table 2

Format of the training (face-to-face, blended, etc)	Blended mode (partly performed on the APP and partly in presence)
Duration of the training	Originally 5,20 hours in total, divided into 3 meetings of 1h30 face to face training which evolved in the final to 6,90 hours in total.
Contents covered	The programme proposed within the Training Plan was fully covered with the following sessions: • Introducing the project and the Prolepsis APP; Module 1 - Information on Breast Cancer and Module 2 - Preventive Habits; • Module 3 - Self-monitoring; • Module 4 - Self-efficacy.
Total nr. of registered learners	10 registered learners
Total nr. of learners who completed the course	9 learners completed the course
Training methods used	• Users encouraged to use Prolepsis APP • Guided discussion; Brainstorming
Use of learning materials from IO2 (use of multimedia, use of all worksheets or partially, adaptations needed, etc)	All materials in the manual were used. Some changes have been made in terms of the order of the exercises.

Table 3. Pilot action configuration in Portugal

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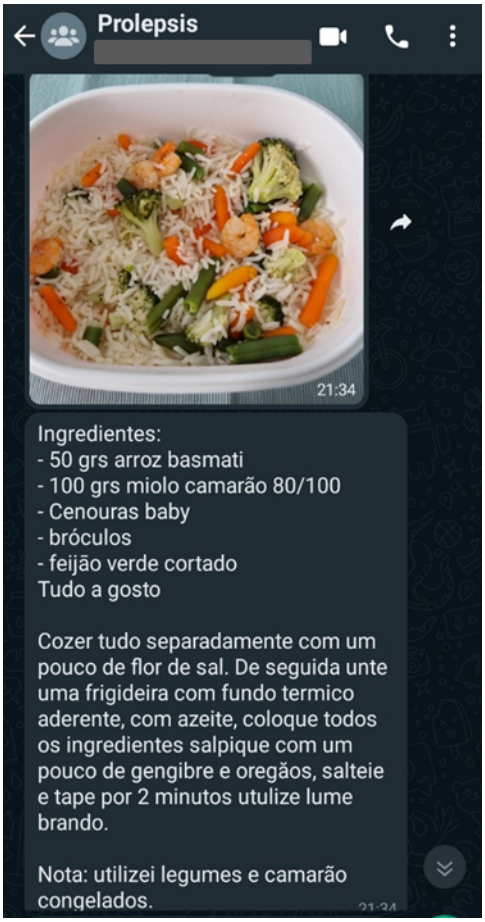
In the first face to face meeting, the introduction and the orientation of the piloting were delivered by Dr. Bruno Alves and Dr. Ana Ribas Teixeira, who are the research team. Bruno Alves and Ana Ribas Teixeira are Coordinators of the Nursing Post Graduating programmes and Professors in Health Higher Education of Jean Piaget Institute of Vila Nova de Gaia. To facilitate dialogue and participation of the users, trainers started with Ice breaker techniques asking users to use 3 words describing them. In this meeting as also participated a public health nurse Anabela Sampaio and a clinical psychologist Dr. Joana Vaz.

The research team introduced Prolepsis project, the pilot and the application. It was also created in this day a WhatsApp group with all participants and trainers in which participants directly downloaded the prolepsis APP link. This was also a good strategy to promote cohesion and sharing experiences as well technical points or activities suggested. WhatsApp promoted communication between trainers and participants.



Participants were in this way invited to do download, create an account, login and do initial test. Being assisted by trainers during this process whenever was necessary.

A brief introduction was made about breast cancer. Anabela Sampaio, Public health nurse presented introductory material, prepared by the Prolepsis partnership, exploring the issues of physical well-being from a nutritional perspective and invited caregivers to share some creative recipes as homework exercise to be shared in WhatsApp.

After, a Clinical Psychologist with experience in Mindfulness, Dr. Joana Vaz promoted a mindfulness exercise with caregivers.

Caregivers reported a very positive mindfulness experience, feeling good and motivated to know more. Participants were suggested to visit the resources of the Prolepsis APP, that present useful training resources. Participants were given orientations to self-education and specifically what they should do: they were invited to view the first and second module on the app as soon as it was available.

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This face to face meeting, due to time constraints didn´t allow us the time to share the recipes and to discuss in group if their choices follow the guidelines suggested.

The presence and the trainers assisting the download of the App was considered very valuable specially by participants with vision problems and low digital literacy.

In the second meeting – on Module 3 – was worked self-monitoring and self-efficacy in managing emotions and fears. Research team proceed with the exercise "False myths about mammography" and "Fear in the box" exercise. Users were also trained how to mark on the Prolepsis App calendar and use chat room.

In the third meeting – on Module 4 – research team conducted training about self-efficacy in the caring role, using the worksheets presented in the manual.

Two participants suggested the mindfulness exercise could be done in this session as it was for some way heavy to talk about emotional burden and guilt feelings related to caring activities besides being conducted by a psychologist.

All participants were very positive and motivated in the final of the prolepsis Pilot.

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Chapter 2: Results and evaluation

Generally, caregivers self-reported an improved knowledge after the piloting of the training programme, and their level of satisfaction is assessed as very high.

2.1 Satisfaction with the training and the app

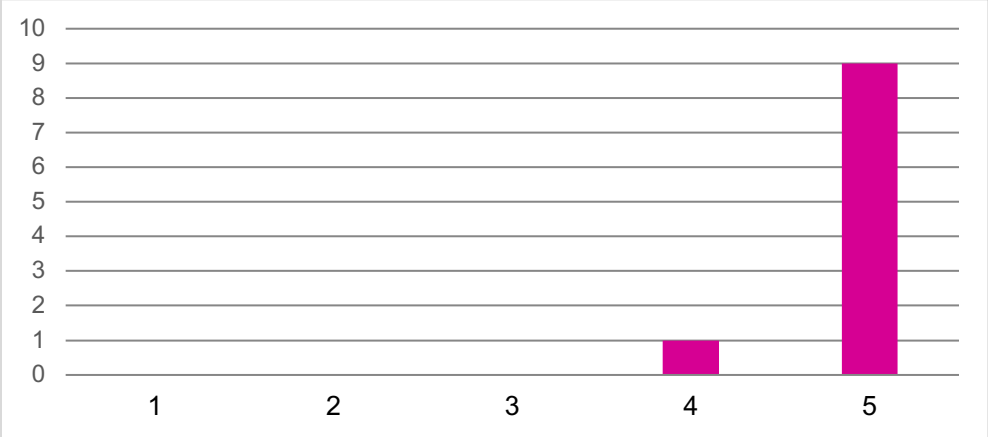
Research team submitted a questionnaire to assess the satisfaction with training program carried out in the framework of Prolepsis project and the app. Nine women participate to the whole training responded to the questionnaire.

Results

Place (City, town)

All respondents live in Vila Nova de Gaia.

Question: Are you satisfied with your participation in this training?



90% of respondents gave a score of *5* and 10% of them gave a score of *4*. Overall, the respondents were very satisfied or satisfied with the training programme.

Question: Were the objectives of the training similar to or different from your expectations?

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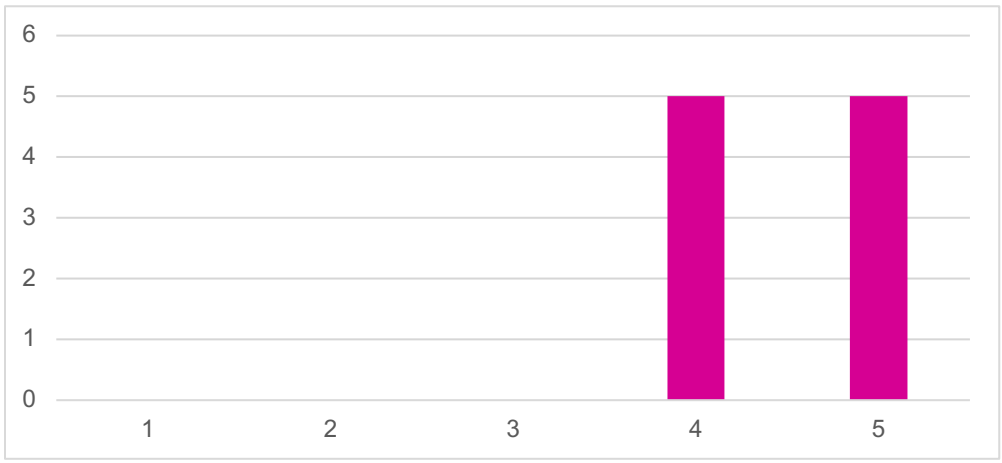
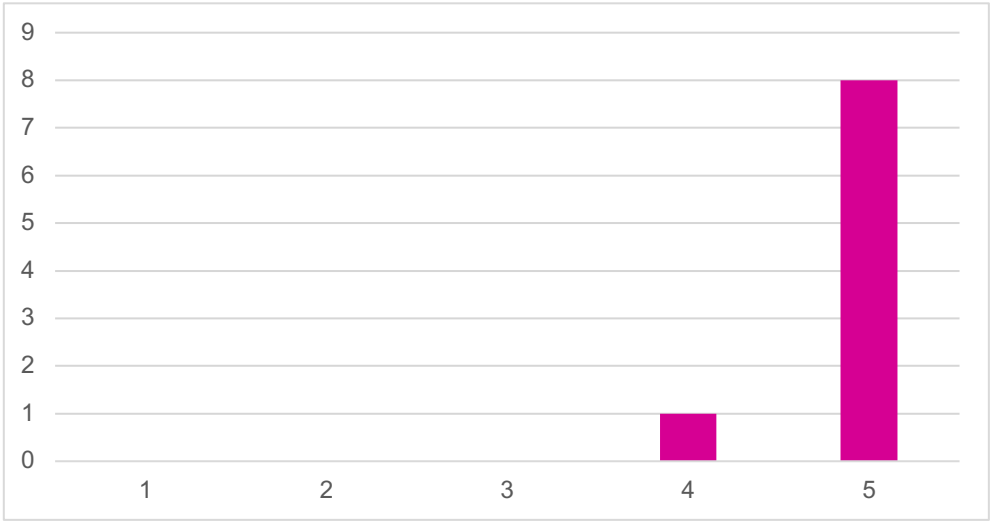


Most of the participants believed that the objectives were **similar** to their expectations. None of them felt that the objectives were different from their expectations.

Question: Do you think you learned something from participating in this training?



On a scale of 1 to 5 (not entirely/ definitely), 11,11% of participants gave a score of *4*. The other 88,89% of the interviewees gave a score of *5*. Overall, participants of the training program received a good level of learning, according to their answers.

Question: The contents of the video modules in the app were… (useful, clear, stimulating)

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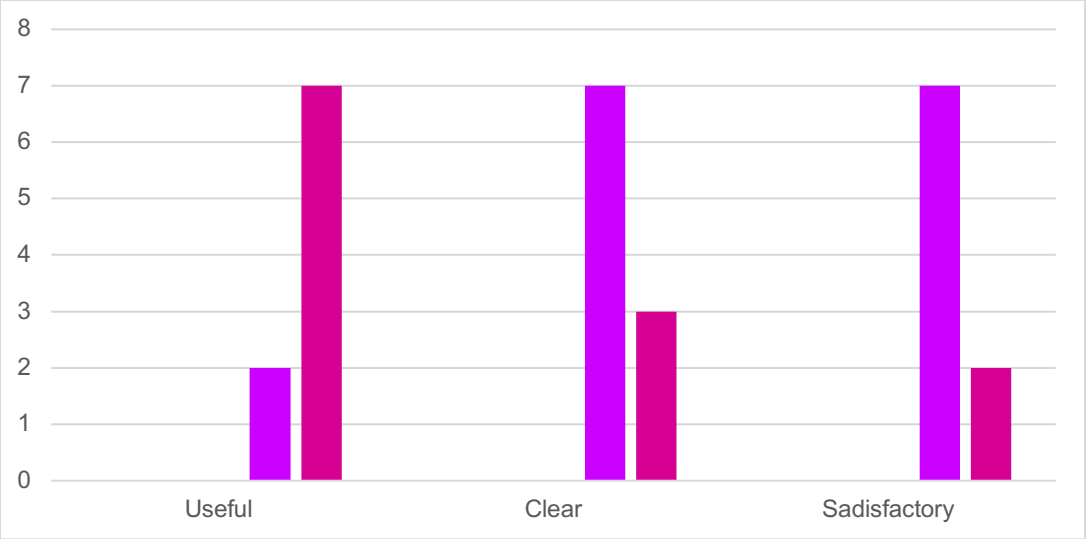
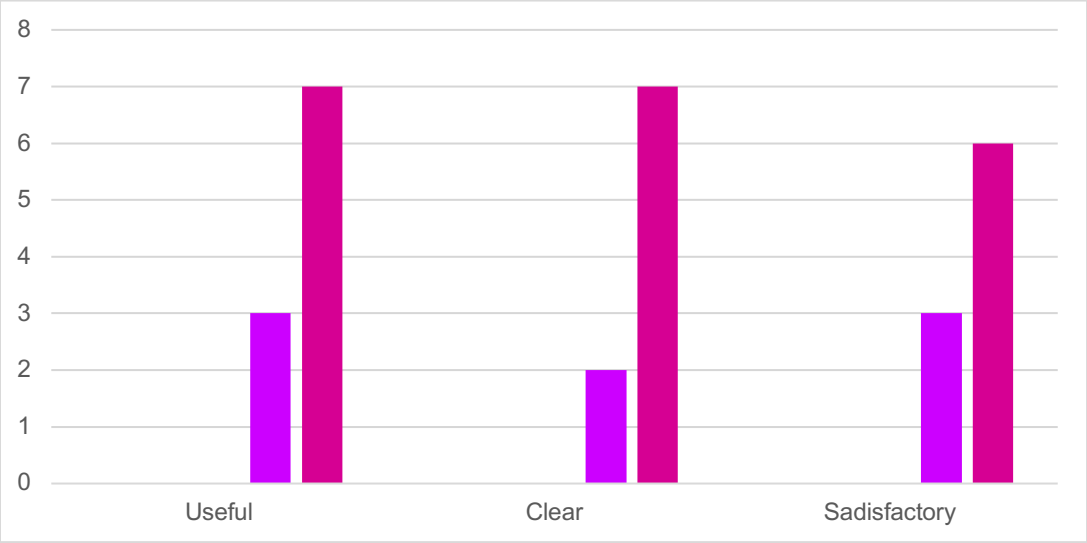


On a scale of 1 to 5 (not at all/very significantly), the participants gave a score to the contents of the video, indicating how **useful, clear and stimulating** they had been. All participants scored 5 or 4: in particularly, 7 participants gave a score of *5* in the *useful*, *clear* and *stimulating* boxes.

Question: The contents of the in-person sessions were: … (useful, clear, stimulating)

On a scale of 1 to 5 (not at all/very significantly), 7 participants indicated that the contents were **very useful** as well **clear** and **stimulating**, giving the maximum score: very significantly. All participants scored this question maximum 5 or as minimum 4.



Question: The participation of experts (external professionals) on the topic was… (useful, stimulating)

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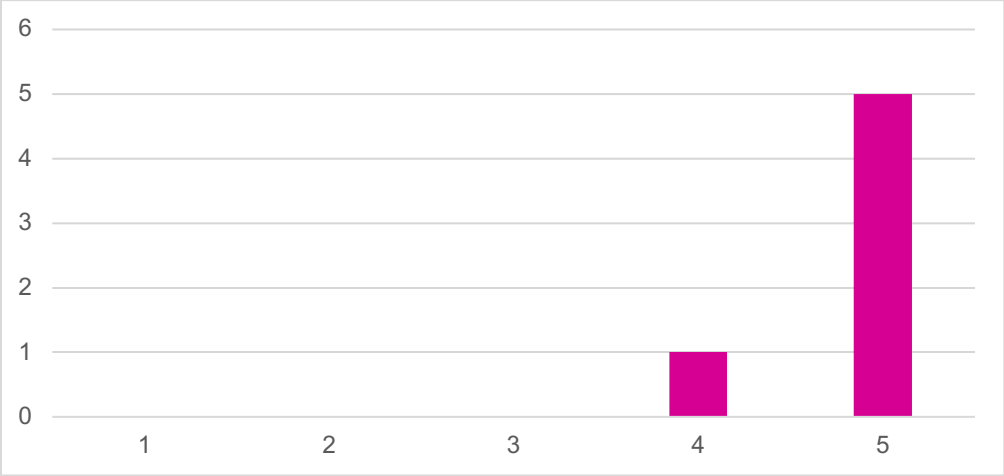
On a scale of 1 to 5 (not at all, very significantly), 90% and 80% of the respondents believed that the participation of experts on the topic was **very useful** and very **stimulating** respectively. Overall, participants were satisfied with the participation of experts in the field.

Question: How would you rate the performance of the internal trainers (i.e., Bruno Alves and Ana Ribas)?



On a scale of 1 to 5 (not effective/very effective), 83,33% of the participants rated the performance of the internal trainers as **very effective**.

Question: Please describe in more details your thoughts on the performance of trainers

The attendees described the performance of trainers as "*very good*", "very good in the dynamics" and "*committed and enlightening*".

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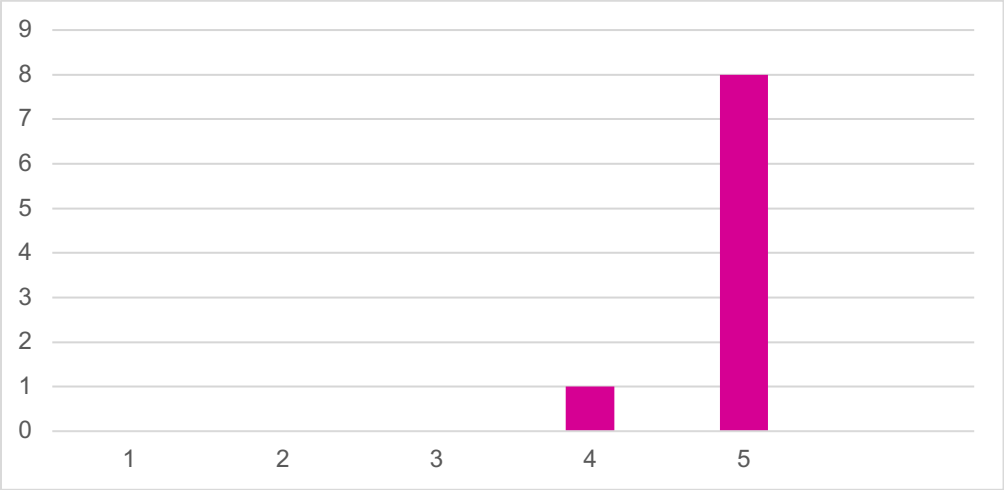
Question: How would you rate the training overall?



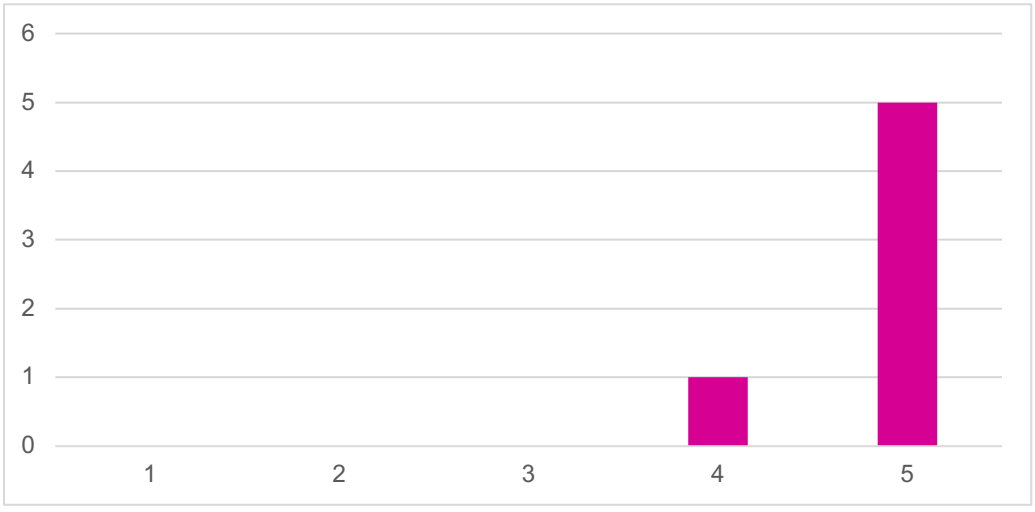
88,89% of participants gave a score of *5* to the training, on a scale of 1 to 5 (negatively/positively).

In general, the attendees believed that the whole training was very positive.

Question: Please describe in more details your thoughts on the training in general terms

The participants described the training using terms as "*I liked very much*", "*it´s always good to know more*"; "*very rewarding"* and "*interesting*".

Question: How satisfied are you with the app?



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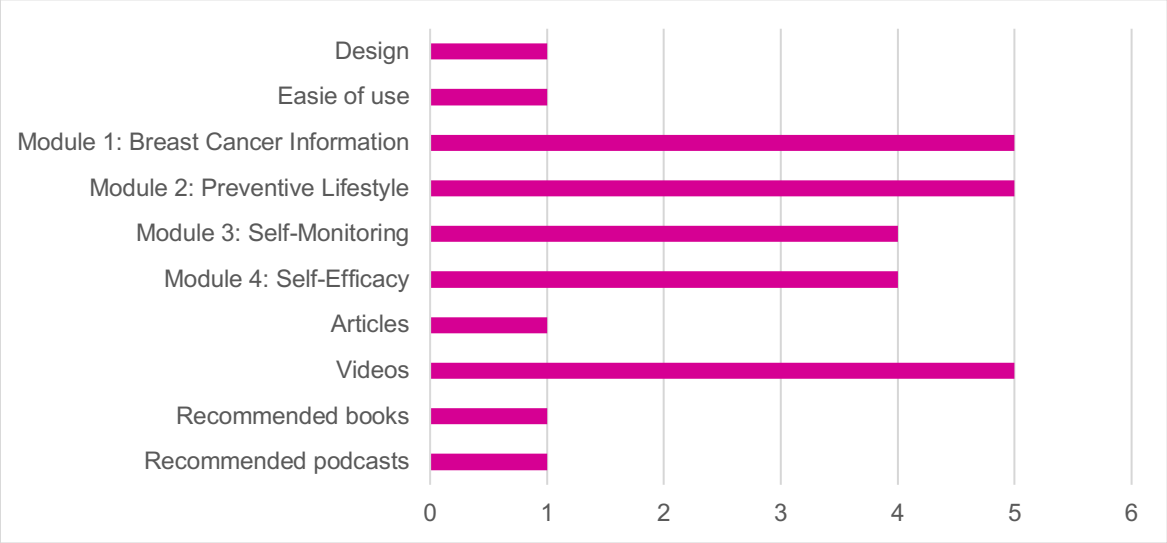
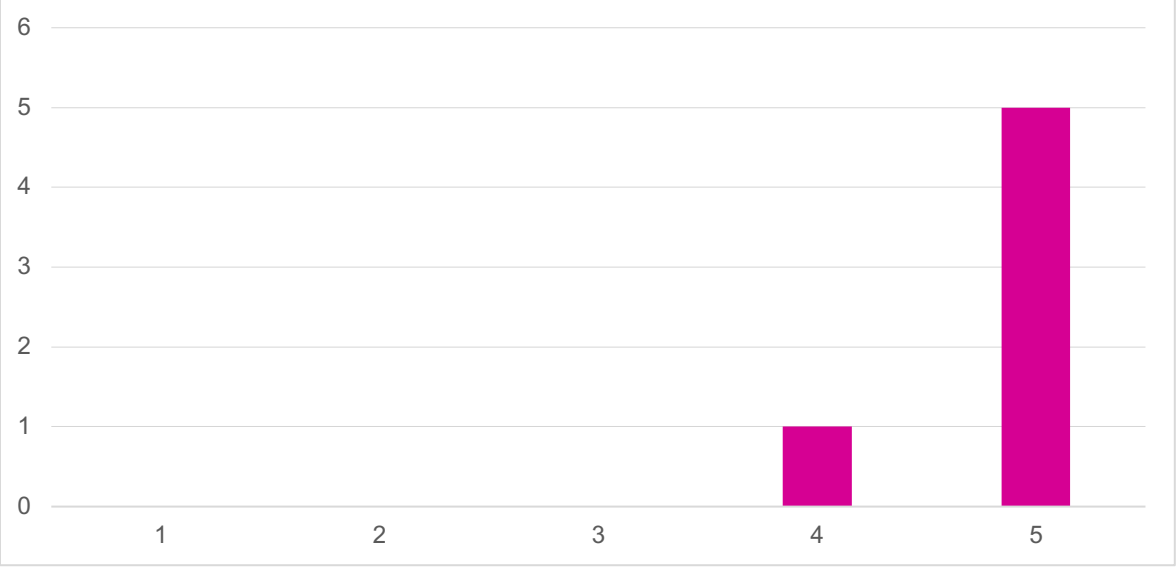
On a scale of 1 to 5 (not at all/ very significantly), 83,33% of interviewees gave a score of 5, while the other 16,67% gave a score of 4. Overall, the performance of the App was considered very satisfying by the participants to the training program.

Question: Which of the aspects listed below is most satisfactory to you? You can select more than one answer



The most appreciated aspects of the App were Module 1 and Module 2, videos, followed by Module 3 and 4. The least voted aspect, 20% of the participants indicated design and user-friendliness (*ease of use*).

Question: How helpful do you think the app can be in self-management of your health?



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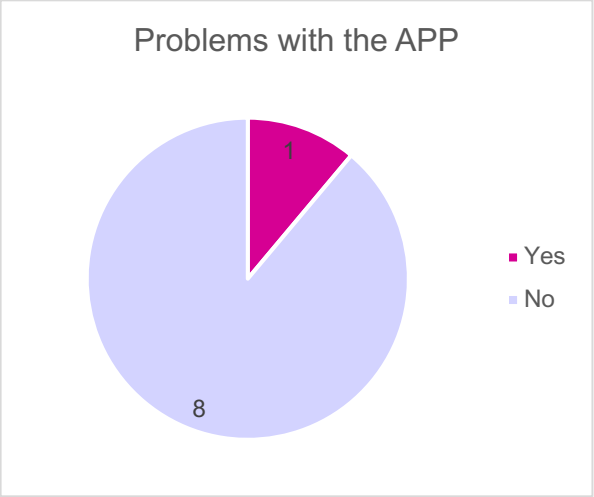
On a scale of 1 to 5 (not at all/very significantly), 83,33% of participants gave a score of *5* and 16,67% of *4*. Overall, most participants felt that the app can be generally helpful in self-management of their health.

Question: Did you have any problems with the app? (Yes/no) If yes, please tell us which one

During the training sessions face to face or by WhatsApp participants reported some constrains related with difficult in login, reading messages "popups" and receiving them in English. In this questionnaire only 11,11% report problems with the App.



Question: Please describe how you think we could improve this app

The participants provided the following suggestions:

"Nothing to add."

"New alert contents to all of us"

2.2 Upskilling of Participants' Competences

Portincarers - Associação Cuidadores de Portugal proceed with a self-assessment questionnaire submitted to the participants before and after the training. The pre-test was done by participants at the end of the introductory first part session on the project using the APP and before Breast Cancer Information Contents. The post-test was done in the last session face to face. Participants self-report a better overall performance (please see graphics bellow in which pink colour representing participants responses after the training course: post assessment). In the end the group was clarified about the correct answers.

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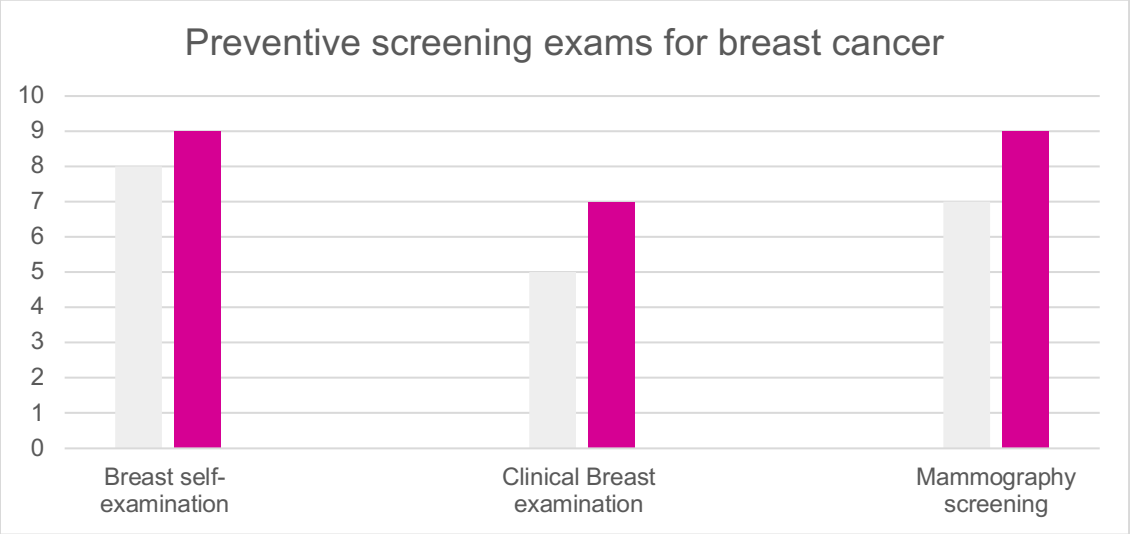
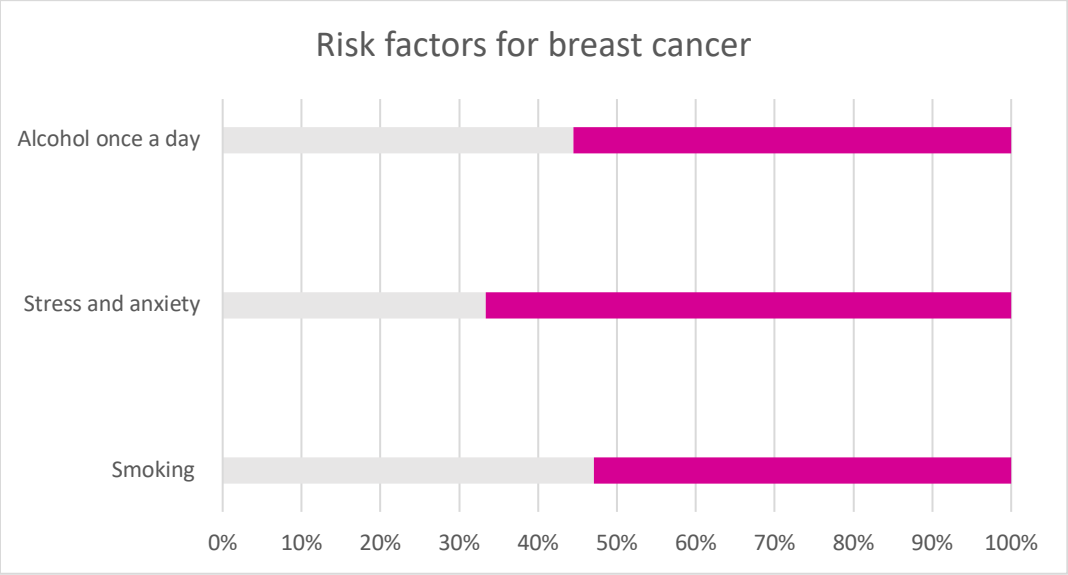
Question: Which of these exams are preventive screening for breast cancer?



In Post assessment shows Informal caregivers´ increase knowledge about preventive screening exams for breast cancer: 88,88% to 100% in breast self-examination; 55,55% to 77,77% in clinical breast examination and 77,77% in mammography to 100%. Woman in pre-assessment underestimate the clinical breast examination.

Question: Which of these are risk factors for breast cancer? You can choose more than one answer



Participants in post-assessment identify more risk factors for breast cancer, particularly for the role of stress and anxiety that was focused in the pilot training with psychologist intervention about mindfulness and the psychoneuroimmunology *versus* stress.

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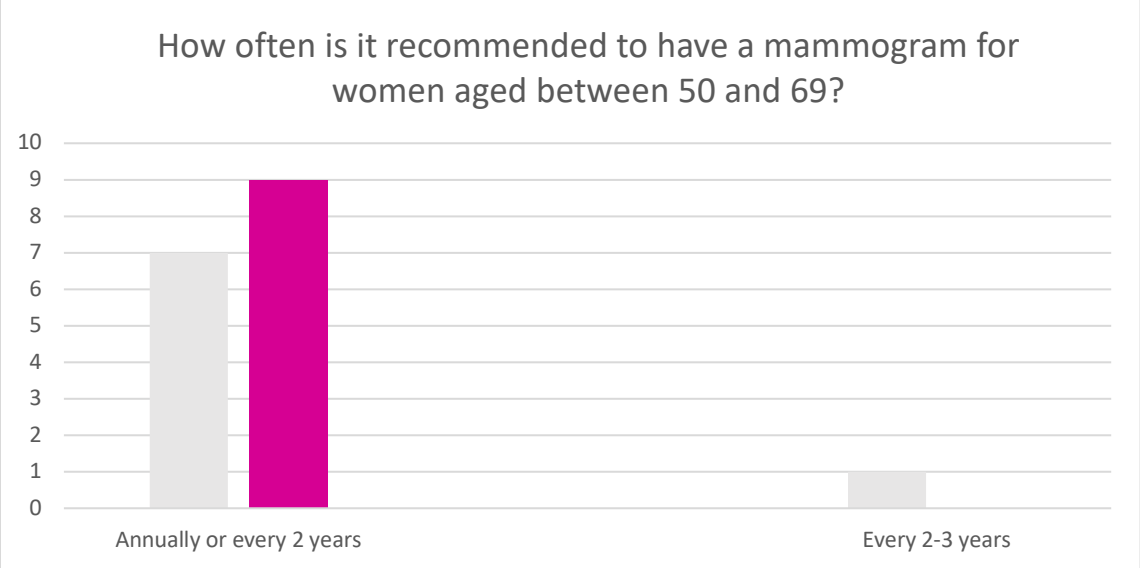
Question: What is a mammography screening?

Additionally, all participants (100%) in Post assessment identify correctly what is a mammography screening comparatively with Pre-assessment 87,50%.

Question: How often is it recommended to have a mammogram for women aged between 50 and 69?



In the pre-assessment questionnaire 87. 50% of participants replied annually or every 2 years, while during post-assessment turned out 100%, suggesting participants learned about the recommendations to have a mammogram for women aged between 50 to 69.

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Chapter 3: Challenges and final remarks

The piloting experience in Portugal was very positive, welcomed by the participants and generally completed as planned. Due to potential raise of dropouts related with carer responsibilities is suggested:

- to condensate for two days the training sessions face to face
- to offer a third day for those who can´t attend the last day can be beneficial in order to promote the number of caregivers with full training
- Chosen time slot, from 18 p.m. to 19.30 p.m. (CET), was ideal for caregivers for conciliation with caring responsibilities. Would be beneficial to do a bigger session (2 to 3 hours) face to face but the challenge is for caregivers be present so much time out of their caring responsibilities.
- Use of WhatsApp became a useful tool to promote communication between trainers and caregivers, promoted group cohesion as well facilitated continuous feedback of caregivers 'experience with the App (this allowed research team to improve the App features). However, vision impairment and low digital skills can limit participants to download and login to the APP. Trainers must be free to assist caregivers to download the APP and do login. Indeed, app features and blended training have been optimized according with caregivers' feedback.
- Informal caregivers enjoyed very much mindfulness activities and the participation of psychologist and public health nurse. It´s recommended the participation of these professionals in training sessions.
- Personalizing the training to caregivers' characteristics, life story and specific needs can help to motivate and create empathy with caregivers.

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Prolepsis piloting: final Remarks

The piloting phase demonstrated the value of promoting breast cancer prevention between informal caregivers through the use of a mobile application. The educational program provided to participants essential information that can be applied in their daily living as a means to promote their breast health. Despite the challenges that technology might impose on potential users (e.g. difficulty in navigating through a mobile application), it was evident that these can be easily overcome with appropriate coaching but also with integrated properties within the application. As the societies move faster towards a digital era the availability of such mobile applications offers an excellent opportunity for an increased number of prospective users to utilize them in a minimally interruptive way. The simple and user-friendly design of the mobile application facilitates access to the material developed through this project.

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