

Wellbeing and Healthy Choices for Older Adults and their Carers

Intellectual Output 4:
Pilot and validation study: feasibility, acceptance,
adherence

04 A 3 Pilots' Summary Report

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Abstract

Introduction

WHOLE: Wellbeing and Healthy Choices for Older Adults and their Carers is a three-year project funded by the European Union. The WHOLE project aims to create a comprehensive physical activity and nutrition program for carers and care recipients, made available online on an e-learning platform, to improve health and wellbeing as well as promote a healthy lifestyle of older adults and their carers, enhance the relationship between carers and care recipients, as well as to support the autonomy of older adults or care recipients respectively. Additionally the e-learning platform aims to contribute to an increased knowledge and skills of carers concerning healthy nutrition and physical activity in old age.

A feasibility and validation study was conducted to evaluate the feasibility, usability and usefulness of the e-learning platform and the physical activity and nutrition content as well as to assess the achievement of objectives.

Methods

114 carers (44.5 ± 13.27 years) and 138 care recipients (78.9 ± 9.9 years, at least able to sit) from Austria, Bulgaria, Germany, Greece, Ireland and Israel took part in two consecutive pilot studies. Participants were recruited per country, following different and individual recruitment strategies according to the preconditions of each partner organization. After a training for carers, the e-learning platform was used for eight weeks by these trained carers. It was envisaged to implement the physical activity content for three days a week for 20 minutes and to use the nutrition counselling according to ones needs. Before and after the implementation, tests and questionnaires were applied to carers and care recipients. Additionally, focus groups were conducted.

Results

The WHOLE program is evaluated positive in its biggest parts. The e-learning platform is usable and user friendly, the information provided are comprehensible and implementable, the physical activity content is safe and appropriate for the target group and both carers and care recipients feel better after the participation. The nutrition content was not applicable for some carers but others found it useful. In contrast, the implementation as planned was not feasible and needed individual adaptations.

Conclusion

Overall, the WHOLE program got positive feedback from carers and care recipients. However, the implementation in daily life is difficult most of the times and only few participants could follow the recommended use of the program. Different concepts were tested and one can conclude that each carer or each care tandem has to find a way to implement the physical exercises and nutrition advices in their lives.

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1 Introduction

WHOLE - Wellbeing and Healthy Choices for Older Adults and their Carers, is a three-year project funded by the European Union running from September 2015 until August 2018 and includes a consortium of experts in the field of physical activity [PA], healthy nutrition [NU] and health care for the elderly from Austria, Bulgaria, Germany, Greece, Ireland, and Israel.

The background of this project is based on the proven positive effect of physical activity and healthy nutrition on older people as they age and how healthy living can promote autonomy, independence and overall mental and physical wellbeing into older age. The benefits of exercise have been demonstrated in various populations of older people from the healthy to the frail. This includes those with multiple, chronic medical conditions such as dementia and depression and those who have experienced major life events such as trauma, surgery, or bereavement. However, despite the proven benefits, the majority of the older population in Europe do not get sufficient physical activity. One of the reasons for this is lack of public awareness as well as limited availability of active aging programs and, for many people, difficulty accessing such programs as they get older, particularly for those older people who are almost or entirely housebound. Therefore, the main innovation of WHOLE is that it aims to bring physical activity into the daily routines not only of older people, but of their formal/informal¹ carers too, as an essential component of daily care giving. Another common problem in the older population of Europe is poor nutrition. Over 20 million older people in the EU are at risk of 'undernutrition'. Many medical conditions along with gradual decline in physical capabilities can hugely affect our food and cooking choices as we age, putting older people at significant risk of malnutrition. Actively maintaining healthy nutrition is therefore even more important for older people. It reduces the risk of developing chronic conditions, or it can help us to manage them better.

The WHOLE project's main objective is to promote active and healthy ageing through physical and nutritional training for frail seniors and elderly people at home, using as a mean the personalised home care services provided to them by formal/informal carers. At the same time, WHOLE equally emphasises on the effect of physical activity and good nutrition on the wellbeing and relief of carers.

Intellectual Output [IO] 4 is intended to evaluate the feasibility, acceptance and adherence of the physical training and nutrition counselling (IO 2) as well as the e-learning platform (IO 3). Additionally, the usability of the e-learning platform (IO 3) will be assessed. The objective of IO 4 is to test the overall structure of the project and to verify the results according to the needs of the target group. This includes following more specific objectives:

- to pilot run and validate WHOLE training courses (feasibility, acceptance, adherence) and the e-learning platform (usability and satisfaction)
- to verify the validity of pilot scenarios
- to assess the overall impact of WHOLE (efficacy, learning)
- to pilot test the accessibility and impact of the e-learning platform

This report summarizes the methodology of the evaluation within two pilot studies (chapter 2) while also presenting (chapter 3) and discussing the results (chapter 4).

¹ Formal care: Providing professional care; Informal Care: Caring for a friend, relative, neighbor, etc.

2 Methodology

The innovation of this project is to integrate physical activity and healthy nutrition into the daily routines of older people and their formal/informal carers, as an essential component of daily care. Both the physical activity content and healthy nutrition counselling are provided on an e-learning platform to allow carers to train themselves in the application of the physical exercises and nutrition counselling. Both innovative aspects have to be approved in practice with pilot studies. As already mentioned, the objective of IO 4 is to test the feasibility, acceptance, adherence, usability and impact of the WHOLE concept, the PA and NU contents as well as of the e-learning platform. These objectives can be translated into the following research questions:

1. Is it possible to implement an e-learning platform offering material to implement PA and NU as part of daily care as planned and developed in the project? (Feasibility and verification of pilot scenarios)
2. How many participants finish the WHOLE program? (Adherence)
3. Are the PA and NU program as well as the e-learning platform feasible? (Feasibility)
4. Are the PA and NU program as well as the e-learning platform accepted by carers and care recipients? (Acceptance)
5. Is the e-learning platform usable? (Usability)
6. What benefits does the program have concerning the health and wellbeing as well as knowledge and skills of carers and care recipients? (Impact)

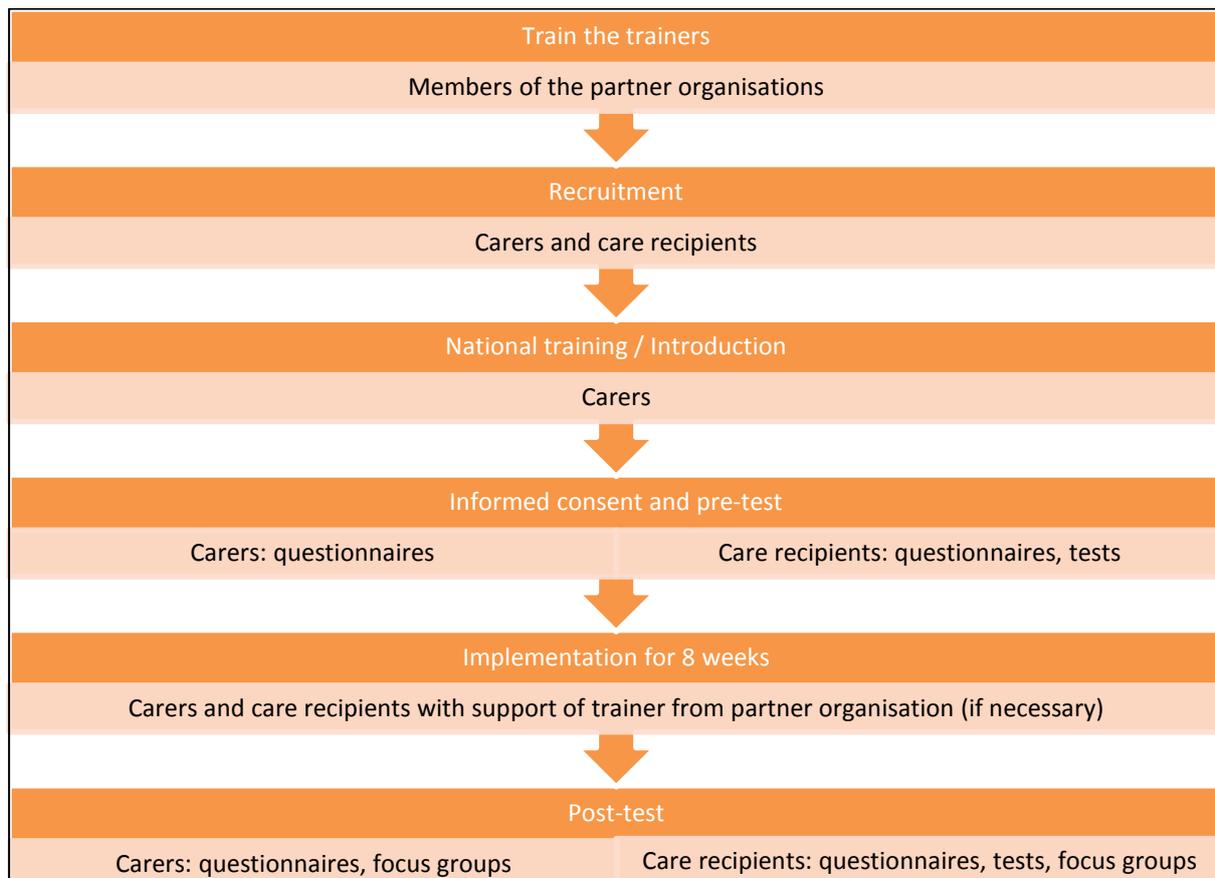


Fig. 1 Overview Methodology

To answer these questions, the following methodology was chosen and agreed upon by all partners in the *Final Methodological Plan* on 14. July 2017. The Methodological Plan contained specific instructions, goals, and deadlines for the pilots. The study got ethical approval of the ethical committee of the department 7 (psychology and sports science) of the Muenster University on 21. December 2017.

Two consecutive pilot studies were conducted in Austria, Bulgaria, Germany, Greece, Israel and one in Ireland following a single arm (without a control group) pre-/ post design. Both pilots focussed on the PA and NU program (content), the WHOLE e-learning platform as well as the overall concept (content mediated via e-learning platform). The feedback from the participants in the first pilot was used to adapt the content, the e-learning platform as well as the procedure for the second pilot. Each pilot ran for eight weeks. In both pilots, quantitative (tests and questionnaires) and qualitative methods (focus groups) were used, both for carers and care recipients [CR]. Roughly, the procedure was as follows: 1) Training for the trainers; 2) Recruitment of participants; 3) Training for the carers; 4) Informed consent and pre-test; 5) Implementation of the e-learning platform and content for eight weeks; 6) Post-test (see also figure 1).

One aim of the evaluation was to verify the validity of the pilot scenarios, also considering the different care settings in the participating countries (Austria, Bulgaria, Germany, Greece, Israel and Ireland) as illustrated in the literature review as part of IO 1 (Project Consortium WHOLE, 2016). Therefore, this section initially shortly summarizes the *planned scenario*, while the actual implementation is described in the paragraphs below. According to the proposal (Project Consortium WHOLE, 2015), it was planned to involve 15 elderly people in physical training and nutrition counselling in each partner organization during each pilot. To achieve this, at least five formal or informal carers should be recruited for each pilot, whereby the number of carers depended on the number of elderly people they care for. A family member i. e. usually cares for a maximum of two people. The partners were free to recruit the carers for the second pilot at the same time as those for the first pilot. By this, all carers could have taken part in the national training event where all carers (both formal and informal) should be trained using the WHOLE e-learning platform as well as the PA and NU program. The national trainings should be run by trained trainers of each partner organisation that would have taken part in the international training event (train the trainers) in May 2017 in Sofia, Bulgaria. The international training covered the following topics:

- Introduction of the e-learning platform: structure and functioning of the e-learning platform
- Physical activity: introduction (effects of PA in old age and safety precautions), tailoring PA classes, communication physical exercises to carers
- Introduction of tests and evaluation
- Care (safety precautions) and working with older adults and carers
- Nutrition counselling: introduction (NU module and NU for the elderly), NU and changing NU habits

After this training, the trained carers could practise for three weeks, supervised by the trained trainers in each partner country, to increase their knowledge and practical skills. After three weeks, the carers should conduct a face to face training to elderly people (inclusion criteria: at least able to sit) for a period of eight weeks with three sessions per week (in total 24 sessions for each elderly person) with support of the material provided on the e-learning platform (O4. A 1 Pilot test in

physical training and nutrition counselling, p. 45). Before and after this period, the carers and CR would complete the relevant questionnaires and tests and would take part in two separate focus groups, one for carers and one for CR (O4. A 2 Validation and testing of the e-learning education and training open platform, p. 45). This process would have been monitored and supported by trained trainers from the partner organisations, for example in offering group meetings or individual appointments. This should enhance the motivation of the carers and allow a scope for questions. No specific guidelines were developed for the supervision process, as each partner organization should tailor the supervision according to the needs of the participants and capabilities of the organization. After the first pilot, a time for implementing the feedback and conclusions to the WHOLE platform and training was planned. The second pilot should follow in the same way as the first. Detailed information on the *actual implementation* such as methods (chapter 2.1), recruitment (chapter 2.2) and procedures (chapter 2.3), as well as the statistical analysis (chapter 2.4) can be found in the respective chapters.

2.1 Methods

Two consecutive eight-week pilot studies were conducted following a single arm pre-/ post design. In both pilots, quantitative and qualitative methods were used, both for carers and CR, to get a diverse impression on expected and unexpected impacts of WHOLE on the participants in an objective (quantitative approach) and subjective (qualitative approach) view. The instruments used are described below.

2.1.1 Quantitative Methods

Several questionnaires and tests were implemented in the pilot study. The evaluation questionnaire was developed by Muenster University and Wohlfahrtswerk fuer Baden-Wuerttemberg. All other questionnaires are established instruments in research.

2.1.1.1 Questionnaires

The **EQ-5D** (van Reenen & Oppe, 2015) is a standardised instrument to measure the *health status*. The questionnaire (version EQ-5D-3L) is two pages long. The first page lists five dimensions of the health profile of a person (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) that are rated in three levels (no problems, some problems, extreme problems). On the second page, the participants rate their health on a visual analogue scale (EQ VAS) ranging from the 'best imaginable health state' to the 'worst imaginable health state'. The questionnaire, available in all languages, was implemented by carers (formal and informal) and CR. In Israel, the EQ-5D was used by carers only, rating the situation of the CR. Furthermore, the questionnaire was shortened to the dimensions mobility, self-care and usual activities. The reason for this adaptation is, that the CR were too frail to answer the questionnaire by themselves. Furthermore, the questionnaire was not relevant for the carers and the dimensions pain/discomfort and anxiety/depression too personal to ask.

The **Burden Scale for Family Caregivers** (BSFC) (Graessel, Berth, Lichte, & Grau, 2014) is a standardised measure to assess the *burden* of family carers in the subjective view. The short version consists of ten items covering different aspects of burden (e. g. life satisfaction, financial situation,

relationship to others). Each item is either rated as ‘strongly agree’, ‘agree’, ‘disagree’ or ‘strongly disagree’. As the questionnaire was developed for family carers, the questionnaire was mainly implemented for informal carers. The formal carers could - but did not have to - complete this questionnaire. There are free versions available in English, German and Greek. The Bulgarian version was translated in a back and forth approach by the Bulgarian partner organisation; however, this version was not validated as the other versions have been before by the authors. The feedback of the carers in the first pilot was that the BSFC was still too extensive and that they would prefer a shorter and easier scale. Therefore, the partners from Israel created an own scale (**Burden of Carers**, see figure 2). This scale was implemented in both pilots in Israel and by all but the Greek partners in the second pilot. The scale was not validated.

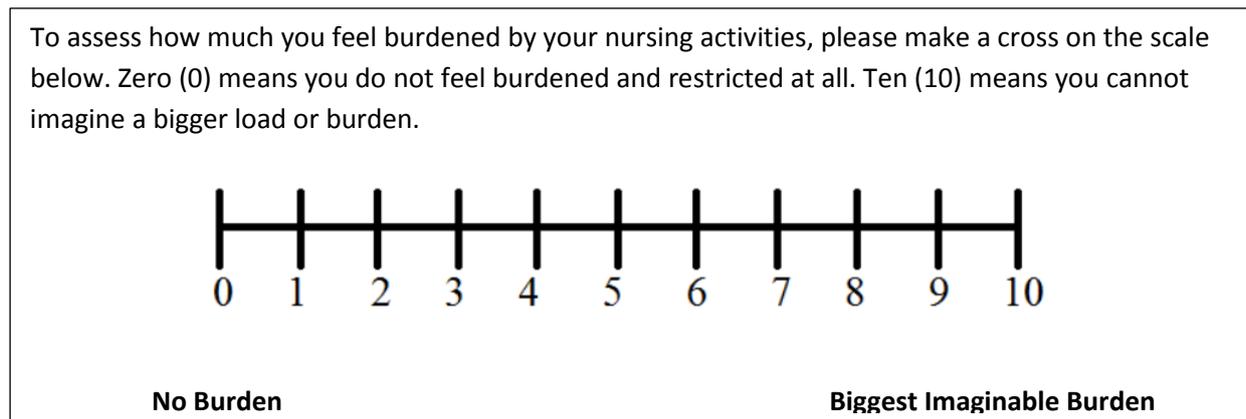


Fig. 2 Burden of Carers

As mentioned before, an **evaluation questionnaire** was designed to assess the feasibility, usability and usefulness of both the e-learning platform and the NU and PA content as well as the achievement of objectives. The evaluation also contributed to validate the learning, skill acquisition, and transferability of new competences and skills. The following sub criteria were defined:

- Feasibility: acceptance, viability, satisfaction, adherence, recruitment
- Usability: user friendliness, functioning
- Usefulness: usefulness, transfer
- Achievement of objectives: benefits (impact), reach

The evaluation questionnaire was completed by the carers after the eight weeks of the pilots. The questionnaire contained statements about the WHOLE program (platform and content), the e-learning platform and the PA and NU content that were rated on a four-point scale from ‘strongly agree’ to ‘strongly disagree’. For example: ‘I can adapt and design exercises and routines for the needs of my care recipient(s)’. Additionally, the carers were asked about the use (frequency and duration) of the platform and its contents.

2.1.1.2 Tests

In addition, the partners choose the following tests to assess the *functional capacity of the elderly* and to objectively assess the impact on the target group: the Modified Functional Reach Test; the Functional Reach Test, the Timed Get Up and Go Test, the 10 Meter Walking Test and the Back Scratch Test. It was envisaged that all participants complete the Modified Functional Reach Test as

this test is completed in a sitting position. All other tests were optional, also to allow the platform user to perform the tests by themselves in order to track the personal progress of the CR. Therefore, assessment guidelines were prepared and are available online <https://www.uni-muenster.de/ProjectWhole/tracking-progress/> (Project Consortium WHOLE, 2018). The tests were applied by CR only, either conducted by the carers or by the trainers.

The **Functional Reach Test (FRT / MFRT)** (Rehabilitation Measure Database, 2013a) assesses a CR's *balance* in either a standing or sitting (modified version) fixed position. The CR reaches forward in this fixed position as far as possible. The maximum distance is measured in centimetre. Additionally, we added reaching to the right and the left side in sitting position.

The **Timed Up and Go Test (TUG)** (Rehabilitation Measure Database, 2013b) is an instrument to test the *mobility, risk of falling* and *balance* of frail elderly persons. The person sits in a chair and, on a command, starts walking a three meter distance, turns around, walks back to the chair and sits down again. The time is measured in seconds.

The **10 Meter Walk Test (10MWT)** (Rehabilitation Measure Database, 2014) measures walking speed (in seconds) over a short distance to determine the *functional mobility* of a person.

The **Back Scratch Test** (Wood, 2008) measures the shoulder flexibility by measuring the distance (centimetre) between the hands that are brought together behind the back.

2.1.2 Qualitative Methods

For the qualitative data collection, focus groups with key questions (guideline) were chosen, both for CR and carers. In case that the organization of a focus group was not possible (e. g. because the CR could not leave their houses), interviews were conducted instead. Topics raised were: experiences with the program, self-reported benefits, meeting the needs of the target group.

2.2 Recruitment

As each partner organizations had diverse preconditions (different care systems per country, existing networks, possibilities to reach the target group, focus on formal versus informal carers, etc.), each partner organization was in charge for the recruitment process by itself. Different approaches were chosen. A short overview of the strategies is provided below. Next to the successful recruitment strategies, also problems will be mentioned as the reach of the target group became very difficult.

Austria: The Austrian partner organization is a leading organization in the vocational educational training for nurses in Austria. The partners recruited one nursing class (health care professionals) per pilot to reach formal carers in training. The students have been in their internship in residential care homes, so that the access to CR was granted. The partners spoke to the institutions before to get their permission to conduct the pilots.

Bulgaria: The Bulgarian partner got in contact with the Bulgarian Nursing Association (BNA) for the first pilot. Even this umbrella organisation experienced problems in the recruitment of carers as the working conditions for carers are bad in Bulgaria (little payment, lack of training, too few people). Still, the BNA did send 34 carers from a hospital to the training. Those carers care for several people in the hospital (from different departments) and some of them are private carers at home too; and

some also care for people in the community. This means that some of the carers are formal and informal carer at the same time. Those who also work at peoples home are still using the program, even after the second pilot. In the second pilot, the recruitment was a bit more difficult, as the BNA was involved in legislative changes and other solutions had to be found. For the second pilot, a private network was used to recruit the participants (16 informal carers).

Germany Muenster: For the first pilot, 20 outpatient care service provider were contacted via letter post, followed by phone contact. Three provider were interested in a training but denied their cooperation for the pilot study after the training as they couldn't see any benefit for their staff or didn't see a possibility to participate as no one would pay for the work of the carers. Others didn't show any interest from the beginning. Some of the reasons given were: 'no time', 'running too many other projects', 'responsible person not available', 'no interest in the topic', etc. Next to this, some personal contacts were used to recruit informal carers (University professors in nursing science, friends, family, newsletter to family carers of the University). As this approach was not successful, the strategy was changed for the second pilot. In the second pilot, the target group 'formal carer' for residential care was expanded from outpatient care service provider to other living arrangements such as residential care homes, day care centres or assisted living facilities. The partner contacted almost all care provider (~30 outpatient care service provider, 33 nursing homes, 12 day care centres, 10 support groups for informal carers, 19 organizations offering offers for relief for family carers) in Muenster and used a CARITAS Network from all over Germany (newsletter). With all these efforts, the partner could still only recruit two facilities (one day care centre and one nursing home). Furthermore, some more private contacts were used to recruit an informal carer. There was contact to other organizations outside from Muenster (e. g. a shared flat for dementia patients) and private carer as well, but finally, all denied their cooperation.

Germany Stuttgart: For the first pilot, an assisted living house in sponsorship of the Wohlfahrtswerk was asked and joined the pilot study. For the second pilot, the partner talked to different people and organizations (that also belong to the Wohlfahrtswerk) but for most of them the pilot would have been too difficult to handle in their daily duties as they have too many task to complete. One possible participant (institution) didn't join the pilot study after almost one year of communication for recruitment. Another institution of assisted living and one day care centre joined instead. The partner introduced the project to the team and the team finally implemented it.

Greece: One part of the Greek partner organization is an agency that provides homecare services. So they could use their professional staff for both pilots. They have built a network/good links to CR during the last years and people trust ATOM. But even for them, it was not easy to convince the elderly to take part in the study, as people are not interested in some topics.

Ireland: Age Action has great networks and good connections with lots of contacts to elderly people and they found a residential home with a day care centre. The coordinator was very happy to get involved. The problem here was, that the board wanted to get ethical approval. The ethical approval from the University of Muenster was not sufficient for them. So they had to find another partner that finally agreed to participate.

Israel: For both pilots, the connection was built to day care facilities using the networks of the Wingate College. Through the day care facilities, they could recruit care tandems (24 hour care).

Participants of the day care are frail elderly. Some of them come to the day care with their carer (the carer lives with the CR). Participants of the pilot were recruited from this population.

2.3 Procedures (Training and Implementation)

The first pilot and validation study was conducted between September and November 2017. The second pilot started in January 2018 and ended in June 2018. Due to a partner change in winter 2017, the Irish partner organization only participated in the second pilot, from June 2018 until August 2018. The pilot started later because of the ethical concerns reported previously. Unfortunately, the pilot ended in the holiday season and results could only be provided partly so that the results for the Irish carers are not included in this report. The second pilot was implemented after the revision of the e-learning platform, its contents and the procedure of the pilot study according to the feedback given by the participants of the first pilot. As already mentioned above, one aim of the evaluation was to verify the validity of the pilot scenarios. While the planned procedure was described in chapter 2, the following section summarizes the *actual implementation* for each pilot site with some first impressions and detected problems in the point of view of the trainers or project partners respectively. Unless otherwise mentioned, the implementation for both pilots was identical.

Austria: The national training in Austria was part of a school class in the nursing training. The training, conducted by their teacher that took part in the international training event, lasted half a day and was obligatory for the students (19 in the first pilot, nine in the second pilot). Consequently, the students were trained in the platform in school and implemented the program in their internship in nursing homes. During the eight weeks of the pilot study, the students visited the CR's home (mostly in a nursing home, some in private houses) on every weekday and did a session on this occasion. All students implemented the physical exercises but could not use the NU module as the food is not prepared by the students. However, the partner organization sees a chance to use the NU material for the lessons in school. The students got support during the whole time by their teacher or the trained partner respectively, either onsite in the school and/or during visits in the facilities as part of the mentoring of the internship. The first impression of the trainer was that both students and CR were happy about the program, especially the social aspect to get in touch with each other besides the daily routine as washing or similar. Most of the students enjoyed the program very much and were thankful to have some tools, others didn't liked the activities. The participants could see changes in the mood but did also experienced the pilots as stressful. The teacher hopes, that the students will use the e-learning platform further, as the program is an enrichment for the training of future nurses. For the CR, it was a break to their daily routine in the teacher's point of view. Nonetheless, for a sustainable implementation of this kind of training and implementation of the WHOLE program, it will be necessary to award credit points, which will count for the annual upgrading as the question was raised, who is paying for the time during the training. This leads to the conclusion that the management has to support the program, otherwise the implementation of the program might be too difficult.

Bulgaria: In the first pilot, the Bulgarian partner offered two national trainings, which were attended by 34 formal (33 female, 1 male) and eight female informal carers respectively. In the second pilot, another 16 informal carers took part in the training. Each national training lasted a full day (six hours

for the training for formal carers as the hospital only allowed the carers five to six hours of training) following the trained approach in the international training event. But also for the informal carers it was difficult to attend a full day training as they have personal problems or are overloaded. On the other hand, both formal and informal carers want to train themselves as they don't get proper professional education and were very happy to get a training and a certificate of attendance at the end. Both the PA and NU module were discussed in the national trainings. Especially in the second pilot however, the focus was on the physical exercises as the carers prefer to talk with specialist or physicians about their nutrition and/or do not see themselves responsible for the nutrition of the elderly. Overall, 45 formal and informal carers implemented the e-learning platform with its content but most of them used the WHOLE program for themselves (on average once a week). Solely nine CR were involved in the pilot studies in Bulgaria. The reason for this is, that the carers wanted to benefit from the physical exercises by themselves to become fresh and have a break from their daily routine and to also get an education in a health related topic. Additionally, they used the opportunity that they don't have to pay for the program. Regarding the nutrition, the participants preferred to ask their physician so that the material was barely used. The BNA though was very interested in these NU materials and would like to integrate it in their education but cannot properly. A lack of computer skills made it difficult for some carers to use the program as they are not familiar with the computer. Some of the participants therefore didn't use the platform but had to ask relatives to print the exercises for them and do the training with the print-outs. One solution to overcome this problem would be to distribute handouts with exercise units to the carers. The biggest problem though, were time constraints. Another smaller problem for the pilot study was, that the questionnaires were too long for some carers and that they did mistakes in filling them in. One of the partners therefore had to write down answers in questionnaires as it was too much to read and complete. To sum up, still, most of the participants liked the platform and the formal carers would like to have a certificate which also would be approved by other countries. For them, this would be an enhancement in their professional education.

Germany Muenster: As the recruitment process was quite difficult in Muenster, individual trainings with interested carers were offered. Overall, three trainings with informal and six with formal carers were conducted (overall five informal and ten formal participants). All trainings with informal carers were successful but only two with formal carers, four organizations did not take part after the introduction. The trainings lasted between one and two hours, depending on the time and individual needs of the carers. The platform with its content was introduced and important information about the safety were given. Also, the most important parts were introduced in detail and example PA units were created using the tailoring tool. Support was offered during the eight weeks of implementation, but none but two participants asked for support in the pilot phase, one via phone contact and one via e-mail. The implementation of the WHOLE-program was different for the participants. For the formal sector, a day care centre and a nursing home participated. Both organizations offered PA daily in group offers. The day care centre tried to test every exercise. The CR however did not visit the day care centre daily, so they haven't had the training for five but maybe for two to three times per week. The nursing home organized a daily group offer, but also here, not all CR joined the group daily. As already mentioned for other partners, the NU module was difficult to use as the food is prepared in a large kitchen. The nursing home however, forwarded the nutrition fact sheets to the kitchen and offer fresh smoothies daily. The three informal participants used different approaches:

one couple used the exercises together as planned using the e-learning platform, another carer prepared exercise units in printed version for his mother and the elderly person implemented the exercises for herself while the last informal care tandem already got the material in printed version that the person in need of care is using by himself.

Germany Stuttgart: The training consisted of a half-day training for one formal carer (social worker, coordinator of the institution) in the first and three formal carers in the second pilot. The e-learning platform was introduced using itself as presentation. The carers were then asked to use the e-learning platform by themselves. There were no follow up meetings of the training. In the assisted living facility (pilot one), each resident is cooking for him- or herself. So the material was made available but there was little influence by the carer to use the material. A small change was implemented in offering smoothies and fruits as refreshment within the exercises session. The PA training itself took part once a week for one hour in a group setting. The carer planned the exercises with help of the e-learning platform and implemented the exercise session. Sometimes, the carer put the elderly together to work together in order to go around to support the participants. Alternatively, the group did the exercises altogether in a circle. Some of the elderly used a walker or needed assistance, others were still independent. The carer was able to design exercise units and she also reported that some elderly use the platform to find some specific exercises for themselves. The group started with ten and ended up with 15 elderly as the group was so successful. Also the social worker was very happy about the program 'I was waiting for it!' and she thinks, that the WHOLE program is a good option for social workers as well. The participants of the first pilot are still using the program regularly and additionally implemented a yoga class in the meantime. In the first pilot, another couple of another assisted living facility participated. The husband, suffering Parkinson, is doing the WHOLE program with his wife. They don't like changes in their nutrition but used the physical exercises once a week. After their opinion, it was a lot to read but the training was helpful. Another couple living at home, the wife is in need of care, used the PA exercises based on the printed material prepared by the trainer. In the second pilot, the day care centre and another assisted living facility started the PA training in a group once a week. The partner offered support, but there were no questions neither from the day care centre nor the assisted living facility. The carers were happy, the platform easy and intuitive to use. The participants of the day care centre even used different exercises from the WHOLE program to do exercises every day for 20 minutes. The warm up though, was too long and was therefore shortened. The institution couldn't use the NU part much. They were interested to cook by themselves, but the material was finally too much to read so they suggested to put the most important information on cards.

Greece: The implementation in Greece was supported by a trained physical education teacher. The same sets of exercises (printed version prepared by the physical education teacher) were used by all carers for both pilots, because it was easier to explain these exercises to all participants and to solve problems or misunderstandings. Another reason for this was, that the tailoring of exercises was difficult for the informal, but also for some formal, carers, as there are too many exercises and it was not visual enough. In the first pilot, five carers (four informal and one formal carer) took part with 13 CR. In the second pilot, again five (three formal and two informal) carers participated with 12 CR. The informal carers, some of them are still working and have a great burden of care, used the program one or two times a week while the formal carer (physical education teacher) worked with six of the CR twice a week. Some sessions in the formal setting were done by a nurse or the physical

education teacher, if the elderly were very frail (the CR sometimes did the exercises with the physical education teacher but with no one else). The CR with a 'good' functioning were motivated to additionally train for themselves. Also the elderly in the informal setting got weekly visits from the staff, so they could ask their questions to trained experts. The training and implementation was small and took place in the home environment (private homes of the elderly) as the motivation is better in the home environment. The NU part was neglected by most of the carers but the physical education teacher. They expressed the wish for more templates for meal plans, as this would have been more useful for them. The current NU module was not practical enough. The physical education teacher shortly reported his experiences: he liked the program as the exercises are good. He started with three minutes walking with traditional music as some found the aerobic exercises boring. He preferred exercises in standing position and used the ball quite often as it was the most wanted material. The CR liked some little games at the end, so he added some (e. g. bowling). His experience was that informal carers are not willing to do the exercises as they don't want the responsibility but do also not want to pay for the program. Finally, the conclusion of the partner was that the carers enjoyed the program more than the elderly did as it was a break in their daily duties.

Ireland: The training in Ireland took place half a day. The partner met with the social worker, activity manager/coordinator, occupational therapists, managers of the organization and all went through the exercises by themselves. These coordinators then met with the carers on three sessions and decided on what exercises to take. Each carer is doing a predefined session of exercises, using the same set of activities. 15 carers (privately paid by families, not paid by the government; care for several people during the week) and 15 CR living at home participated. People on management were quite apprehensive and thinking of what happens if someone falls or if someone has a cognitive impairment etc. But when they met the carers that were delighted and happy to get something new, the opinion of the managers changed by these reactions of the carers. Also two families were concerned and finally dropped out. The Irish partner did only participate in the second pilot.

Israel: The carers (24 hour paid carers from Nepal/India/Philippines etc., living with the CR and caring for them 24 hours a day) were trained for approximately eight weeks (a bit less in the second pilot) in weekly sessions by a trainer/expert from Wingate Institute. All carers are regularly visiting a day care centre with the CR for a few hours per week. The first meeting (training) with carers was in the day care centre, where the carers were introduced to the e-learning platform and WHOLE program and the trainer explained all the exercises. The carer then should do the exercises with the CR at home. In the following week, the carers could ask questions to the trainer. There is no information available what program the carers finally did at home, but some reported to implement the exercises almost every week (mostly using their smartphones). Others were not active as it was not possible for some (if a family gets a 24 carer for one to one support, then the CR are very frail). It was difficult to meet the carers regularly, but a way was found. Most follow up meetings were with the carers only, while the CR were involved in other activities of the day care centre at this time, but some of the meetings were attended by the CR as well and exercises were done altogether. The carers were happy during the training and to learn something new. They also liked to practice with the CR and were happy to get a certificate at the end. The NU part could be enhanced using more pictures. One CR stated about a change in his/her eating habits: 'Food is the only thing in life that I enjoy!', which shows, that it was also not easy to use the NU part in Israel as well. In the first pilot, 12 carers started with 12 CR, but two died within the eight weeks. In the second pilot, 13 care tandems participated.

2.4 Data Analysis

The data were collected by the partners/study coordinators in each country and anonymously transferred to the server of Muenster University for data processing. The data processing and assessment of the quantitative data was done using IBM SPSS Statistics 24. Data were processed according to the user manuals of the questionnaires applied using frequencies for the dimensions and levels of the *EQ-5D* and mean values for the VAS-scale (van Reenen & Oppe, 2015) as well as a sum-score of all items of the *BSFC* (Graessel et al., 2014). For the assessment of the questionnaire *Burden of Carers* the number ticked on the scale from one to ten as value. The higher the value, the higher the burden. For the *evaluation questionnaire*, criteria for the sub criteria feasibility, usability, usefulness and achievement of objectives were defined and assessed descriptively accordingly. The test data for FRT/MFRT, TUG, 10MWT and BST did not had to be processed before assessment as they already were reported in either centimetres or seconds according to the test manuals. For the EQ VAS scale of the EQ-5D (health state) and all tests, a t-test for dependent samples was used to assess the data. Only cases with data from the pre- and post-test were included in the analysis. Both, the EQ-5D health profile and evaluation questionnaire were descriptively assessed only. Please consider that the number of participants for the descriptive analysis varies in between variables as not all participants completed all parts of the questionnaires. On the other hand, we would have to exclude too many cases due to missing values. Therefore we decided to include all cases in the descriptive statistics. The number of participants are reported in the result section and results are shown in percent for valid results (without missing values). All quantitative data but the EQ-5D-3L health profile are shown as mean values and standard deviation. The qualitative data were summarized taking into account the opinions of all participants.

3 Results

The following section shows the results for the carers (chapter 3.3) and care recipients (chapter 3.4). The participants are presented in chapter 3.1. The results of the evaluation are part of chapter 3.2.

3.1 Participants

3.1.1 Carers

Overall, 114 carers (86.8 % female) in the mean age of 44.55 (\pm 13.27) years from Austria, Bulgaria, Germany, Greece and Israel took part in two streams of the pilot study. 43.9 % of all carers were formal carers or in vocational training to become a professional carer, 17.4 % were informal and 30 % were paid but non-professional carers. On average, their care experience was 10.14 (\pm 11.75) years ranging from 0 to 40 years of care experience. The main modus of participation overall was one to one (care tandem) with 57.9 %. Some Bulgarian carers used the program for themselves (27.2 % of all participants) and in Germany, some carers offered the program in a group setting (3.5 % of all participants). In Greece, one carer worked with several CR (7 % of all participants). About 60 % of the participants already had experience in using computers or laptops, while 45 % have used an e-learning platform before. Further, country specific, demographic data can be found in table 1.

Tab. 1 Demographic Data Carers

		Austria*	Bulgaria	Germany	Greece*	Israel	International	
		No.	No.	No.	No.	No.	No.	%
		28	45	8	10	23	114	
Gender	Male	4	0	3	5	3	15	13.2
	Female	24	45	5	5	20	99	86.8
Type of Care	Formal**	27	15	3	5	0	50	43.9
	Informal	1	11	4	5	0	21	18,4
	Other***	0	1	1	0	23	25	30,0
	Missing	0	18	0	0	0	18	15,8
Modus of Participation	1 to 1	28	9	4	2	23	66	57.9
	Group	0	0	4	0	0	4	3.5
	Alone	0	31	0	0	0	31	27.2
	1 to x	0	0	0	8	0	8	7.0
	Missing	0	5	0	0	0	5	4.4
Experience Laptops	Yes	28	25	7	8	0	68	59.6
	No	0	4	1	2	0	7	6.1
	Missing	0	16	0	0	23	39	34,2
Experience e-learning	Yes	19	21	4	7	0	51	44.7
	No	9	8	4	3	0	24	21.1
	Missing	0	16	0	0	23	39	34.2

*some carers took part in pilot 1 and 2

**Austria all formal carer in vocational training

*** social service, formal and informal carer, paid but non-professionals

3.1.2 Care Recipients

Tab. 2 Demographic Data Care Recipients

		Austria	Bulgaria	Germany	Greece	Ireland	Israel	International	
		No.	No.	No.	No.	No.	No.	No.	%
		28	9	40	25	13	23	138	
Gender	Male	11	3	7	7	4	4	36	26.1
	Female	16	6	33	18	5	18	96	69.6
	Missing	1	0	0	0	4	1	6	4,3
Modus of Participation	1 to 1	28	9	4	25	13	23	102	73.9
	Group	0	0	36	0	0	0	36	26.1

Overall, 138 CR (69.6 % female) in the mean age of 78.9 (\pm 9.9) years from Austria, Bulgaria, Germany, Greece, Ireland and Israel took part in two streams of the pilot study. On average, the CR were in need of care for 4.6 (\pm 6.8 years), ranging from 0 to 58 years in need of care since birth. 73.9 % of the CR were involved in a care tandem while 26.1 % participated in a group setting. The reasons for care differ and were e. g. frailty, ageing, diabetes mellitus, Morbus Parkinson, surgeries in joints, heart diseases, obesity, depression, dementia or strokes. See country specific data in table 2.

3.2 Evaluation of the WHOLE program

The following chapter presents the results of the evaluation and provides an overview of the use of the WHOLE program.

Use of the e-learning platform, the physical activity and nutrition module

As mentioned before, the number of carers answering the questions of the evaluation questionnaire varies from item to item. The numbers are presented in each figure. The number of complete questionnaires is small, therefore we decided to report the answers of those completing the items. The results below are shown in valid results and do not necessarily reflect the view of all 114 participating carers.

Figure 3 shows the *use of the platform* in times per week as well as the time spent on the platform. 72 % of carers used the platform once or twice a week. 18 % three to four times a week and 10 % used it more often. 61 % of carers spent maximum 15 minutes on the platform. 30 % used the platform for a maximum of 30 minutes, and 9 % for 45 minutes and more each time.

The *physical activity module* instead is mainly used once or twice a week (62 %) for maximum 20 minutes (43 %). 38 % used the exercises of the PA module for a maximum of ten minutes, 15 % for maximum 15 minutes and 4 % more than 30 minutes. The second highest use of the PA material is three to four times per week (27 %). 11 % used the PA module more than 5 times per week (see figure 4). Half of the participants used the *meal planning tool* once in eight weeks. 23 % used it in one week, 22 % in most of the weeks. 2 % used the meal planning tool in all eight weeks (see figure 5).

44 participants confirmed that they used the platform and materials for eight weeks, while 26 carers did not. 44 carers did not provide an answer (no figure).

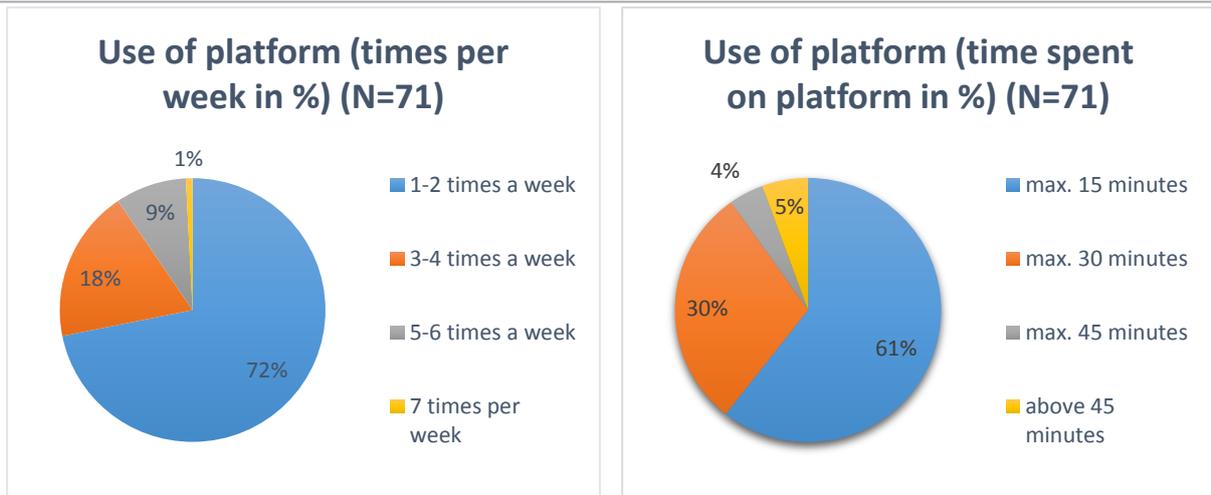


Fig. 3 Use of the platform times per week (left box) and time spent on platform (right box) in percent

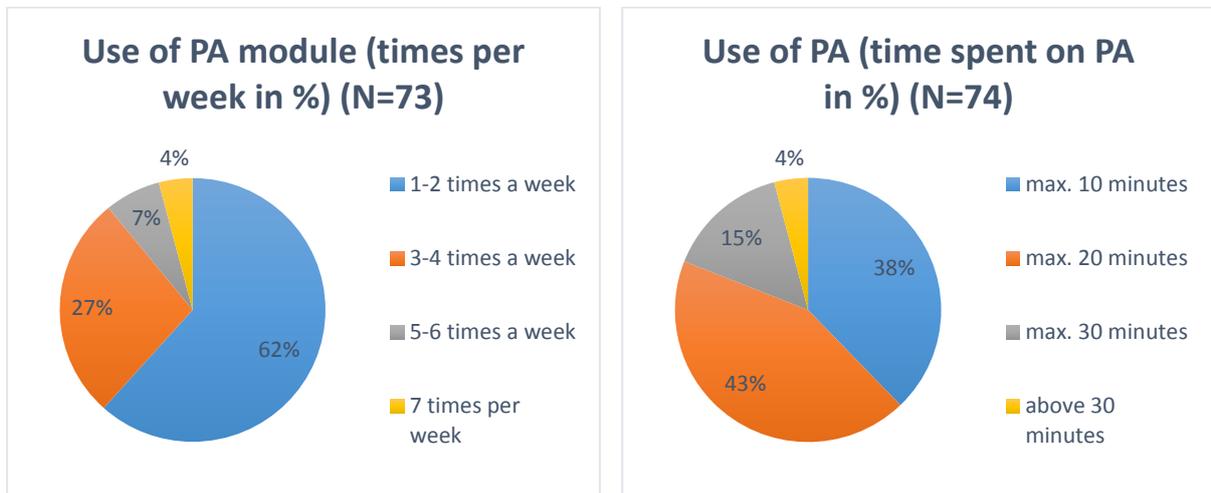


Fig. 4 Use of the physical activity module times per week (left box) and time spent on physical exercises (right box) in percent

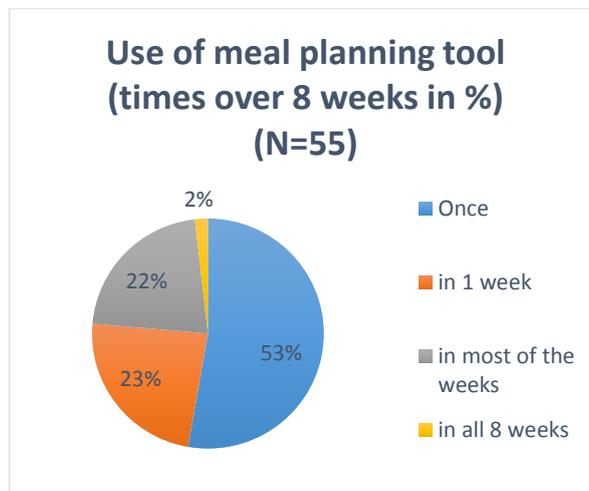


Fig. 5 Use of the meal planning tool times over eight weeks in percent

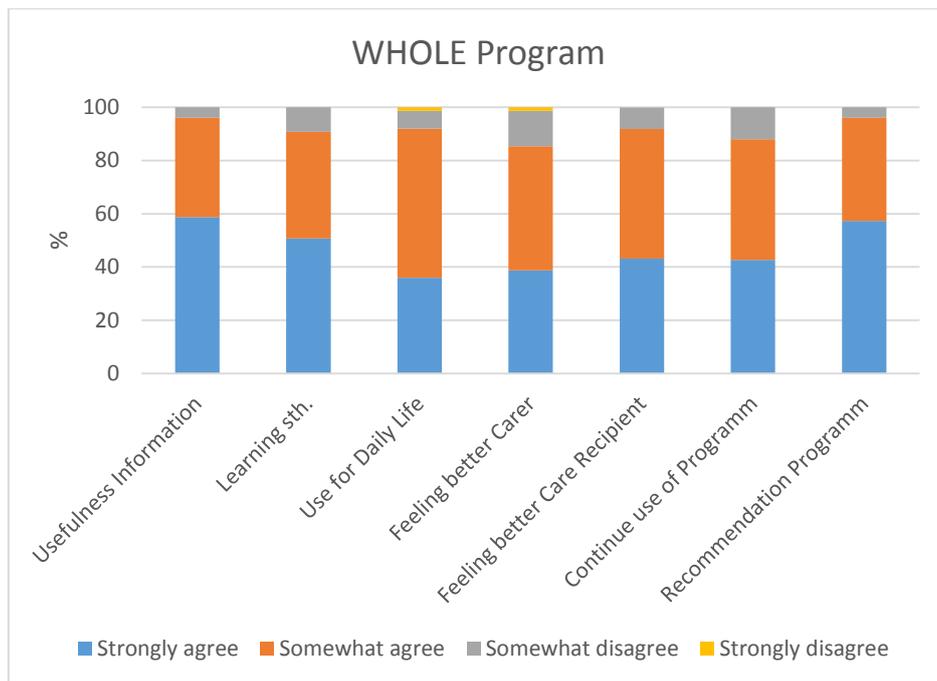
Evaluation of the e-learning platform, the physical activity and nutrition module


Fig. 6 Evaluation WHOLE Program (E-Learning Platform introducing Physical Activity and Nutrition) as valid percent (N=74 [Feeling better Care Recipient] and 75 [all other])

Of those completing the evaluation questionnaire considering the overall concept of the *WHOLE program* (figure 6), most carers (59 %) found the information provided on the e-learning platform useful for the daily work and half of them do strongly agree that they have learnt something about how to introduce PA and healthy NU in daily care (40 % do somewhat agree). Around 56 % do partly and 36 % do fully agree that they can use the PA and NU content in their daily life/work. About 85 % of carers do feel better after using the WHOLE program, while 15 % do not. 92 % of the carers strongly or somewhat agree, that their CR do feel better after the program, while 8 % somewhat disagree. About 88 % want to continue to use the WHOLE program and 96 % would recommend the program to others.

63 % of those carers that completed the evaluation questionnaire are fully, 36 % are partly satisfied with the *e-learning platform*. Around 92 % do strongly (45 %) or somewhat (47 %) agree that the e-learning is tailored to the needs of the target group. About half of the carers evaluated the e-learning platform as easy to use (full agreement), 15 % do not (partly or fully). Most of the users (93 %) are satisfied with the design, layout and writing style of the e-learning platform as well as the usefulness of the guide. The same is valid for the technical functioning of the platform. 9 % however experienced technical problems. (See also figure 7).

Figure 8 shows the results of the evaluation of the *physical activity program*. 65 % are fully, 35 % partly satisfied with the PA program (layout, information, materials). 64 % of carers do fully and 26 % somewhat agree that they could use the exercises for themselves (10 % do at least somewhat disagree). 55 % do think, that they could use the program with their CR, 38 % do somewhat and 7 % do not. 84 % do agree that the PA program is tailored to the needs of the CR (the exercises can be adapted and designed according to the needs of the CR), 16 % disagree. About half of all carers find

the PA materials useful for their daily care giving, 40 % do partly agree and 8 % partly disagree. Almost all carers (96 %) evaluate the PA content as safe (no injuries occurred), while 4 % do not. More than half of the carers somewhat agree that they would continue to use the exercises. Additional 40 % do fully agree. 5 % will not continue to use the PA program. 2/3 of the carers would fully recommend the PA module to others, 30 % would somewhat, while 4 % would not.

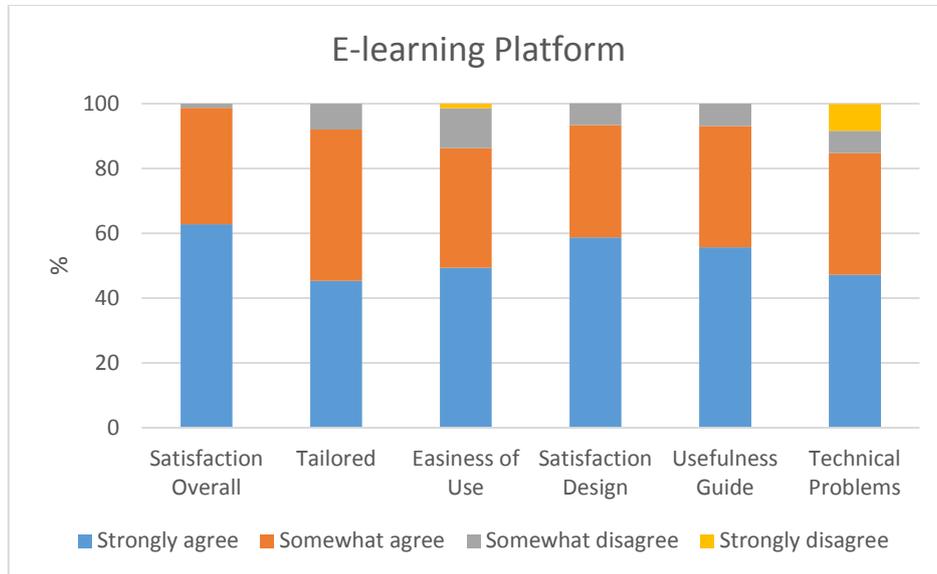


Fig. 7 Evaluation WHOLE Platform as valid percent (N=72 [Usefulness Guide, Technical Problems], 73 [Easiness of Use], 75 [all other])

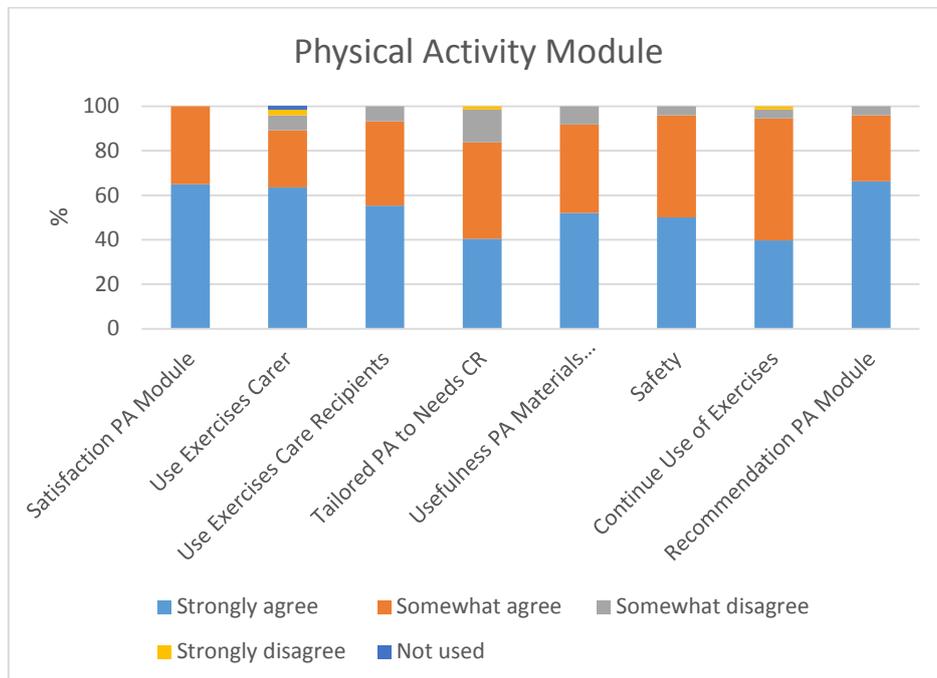


Fig. 8 Evaluation Physical Activity Module as valid percent (N=68 [Use Exercises Carers], 73 [Usefulness PA Materials Caregiving, Continue Use of Exercises], 74 [all others])

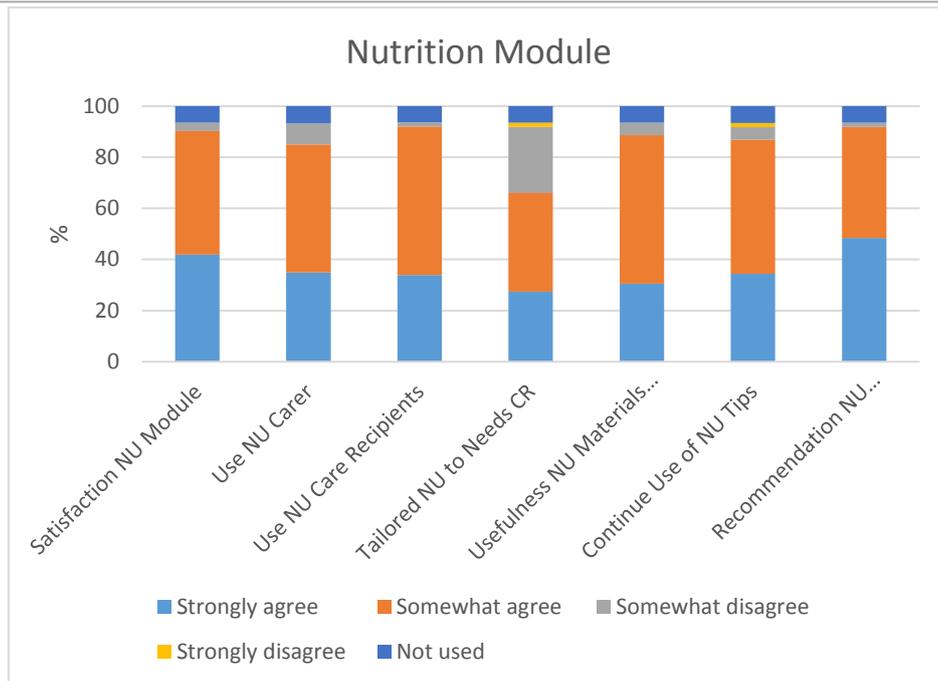


Fig. 9 Evaluation Nutrition Module as valid percent (N=60 [Use NU Carer], 61 [Continue Use of NU Tips], 62 [all others])

Almost half of the carers do somewhat agree that they are satisfied with the *healthy nutrition module* (see figure 9, please consider that 6.5 % of those carers that answered haven't used the NU module). Another 42 % are fully satisfied, 3 % are partly dissatisfied. 35 % of the carers find the NU material useful for themselves, 50 % do somewhat. 8 % do somewhat disagree. 1/3 of the participants find the material useful for the CR, another 60 % do somewhat not. The opinion is diverse on the question whether the meal plans can be adapted (tailored) to needs of CR: 28 % do strongly agree, 39 % do somewhat and 26 % do somewhat disagree. 2 % even strongly disagree. About 60 % find the NU module somewhat useful to implement healthy nutrition in daily care/life, 30 % find it useful, 5 % partly disagree. Around 87 % would continue to use the NU module while 7 % would not. However, all but 2 % would fully or partly recommend the NU program to others.

Suggestions of improvements and changes after the first pilot

The evaluation revealed the following suggestions for improvement that was implemented: the navigation could be clearer. Other feedback could not be implemented yet, but will be considered for the long term such as: including exercises with materials as ladders or sticks or adding a self-generating certificate for the carers.

3.3 Carers

After this insight into the use of the program and the evaluation of the WHOLE concept, the following chapter shows the results of the questionnaires (chapter 3.2.1) and the focus groups (chapter 3.2.2) from the point of view of the carers.

3.3.1 Questionnaires

EQ-5D

The results show no statistically significant change of the health state of carers (EQ-5D VAS) after the eight weeks of the WHOLE program $t(70) = -.675, p = .502$ (see also figure 10).

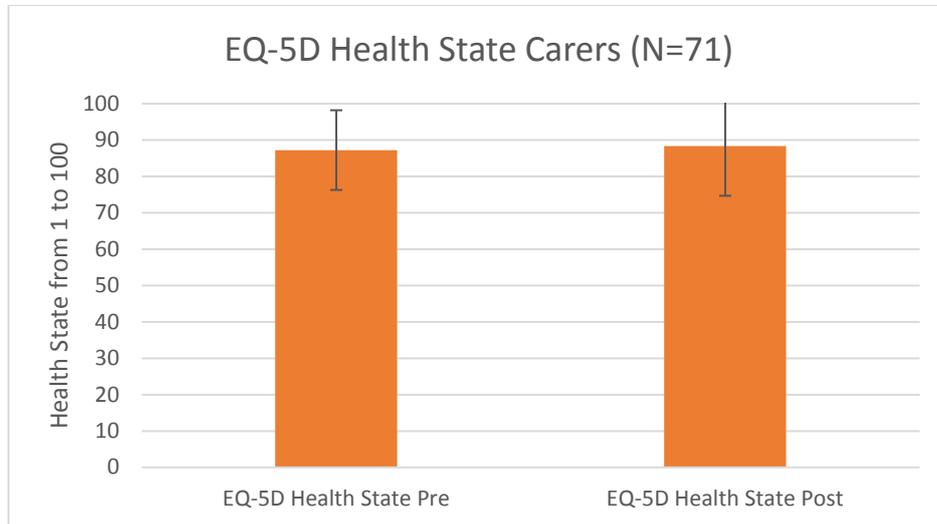


Fig. 10 Health State Carers EQ-5D VAS (left: pre-test, right: post-test)

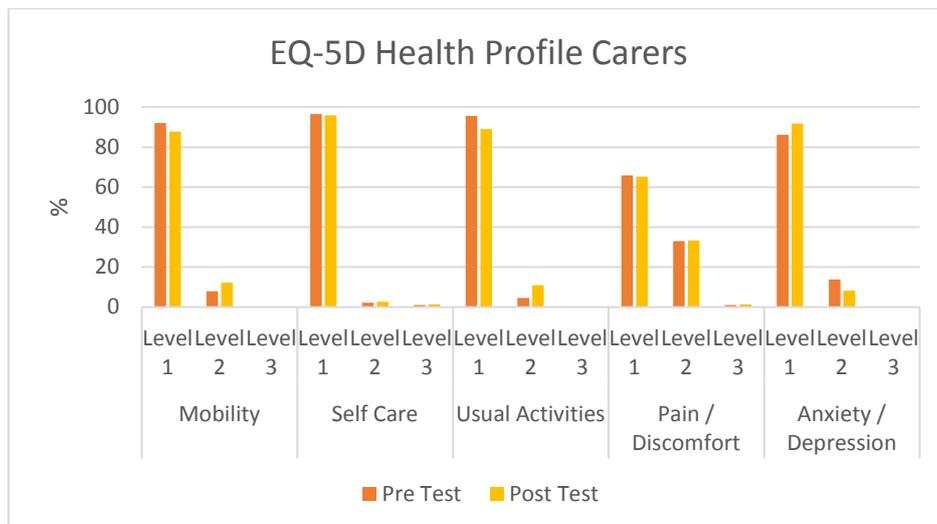


Fig. 11 Health Profile Carers (percent reporting no problem = Level 1, some problems = Level 2, extreme problems = Level 3 for each dimension)

The carers first mainly report having no problems in the dimensions mobility, self-care, usual activities, however, some report having some pain or discomfort and a few additionally report being a bit anxious or depressed. After the pilot study, there is a light increase of those reporting some problems in their mobility with a decrease in those reporting no problems. The same trend can be seen in the dimension usual activities. There is no change in the dimensions self-care or pain/discomfort. In the dimension anxiety/depression however, the trend is vice versa, namely a slight increase of participants that do not experience problems with a decreased number of people reporting some problems at the same time. These changes concern about 5% of participants. The

results are shown in figure 11. The number of carer completing the dimensions of the EQ-5D-3L can be found in table 3.

Tab. 3 Number of Carers completing the EQ-5D-3L dimensions

Dimension	Mobility	Self-Care	Usual Activities	Pain / Discomfort	Anxiety / Depression
N Pre	88	89	88	88	87
N Post	73	73	73	72	73

Burden Scale for Family Caregivers (BSFC) and Burden of Carers

The burden of carers was measured with two different scales. One validated scale developed for family caregivers (BSFC) and a self-developed, simple scale (Burden of Carers). The BSFC does not show a significant change of the burden after eight weeks of participating in the WHOLE program ($t(45) = 1.214, p = .231$). Using the Burden of Carers however, there is a significant decrease of the burden experienced by carers after eight weeks of intervention ($t(39) = 2.077, p = .044$). The results are illustrated in figure 12.

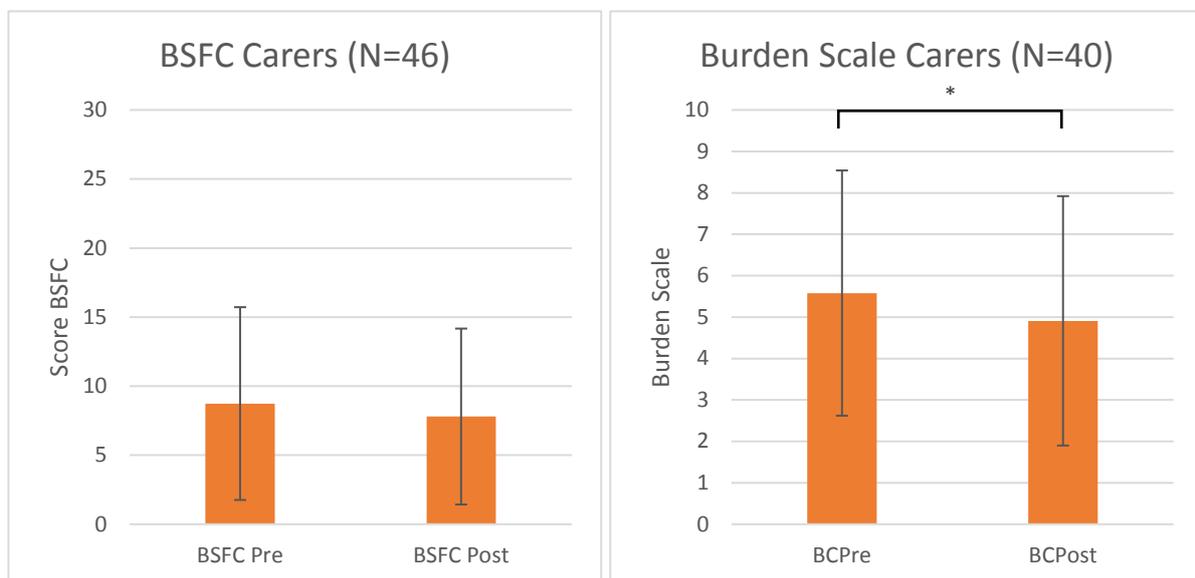


Fig. 12 Burden of Carers measured with the BSFC (left box) and with the Burden of Carers scale (right box) (left bars: pre-test, right bars: post-test)

3.3.2 Focus Groups

20 carers (18 women; 3 formal, 11 informal and 6 paid but non-professional carers) from all countries but Ireland took part in the focus groups or interviews in their respective country in the first pilot. In the second pilot, 29 carers (25 women; 9 formal, 10 paid but non-professional and 10 informal carers) participated. The following paragraph summarizes the results of the focus groups for all countries and both pilot studies. It has to be considered, that the participants partly didn't want to share their experiences but preferred to answer only with 'yes' or 'no' as they were not used to 'interview occasions'.

Experiences with the program

The WHOLE program was used differently by the carers. Some used the platform as intended to prepare the exercises of the PA module, some others that were not used to computers had some relatives to print out the exercises of the PA module and the nutrition factsheets for them. Others could use the platform easily but still preferred the printed sets of materials. Generally spoken, the PA module was used more often than the NU module as most carers were or felt not responsible or didn't had an influence on the meals of the CR (e. g. meals on wheels; meals prepared in commercial kitchens for nursing homes). Others used the nutrition factsheets on occasions when they needed information. The opinions about the program range from 'very important to avoid injuries and falls', to 'physically demanding, which makes it difficult to execute'. Some carers used a small amount of PA exercises only (as only a small amount of exercises were suitable for the CR or because it was easier to implement a fixed set of exercises/too much exercises to select from), while others tried to use the full range of exercises. The amount of exercises led to diverse opinions: some especially liked the variety of exercises, while others think that this complicates the process of tailoring an exercise unit. Another critical point was, that some experienced problems with the tailoring tool as it was too difficult to handle. On the other hand, the opportunity to create those self-customized sets of exercises were praised by others. More internal and external factors (*barriers*) became obvious that hindered or complicated the use of the e-learning platform, the PA as well as the NU module in the point of view of the carers. A systematic overview is provided in table 4.

Next to these barriers, there were also supporting factors mentioned by the carers that facilitated the use and implementation of the WHOLE program. Some of the statements are provided below:

Appropriateness of the WHOLE program:

- Easy reachable information, easy to surf in the platform, appropriate advises for old people's nutrition, good adapted physical exercises for people with healthy problems.
- The physical exercises have a lot of variety and can be adapted for each individual easily.
- In my opinion the program is useful. I never met such special developed and interactive program for healthy nutrition and physical activity for elderly.

Experiences of benefits:

- During the program the beneficiaries showed interest in the variety of exercises. They were not bored. They were euphoric and every week they seemed to have more self-esteem in doing the exercises, they were willing to perform and also showed signs of improvement of the exercise.
- I think everybody can find useful advices concerning healthy nutrition and also some unknown facts. I tried to make small changes in the diet of the person who I am caring about.

Being active together:

- My father is 83 years old but he liked the idea to make them together.
- For me was also good to make exercises together with my patient, we enjoyed the time we spent together.
- Exercising with my relative gives us some time to forget the problems or our disagreements.

Tab. 4 Internal and external barriers to use the WHOLE program

Internal factors	External factors
WHOLE program	
Lack of devotion for the program	No possibility to apply program in daily work.
Lack of time / Too many other tasks	Difficulty to learn the program.
The barrier was to think of it and to integrate it into the daily practise.	
No mood	
e-learning platform	
Lack of computer skills	
No technical possibilities in a/the nursing home.	
PA module	
Hesitation of the carer to do the exercises (not feeling comfortable with delivering exercises to others/CR).	Lack of collaboration of the CR
Lack of knowledge to choose appropriate exercises (tailor exercises to need of CR).	Lack of motivation of the CR
Negative experience with physical activity.	Exercising is not considered as important (usually those not used in exercising even in younger age, or those with mobility restrictions).
Lack of time/capacity	Possibilities of the CR
	Too many exercises to select from.
	Tailoring tool too difficult.
	No tablet to show exercises to the elderly in their home.
NU module	
Missing relation to CR (in assisted living), did not want to dictate NU prescriptions.	Elderly do not see the need and were afraid to make regulation.
	Special diet of the CR made by a physician.
	No influence on the diet of the elderly.

Self-reported benefits

Next to the expected benefits that we queried with the questionnaires, we were also interested in the self-reported benefits. The answers provided below illustrate the benefits experienced by the carers themselves but do also reflect their impression on the benefits for the CR they care for.

Learning something:

Some carers report that they gained new knowledge in healthy nutrition for elderly people, third age physical training and how to apply both in daily life. The carers also received many new ideas and opportunities to create training sessions but also customize care. Additionally, the carers had the chance to train themselves and gain confidence on making simple PA exercises in home and to vary their care giving program. Generally, especially the carers in Bulgaria and Israel were very happy about the possibility to be part of the program and to have the chance to learn something new.

Physical benefits:

- Increased mobility level of the patient through a harmless and entertaining way.
- Despite this short period of time, the flexibility and mobility of CR's increased.

- Helped the care recipients to stay awake and prevent tiredness.
- Feeling physically better and improved possibilities to continue with everyday tasks of carers.
- Improved body posture for the carer.

Psychosocial benefits:

- Motivating for other elderly of the assisted living to become active by themselves.
- It does not change the world, but it is good for the body and mind! The elderly experienced feelings of success and self-confidence as they could touch their back of the head, which they couldn't before anymore. But it is important for them to be able to do their hair.
- More energy and better mood after the physical exercises for carers.
- Relaxation and mean to reduce stress for carers (also in the work as carer).
- Reduced burden of care because physical exercising has unique effect not only in physical but also in mental decompression. Also, it offers an escape of everyday routine, and the opportunity to engage to CR into an activity something that it is not always easy to do.
- Enjoying a fun and relaxed time together.
- Break from the daily routine/reality for CR and carers.
- The exercises done together with my patient were something completely new in our daily life. This brought us good mood and positive feelings.

Relationship:

- The confidence between the patient and the carer become bigger.
- The program improved the connection/bonding between the care recipient and the carer.

Unexpected results of individual carers:

- Sometimes the CR showed less motivation in concluding the sessions. For others it was so fun that they even wanted more times than the scheduled ones.
- It is not usual, that the elderly take part so diligent in an offer in the institution. Even one women with an incipient dementia could remember the schedule.
- Was surprised to find out that the CR was able to do quite a lot of the exercises, and even to remember them. E. g. the CR remembered the aerobic exercises, which felt good to both.
- My patient didn't agreed to do any physical exercises despite my efforts to motivate her and to show all benefits from it. I am very disappointed.

One Greek partner summarizes his impression as follows: 'This program provides me the opportunity to make a break from my care giving tasks, to establish a new way of communication with my patient and to relieve my burden of care giving.'

Meeting the needs of the target group

The carers that took part in the focus groups do agree that the WHOLE program meets the needs of the target (at least partly) and some do also think that it would be beneficial for nursing homes as well. The carers think, that the exercises are well suited for the elderly especially as they can be adapted. Still, many of the elderly people do not seem to give special attention in physical exercising for a variety of reasons. This is also summarized in the statement of the Bulgarian partner:

‘The WHOLE program meets the needs of the target groups. All patients understand how important healthy nutrition and physical activity are but not all of them want to follow advises given in the modules of the online platform because of different reasons – lack of time, lack of mood, following specific doctor advises etc. We don’t have yet real results how the program influents the physical condition of the participants.’

The carers report that the training course together with the information provided on the platform is sufficient to understand the modules and to continue the PA program via the e-learning platform.

Suggestions for improvements

At the end, the carers were asked what they missed or what they would do otherwise. The following statements were provided:

- The tailoring tool for the physical exercises could be more simple/improved by naming the exercises differently or by providing short descriptions or pictures of the exercises in the tool.
- The exercises could be printed on cards to take them to the CR more easily.
- It would have been good if in the platform there was a separate section having dance sessions because elderly love dancing.
- The NU module could have included typical examples of diets for elderly people and could be divided to single elements as there are too many pages.

3.4 Care recipients

The following chapter shows the results of the care recipients for the health questionnaire EQ-5D (chapter 3.3.1), the tests (chapter 3.3.2) as well as the focus groups (chapter 3.3.3).

3.4.1 Questionnaire EQ-5D

The results show a statistically significant increase of the health state of CR (EQ-5D VAS) after the eight weeks of intervention $t(113) = -2,432$, $p = .017$. The results can also be seen in figure 13. The health profile of the participating CR for the five dimensions mobility, self-care, usual activities, pain/discomfort and anxiety/depression are depicted in figure 14. One can see, that the participants mainly report some or no problems in their mobility before the eight weeks of intervention. The amount of people reporting some problems in walking about (mobility) slightly decreases after eight weeks, while a few more elderly report having no problems. Most CR report no problems, but some do also report some or extreme problems in self-care (washing or dressing oneself) in the pre-test. After the intervention, less people report some problems and more report no problems. However, also more people report extreme problems in self-care after the intervention. In the dimension usual activities (e. g. work, study, housework, family or leisure activities) people mostly report to have some problems followed by no and extreme problems at the beginning. After the intervention, less people report having extreme problems while slightly more elderly report having no and some more report having some problems. Most elderly report experiencing moderate pain or discomfort followed by no pain. A few report having extreme pain before the intervention. The amount of CR reporting some or extreme pain or discomfort decreases while the one reporting no pain increases

after the intervention. The same trend is valid for the dimension anxiety or depression. See table 5 for the number of participants completing each dimension of the questionnaire.

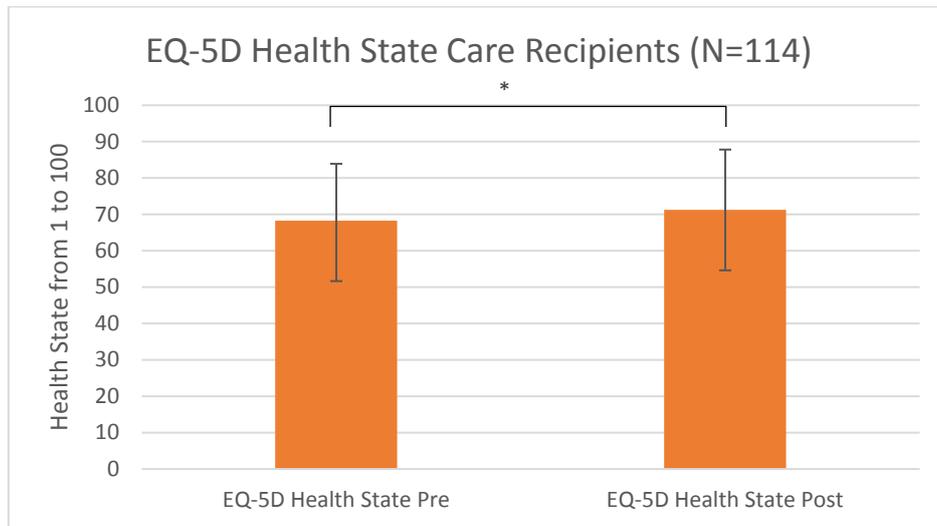


Fig. 13 Health State Care Recipients EQ-5D VAS (left: pre-test, right: post-test)

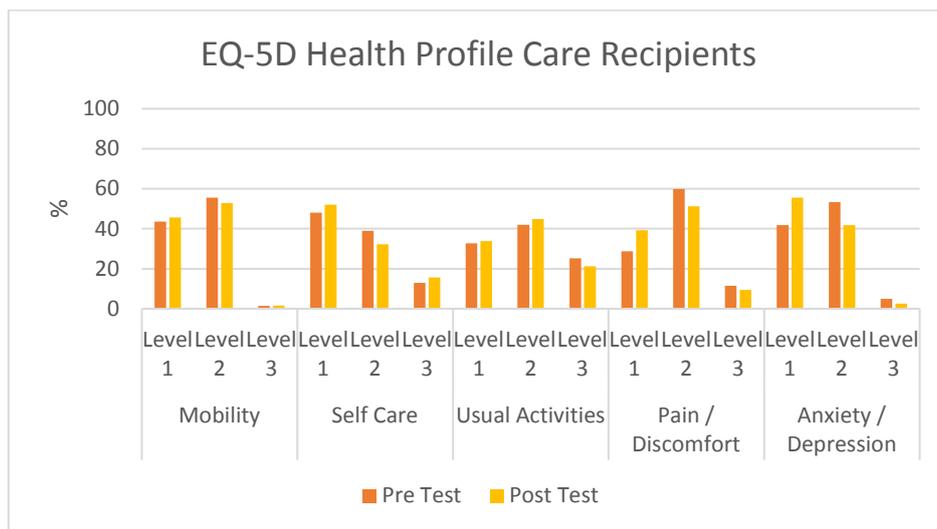


Fig. 14 Health Profile Care Recipients (percent reporting no problem = Level 1, some problems = Level 2, extreme problems = Level 3 for each dimension)

Tab. 5 Number of Care Recipients completing the EQ-5D-3L dimensions

Dimension	Mobility	Self-Care	Usual Activities	Pain / Discomfort	Anxiety / Depression
N Pre	131	131	131	122	122
N Post	127	127	127	117	117

3.4.2 Tests

The following chapter shows the results of all tests that were applied. Please do consider, that also here the number of participants, that were able to apply the tests differ from test to test (see table 6). The numbers depict complete cases that have conducted both the pre- and the post test.

Tab. 6 Number of Care Recipients completing the Tests

Test	MFRT Front	MFRT Right	MFRT Left	FRT	TUG	10MWT	BST Right	BST Left
N	89	88	79	31	64	52	38	39

Functional Reach Test / Modified Functional Reach Test (MFRT / FRT)

After eight weeks of using the WHOLE PA program, there is a significant increase in the performance of the MFRT to the front $t(88) = -4.572$, $p = .000$, to the right side $t(87) = -3.703$, $p = .000$ and to the left side $t(78) = -3.521$, $p = .001$ (see figure 15). There is no significant change in the results of the FRT $t(30) = -1.682$, $p = .0103$ (see figure 16).



Fig. 15 Modified Functional Reach Test Sitting (left bars = front reach, middle bars= right reach, right bars = left reach; each left bar = pre-test, each right bar = post-test)

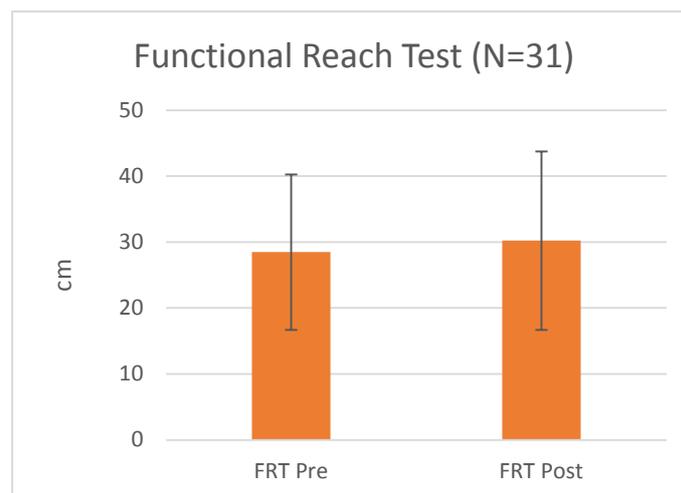


Fig. 16 Functional Reach Test Standing (left: pre-test, right: post-test)

Timed Up and Go (TUG) and 10 Meter Walking Test (10MWT)

There is no significant change in the TUG after the implementation of WHOLE over a period of eight weeks $t(63) = .578$, $p = .566$ (see figure 17 left). The performance of the CR in the 10MWT significantly increases after those eight weeks $t(51) = 2.286$, $p = .026$ (see figure 17 right).

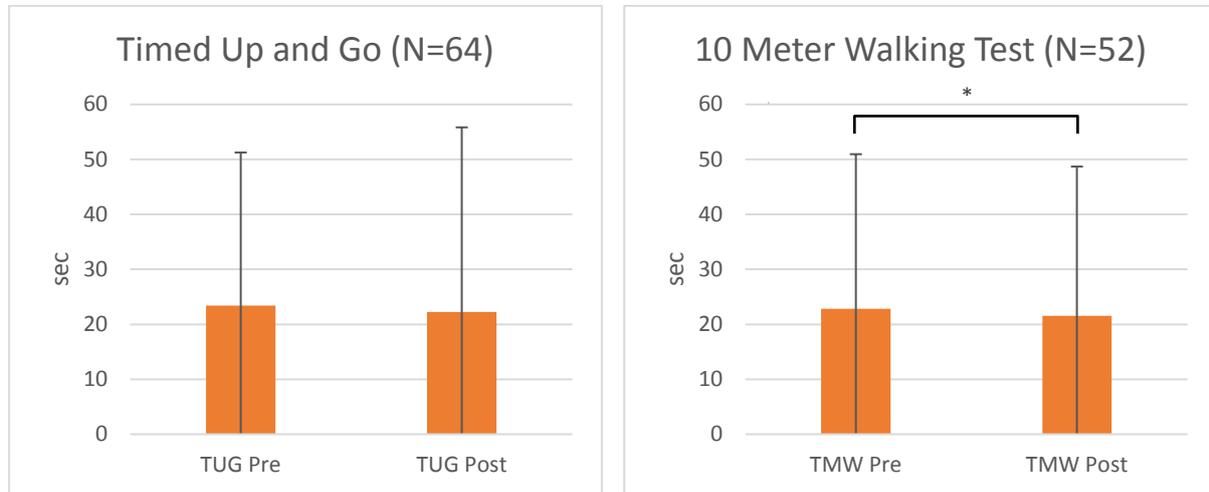


Fig. 17 Timed Up and Go Test (left) and 10 Meter Walking Test (right) (left bars: pre-test, right bars: post-test)

Back Scratch Test (BST)

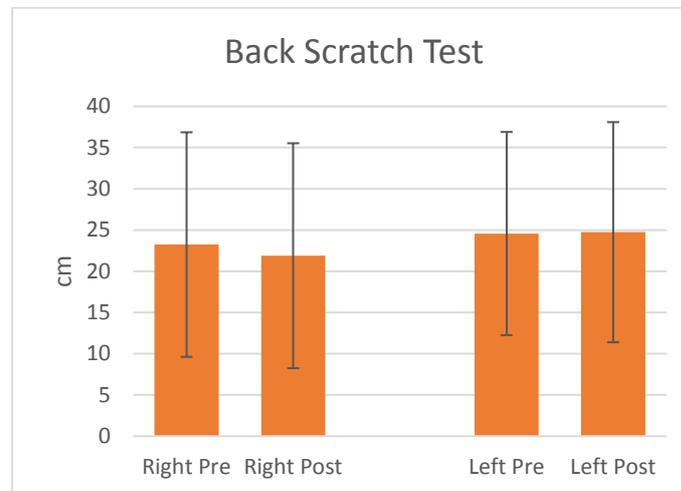


Fig. 18 Back Scratch Test right arm (left) and left arm (right) (left bars: pre-test, right bars: post-test)

There is no significant change in the BST neither on the right $t(37) = .1448$, $p = .156$ nor the left arm $t(38) = -.212$, $p = .833$ (see figure 18). It is interesting to note that there is a small decrease in the distance between the right and the left hand when the right arm is on top, while there is no change when the left arm is on top. As already mentioned, this result is not significant.

3.4.3 Focus Groups

34 CR (7 men) from Bulgaria, Germany and Greece took part in the focus groups or interviews in their respective country in the first pilot. In the second pilot, 29 CR (11 men) from Austria, Bulgaria,

Germany and Greece participated. The following paragraph summarizes the results of the focus groups for all countries and both pilots. Not all CR could participate and not all countries could organize focus groups due to limited communication skills or limited mobility of some elderly.

Experiences with the program

The WHOLE program was used differently by the elderly and CR. Some did the exercises daily, others practiced sometimes depending on their time, mood or condition; maybe once a week, sometimes less. Others did the program each time the carer visited. Some did the exercises by themselves, others did them together with their carers. Some experienced the program as 'extremely innovative' and that the nutrition information is interesting. Also the PA program was experienced well by most participants, but for some, it was more exhausting than expected or not easy to do in case that one is not in form at this day. Even though some had some motivational problems at the beginning of the sessions, they then still enjoyed it. Concerning the NU module, some CR got the information by their carers, others read the factsheets by themselves. Most participants found it interesting to read and some reported that they got reassured about their appropriateness of their diet by reading the information. Others again could not be motivated to implement even small changes to their diet.

Supporting factors for the WHOLE program were having been active in their past ('I missed having workout') and doing the exercises with music. Another supporting factor for one participant was that someone has developed special exercises and healthy nutrition advices especially for people like him/her. What the CR also liked was the fact, that there was a wide variety of exercises that allows the carers to use them for elderly with different diseases. Last but not least, the program was a new element in their daily life that facilitated the use as it was some interesting and new.

Self-reported benefits

Next to the expected benefits that we assessed with the questionnaire and tests, we were also interested in the self-reported benefits by carers.

Learning something:

The CR reported that they learned interesting facts about healthy nutrition of old people and gained more knowledge about a healthy lifestyle. Some participants changed their opinion concerning the need of PA in their daily life. One participant additionally is joining a gymnastic class; she now knows some new exercises that she wants to share with here instructor to include it in the group lesson.

Physical benefits:

- Better physical health that helps in autonomy and preservation of mobility.
- Better physical condition (as reduced muscle tension or muscle development, maintenance of flexibility, improved balance).
- Physical activity important to slow down the Parkinson.
- Relief and relaxation by the physical activity. One can feel it even if one is just doing some exercises to lose the muscles.
- During the program they did not realize a big physical difference but they were very surprised when they saw the results of the functional reach test.

Psychosocial benefits:

- The gradual application of the program helps in improving overall health.

- The participants feel better (mood and physically) and more alive. They are more energetic and are having a nice and fun time while doing something different.
- It helps me being empowered.
- Feeling safer due to improved balance.
- Having more confidence and good energy.
- The care recipients felt motivated to be more physical active.
- I have more appetite than before starting exercising.
- It reminds me of my young years.

Relationship:

- I like to exercise together with someone else. / Having fun with my daughter/together.
- It helps in improving the collaboration and also to decompress tension between the carers and the care recipients.

Unexpected results of individual care recipients:

- That they will enjoy so much the physical activity sessions.
- The care recipients did not expect that so many participants would attend the program on a regular basis throughout the whole pilot.
- The participants did not expect to gain flexibility and mobility in such a short time.

Meeting the needs of the target group

The CR think, that the program can be integrated in care as it is flexible and adaptable for different cases. Third age absolutely needs exercising sessions at home, it gives the opportunity to elderly to be active and not feel confined and without options into the home environment. However, some do also wish to get some corrections that are missing when practicing by themselves with the videos only. Another relevant aspect mentioned is that the CR want to do the exercises in their pace and according to their disposition when feeling the necessity to do so, and not in regular base.

Suggestions for improvements

When asked for aspects that need improvement, it was mentioned that the NU module contains too much text and that the videos should be presented in each language instead of the subtitles used.

4 Discussion and Conclusion

Summary

Over a period of eight weeks, the WHOLE concept was tested in two consecutive pilot studies between September 2017 and August 2018. As explained above, the concept was, that formal and informal carers will be trained in the appropriate use and implementation of the e-learning platform and its contents in PA and NU, then use the e-learning platform to gain further knowledge and skills to be able to prepare exercises sessions from the PA module to implement them on three days a week for at least 20 minutes with CR in their homes. The healthy nutrition counselling should be used according to ones needs or according to ones reason of care respectively. 114 carers and 138 CR from Austria, Bulgaria, Germany, Greece, Ireland and Israel took part. The aim of the study was

- to pilot run and validate WHOLE training courses (feasibility, acceptance, adherence) and the e-learning platform (usability and satisfaction)
- to verify the validity of pilot scenarios
- to assess the overall impact of WHOLE (efficacy, learning)
- to pilot test the accessibility and impact of the e-learning platform

to answer the following questions:

1. Is it possible to implement an e-learning platform offering material to implement PA and NU as part of daily care as planned and developed in the project? (Feasibility, reach and verification of pilot scenarios)
2. How many participants finish the WHOLE program? (Adherence)
3. Are the PA and NU program as well as the e-learning platform feasible? (Feasibility)
4. Are the PA and NU program as well as the e-learning platform accepted by carers and care recipients? (Acceptance)
5. Is the e-learning platform usable? (Usability)
6. What benefits does the program have concerning the health and wellbeing as well as knowledge and skills of carers and care recipients? (Impact)

Discussion

Concerning the *feasibility* of the *WHOLE concept* [question 1.], the results presented above indicates that the concept is feasible, but with limitations. The concept was roughly sketched above and is described more detailed in chapter 2. The actual implementation showed diverse variations, for example in implementing weekly but one-hour sessions instead of several short units, offering group offers instead of one-to-one exercising or in using the e-learning platform for carers only to be prepared for the daily care afterwards. This let suggest, that the concept itself is working but that the actual implementation has to be more open to allow individual adaptations. Therefore, also the *validity of pilot scenarios* is limited due to the adaptations reported above. This assessment is supported by the following considerations. First, the reach of the target group [1.], and second, adherence to the program [4.]. For the first aspect (*reach*), the objective to reach 70 carers and 210 CR was only partly met as we could namely reach more carers (114 carers) but less CR (138 CR). The reason for this is connected with the aspect to reach formal and informal carers in the home-care sector. It was envisaged that one formal carer in the outpatient care sector can implement the

program for three CR each. Instead, we had quite a lot care tandems in the informal home-care sector but also some group offers in the nursing-home setting that were implemented with one carer and several elderly at the same time. The reason for this was that - after several unsuccessful attempts to reach formal and informal carers at home - the target group was expanded to other forms of living arrangements such as nursing homes, assisted living facilities or day care centres in some organizations. Overall, all partners experienced some difficulties in the recruitment process, some more than others. Issues raised for a refusal of participation were for example time and budget constraints for outpatient care service provider and safety concerns or overload for informal carers. On the other hand, we improved the possibilities of a bigger reach of WHOLE, as those facilities now might act as multipliers and disseminate the concept to family members visiting their relatives in the facilities. The second aspect (*adherence* [2.]) is difficult to answer, as not all dropouts were reported and gaining information was quite difficult, as mentioned earlier. This can also be seen in the varying participant numbers for several data. For example, of 114 carers, solely 70 carers answered the question, whether the WHOLE program was used for the full eight weeks. According to this question, 62.9 % did finish the eight weeks, while 37.1 % did not. They used it only for five to seven weeks. Reasons given were, that it took too much time to select the exercises from the platform, or that there was no computer available (or the skills to use the computer were limited). Others mentioned, that the CR was too tired after six weeks or that the professional carer could no longer visit a certain CR. Finally, no reliable statement can be given, as others also completed the final assessments but one does not know whether they participated for the eight weeks or not.

Concerning the *acceptance and feasibility* of the *e-learning platform* [3. & 4.] one can summarize that the carers accept the platform as most of the carers used the platform regularly, others however used it only once to get all necessary information for them/the CR. So also here, the feasibility is given with limitations. Nevertheless, the carers found the information provided on the platform useful and that the platform can be used in (transferred to) daily life. Most carers additionally agreed that the e-learning platform is tailored to the needs of the target group, which leads to the conclusion that the *usefulness* for carers is given. This result is supported by the feedback provided in the focus groups, both from carers and CR. It is also valid here, that individual arrangements have to be found to fully satisfy the carers and CR's needs, for example concerning the regularity of implementation. Additionally, the carers rate the *usability* (user-friendliness and functioning [5.]) of the *e-learning platform* as suitable. The design and structure of the platform is rated as appropriate for older adults. Some suggestions for revisions were provided after the first pilot that were implemented partly, but overall, the carers were satisfied with the e-learning platform and evaluated the platform as easy to use. Also the guide was useful in their opinion. Some carers reported some technical problems but most users confirmed that the platform is working well. Overall, we concluded that the e-learning platform is usable for carers. On the other hand, some did also report problems in using the platform in the focus groups as they weren't used to work with computers. Not all carers completed the evaluation questionnaire, so it might be possible that those carers reporting problems haven't completed the questionnaire.

Also the *feasibility* of the *PA module* [3. & 4.] was evaluated. Topics assessed were the *acceptance* of the program, the feasibility of and the satisfaction with the content. The PA module is accepted by the carers, which is shown in the fact, that more than 60 % would definitively recommend the module to others. Only 40 % do want to implement the exercises further, which speaks against an

acceptance. However, 54 % will probably use it further. Another factor contributing to the acceptance of the PA module is the use of PA content at least three times a week for eight weeks. If considering this item, one might assume that the PA module is not accepted as well as most carers only used the PA module once or twice a week but on the other hand, others used the program daily or for a longer time than the recommended 20 minutes. So, overall the PA program might be rated as accepted but again, individual preferences and preconditions have to be considered and different modes of use have to be accepted instead of prescribing a fixed schedule for the carers and CR. The carers rate the PA program as feasible regarding the possibilities to use the exercises for their CR and assess the exercises as safe to implement. The tailoring of exercises is again evaluated as feasible by most carers, however, about 20 % experience the tailoring process as difficult. More information should be provided and special attention should be given in future trainings to the possibilities to tailor the content according to the needs of the CR. All carers are satisfied with the materials, but suggestions for improvements were given (e. g. spoken language in videos should be adapted to the mother tongue).

Many carers reported that the *NU module* was not *feasible or rather not applicable* for their institution [3. & 4.]. More than half of all participants did not even complete the evaluation questionnaire for this part. Therefore the validity about the feasibility of the NU module is limited. Those carers completing the evaluation questionnaire *accept* the NU module as they used it at least once over eight weeks but will not necessarily use it after the pilot studies. About half of the carers would recommend the NU module to others though. Adaptations might be necessary to improve the acceptance of the NU module. This is that there should be less text and more meal suggestions. On the other hand, most carers are satisfied with the material and information provided. Maybe another way to improve the acceptance by carers would be to increase the awareness of the importance of the topic that they do feel more responsible to at least forward the information to the CR if they do not prepare their meals. The carers rate the feasibility of the NU module as partly feasible as they received useful information for their CR that is also helpful in their work as carer, but some had problems to adequately use it for their CR (tailoring).

The results detected some positive *benefits*, both for carers and CR in the objective and subjective point of view of the target group [6.]. We expected that the program will

- Improve the health and wellbeing of care recipients and carers.
- Promote a healthy and active lifestyle for care recipients and carers.
- Improve the relationship between care recipients and carers.
- Contribute to an increased knowledge and skills of carers concerning healthy nutrition and physical activity in old age.
- Support the autonomy of care recipients.

Both, carers and CR reported improvements for their physical and psychosocial health such as ‘better physical health that helps in autonomy and preservation of mobility’ for CR or ‘break from the daily routine/reality’ for CR and carer, and also the relationship between the carers and CR was positively influenced (improved confidence or connection, as well as reduced tension between carers and CR). These benefits were perceived in the subjective view of the participants, but are partly supported (for CR) by significant results of our objective measures, namely the health state as well as the

functional mobility measured with the Modified Functional Reach Test. The burden of care of carers, measured with a self-developed scale, was also significantly reduced, while there was no effect using a validated scale. This result therefore has to be considered carefully. What one has to keep in mind, especially considering the CR, is that also the maintenance of a health state is also a success as the functional mobility and health might decrease within days without any activity. Another aspect that needs consideration and which is supported by the results, is that the healthy nutrition and physical exercises do not only support the physical health but also psychosocial factors as well as the relationship between the care-tandem. For some carers, it was important to have the possibility to have a break from the daily routine and spent some quality time and fun together. Last but not least, it was also envisaged that the carers would increase their knowledge and skills by using the e-learning platform. 90 % of carers agreed that they learnt something and specified in the focus groups that they gained new knowledge in healthy nutrition for elderly people, third age physical training and how to apply both in daily life. The impacts on the long term have to be awaited.

Limitations

As already mentioned, the results of this report has to be considered carefully. The implementation took place in the 'real-world' and one aim was to assess the appropriateness of the WHOLE program and its feasibility for daily life. It became obvious that not all pilot sites and carers could follow the recommended use of the e-learning platform and modules. Also the targeted sector varied and finally, also the care systems in the participating countries differ. Last but not least, the training differed between countries so that a comparison of results would not be allowed, if a strict research protocol would have been followed. Some care tandems for example did exercises daily, others once a week; this itself leads to different effects on CR and carer. As this wasn't our intention and considering these limitations though, one can get a good impression of the feasibility of our concept. Another point that has to be kept in mind is the fact that the participant numbers partly vary from item to item in some questionnaires and that the number of participants overall is small. The generalization therefore is very restricted.

Conclusion and practical considerations

Overall, the WHOLE program got positive feedback from carers and care recipients. However, the implementation in daily life is difficult most of the times and only few participants could follow the recommended use of the program. Different concepts were tested and one can conclude that each carer or each care tandem has to find a way to implement the physical exercises and nutrition advices in their lives. Still, recommendations should be given about an appropriate implementation of physical activity but the realisation should be open for the care-tandem. For the recruitment, word-of-mouth recommendation in personal networks might work best to reach the target group in the home-care setting, but it is also worth to think about the implementation in groups such as support groups as it is shown, that also the group setting is working. As a conclusion, one can read the following statement of a carer:

'It [the WHOLE program] does not change the world, but it is good for the body and mind! The elderly experienced feelings of success and self-confidence as they could touch their back of the head, which they couldn't before anymore. But it is important for them to be able to do their hair.'

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