

Training in non-pharmacological approaches to dementia and Alzheimer

Elena Luppi
University of Bologna

Abstract

The increase in the elderly population is leading care services to reconsider their models of intervention and their practices. When taking care of older adults suffering from Alzheimer's or dementia, it is fundamental to take into account not only their medical needs, but also any psycho-social dimension that has an impact on their lives and well-being (Kitwood 1997). This contribution presents the first results of an Erasmus+ EU project based on these assumptions. The project, called "SALTO – Social Action for Life Quality Training and Tools" starts by considering that the training of social workers needs to be improved in order to equip professionals with a wider range of approaches and methods to cope with Alzheimer's and dementia. When dealing with such diseases, it is important to improve people's quality of life, at the same time minimising the effects of behaviour-related disorders. Long-term care is the responsibility of both medical and social organisations. Elderly care is "medical" because their beneficiaries require care, whether routine or occasional, which is essential for their daily comfort; but they are also "social" because they target protection, independence, social cohesion, active citizenship and the prevention of isolation (Brune 1995, 2011; Calkins 2002; Rahman & Schnelle 2008; Shura, Siders, Dannefer 2010).

Keywords: Dementia, Life Quality, Non-pharmacological approaches, Education, Training

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

Abstract

L'aumento della popolazione anziana sta portando i servizi di assistenza a riconsiderare i interventi e le proprie pratiche e i relativi modelli di intervento. Quando ci si prende cura degli anziani malati di Alzheimer o demenza, è fondamentale tener conto non solo delle esigenze mediche, ma anche dell'impatto che la dimensione psico-sociale può avere sulla loro vita e sul loro benessere (Kitwood 1997). Questo contributo presenta i primi risultati di un progetto Europeo Erasmus+ basato su tali assunti. Il progetto, denominato "SALTO - Azione sociale per la formazione e gli strumenti di qualità della vita", scaturisce dalla convinzione che la formazione degli operatori dei servizi per anziani debba essere migliorata per fornire a questi professionisti una gamma più ampia di approcci e metodi per far fronte all'Alzheimer e alla demenza. Ciò che è importante, nel trattare tali malattie, è migliorare la qualità della vita delle persone, riducendo al minimo gli effetti dei disturbi legati al comportamento. La cura degli anziani non autosufficienti è in carico a organizzazioni che sono sia mediche che sociali. L'assistenza agli anziani è "medica" perché i loro beneficiari richiedono cure, sia di routine che occasionali, essenziali per il benessere quotidiano; ma sono anche "sociali" perché lavorano per offrire protezione, indipendenza, coesione sociale, cittadinanza attiva e prevenzione dell'isolamento (Brune 1995, 2011; Calkins 2002; Rahman & Schnelle 2008; Shura, Siders, Dannefer 2010).

Parole chiave: Demenza, Qualità della vita, Approcci non farmacologici, Educazione, Formazione.

Elena Luppi - *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

Introduction

The European Erasmus+ SALTO project aims to combine “life projects” with “care projects” in long term care; this means breaking down the compartmentalisation of health-care and medico-social environments, in order to start thinking and working in a more integrated perspective. The project aims to promote innovate training of social workers to improve their competences related to non-pharmacological approaches: any method and technique that can enhance the quality of life of elderly patients in a psychosocial and environmental perspective (Feil 1993, 2006; Johnes 1996).

The project objective aims at the full integration of non-pharmacological approaches in daily medical therapy in the training of formal carers. The SALTO project aims to integrate social-educational methods as part of the daily therapy, in order to develop or maintain cognition, body motion and social skills, which are all fundamental for the quality of life of elderly persons suffering from dementia. To provide a coherent and operational response to this issue, the project brings together professionals and organisations, pooling their resources to match and combine the perspectives of researchers and professionals, trainers/educators and social development specialists, healthcare and socio-medical professionals.

This document presents the first delivery of a social animation training programme that can be offered in universities and vocational training centres, as well as in-service training courses for practicing professionals.

1. Theoretical framework

The training model refers to some empirically validated paradigms that focus on theoretical bases and values. These models overcome adult-centric stereotypes of the elderly to focus on the person him/herself, his/her needs and the promotion of quality of life in the third age. Elderly care, particularly that provided in institutionalised care contexts, is historically

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

characterised by a prevailing medical-health approach, often with low consideration of psycho-social needs. Today many people express the need to reintegrate the various aspects of formal and informal care, in order to respond to both medical-health and psycho-social and human needs.

Quality of Life is defined by the World Health Organisation (1993) as an individual's perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. This definition reflects the idea that quality of life refers to a subjective evaluation, embedded in a cultural, social and environmental context. As such, quality of life cannot be simply equated in terms of "health status", "life style", "life satisfaction", "mental state", or "well-being". It is rather a multidimensional concept, incorporating the individual's perception of any aspect of life.

According to Monique Formarier (2012), the areas influencing a person's quality of life include their state of health, the severity of their disability, psychological and spiritual aspects, their family and friends and socio-economic level. Quality of life varies according to each person's appreciation of his or her own norms and values; it changes over time, at different ages of life.

1.1 Innovative organisational models for Elderly care

Particular inspiration came from the models of the *Culture Change Movement* (Brune 1995, 2011, Rahnam & Schnelle 2008, Calkins 2002, Thomas 2006, Shura, Siders, Dannefer 2010) and the principles of quality of care described by Coons and Mace (1996). All these authors underline the need to see elderly well-being from a holistic perspective, consequently designing care services that respond to individual needs, in physical, psychological, social, intellectual, emotional and spiritual spheres.

The *Culture Change Movement* was born in the United States, with the transition of elderly care facilities from a med-

ical and managerial model to a social-humanistic model, and spread throughout the world, bearing witness to a real change in the elderly care culture. Adopting a range of approaches, this model is in contrast to the management models of residential facilities established in the Sixties (LTC: *Long-Term Care Management Models*) based on organisational optimisation, using a bureaucratic managerial system focusing on efficiency, service standardisation and cost optimisation, adapting services for the elderly in a manner very similar to those of hospitals. According to these models, the facilities were designed as places shut off from the outside world, governed by strict routines, marked by spaces and times in which the role of the staff focused far more on control than on support (Calkins 2002).

The ultimate objective is to achieve the best possible quality of life, for both guests and members of staff. To do so, the importance of in-service training for staff and coordinators is emphasised, in a perspective of what is defined as *wise leadership* (Thomas 2006, Brune 1995), a care culture focusing on people and an individualised approach to organisational and project choices. This individualisation does not only concern the guests, but also considers the importance of the care relationship between guests and workers, including the latter in the needs analysis and the consequent design of interventions.

Recognising and safeguarding freedom, autonomy and dignity, these person-focused approaches privilege all possible strategies to reduce medicalisation or measures of containment of the disorders the guests suffer from. At the same time, the organisational style promoted revolves around dialogue among the staff, to reduce distances, vertical relations and excessive bureaucracy, to foster the most direct dialogue possible between the staff and the elderly and their loved ones.

It clearly moves away from the adult-centric perspective in which the needs of the elderly are established independently of the actual conditions and wishes of the elderly themselves.

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

1.2 Innovative models and concepts in Elderly care

The training programme developed by the EU SALTO project aims to accompany care professionals and care organisations towards the transition indicated by the *Culture Change Movement*. For such purposes, the training contents and methods are based on a few key concepts and models in the innovation of elderly care: the “*Gentle care*” model, (Jones 1996), “*Person centred care*”, “*Validation*” and the “*Bientraitance*” model. All these models focus on a change of perspective towards ageing and frailness and on the importance of the humanisation of care.

1.2.1 The “gentle care” model

The Gentle Care model, created by Moyra Jones (1996), is an approach for seniors and caregivers that promotes well-being for the former and reduces the risk of burnout for the latter. This approach is centred on elderly people and the preservation of the continuity of their life. As a starting point, the model analyses the person, not only in terms of clinical issues, but also regarding their biography, personal characteristics and their relationship with the environment (Guaita A, Jones M., 2000). This broad-spectrum analysis is completed by assessing the impact of the disease on the person, both physically and psychologically, in their daily life and in terms of related coping strategies. This evaluation is carried out using the quantitative tools typical of multidimensional and qualitative evaluation, where the (formal or informal) caregiver acts as an active observer and the elderly person is the subject of evaluation and self-evaluation. This assessment includes the recognition of the elderly person’s residual capacities, daily actions and routines, caregiver actions and responsibilities, and relative peaks or risks of stress. This complex, in-depth evaluation process leads to the design of a care project, based

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

on realistic goals, following the analysis of the patient's strengths and weaknesses (Carbone G., Tonali A., 2007). In designing care, the model focuses on the physical environment, i.e. the place and space (or spaces) of care (Guaita, Jones 2000), which should be characterised by security, easy access and mobility, functionality, flexibility and possibility of change.

The caregiver also plays an important role in the care project, both by sharing it and communicating with the care providers, who must be aware of the relational dynamics within the elderly person's family and their family's resources (from day-to-day organisation and management to strategies for coping with critical situations (Vitali, 2004).

1.2.2 Person centred care

The Person centred care model (Hafskjold, L., Sundler, A. J., Holmström, I. K., Sundling, V., Van Dulmen, S., & Eide, H. 2015; Lloyd, B., & Stirling, C. 2015; Ross, Tod, & Clarke, 2015) distances itself from the idea that the attention provided in most elderly care services is closely linked to people's deficits and pathologies, which makes it difficult to see the person as a singular, valuable individual. In this sense, care is conceived from a very "paternalistic" perspective, where the professional and the institution decide for the good of the elderly person (to improve their health, keep them safe ...) ignoring what each person feels and thinks and far from considering that the most important issue is to ensure that people enjoy life and are happy in old age.

Person-Centred Care (PCC) is a personalised way to support people, developing their own life project with their effective participation, taking into account not only their needs but also their preferences and desires. It is based on the recognition of the dignity of each person and their right to be in charge of their own lives.

When a person needs support, health and personal care are essential, but the things that the person likes, their habits

and personal relationships are equally important. A central point of this model is the recognition and support given to the person to focus on what is really important for them at the present time of their life. Everyone, consciously or unconsciously, has their own life project. Elderly people also have their own life project. In the PCC model, professionals and organisations become the support the elderly need to develop their life projects in a positive way (Rokstad, Vatne, Engedal, & Selbæk 2015).

1.2.3 Validation

This method, developed by Naomi Feil between 1963 and 1980, promotes mental development in elderly people with problems, classifying their behaviour and helping them to recover personal dignity. The Validation method is founded on the life stages theory of Erik Erikson (Erikson 1986) and emphasises the close dependence between biological, mental and social aspects of life. Erikson stated that we can only succeed in completing a given task assigned to us in a given phase of our life if we have positively completed the tasks in the early years of our existence. Every moment of our life sets us tasks to achieve; if we are not able to achieve our objective, it will be set for us again. It is often very hard to achieve a task the first time round, and moreover, it is possible that we will never really be able to achieve one or more tasks. In this perspective, the third age represents the period in which emotions that were not resolved in the past need to be released. (Day 1997).

A fundamental task of the Validation method operator is therefore to listen, even though, given the late stage in life, it is not always possible to achieve resolution.

The fundamental points of the Validation technique include:

- 1) Gathering information on the elderly person. In particular it is fundamental to know: their stage of disorientation; their unresolved tasks and emotions; their past human

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

relations and affections; their profession, hobbies; religious attitudes and beliefs; the way in which they tackle difficulties and losses; their history. This information can be gathered by asking the elderly person questions, at different times of the day, and for at least two weeks. The questions were drafted by Feil, and have to be fairly precise in order to guide the operator.

2) Assess the stage of disorientation. These stages may be:

- First stage: difficulty in orientation.
- Second stage: confusion with time.
- Third stage: repetitive movements.
- Fourth stage: vegetative life.

3) Meeting the person regularly and using the Validation techniques.

The length of each meeting depends on the person's stage of disorientation: from a minimum of one to a maximum of fifteen minutes (less time is spent with those with greater problems). In any case, it is not so much the quantity but rather the quality of time that is important. The ideal frequency also depends on the specific situation: from several times a day to a few times a week, or even less frequently. It is important to recognise the elderly person's feeling of less discomfort that indicates the length of the meeting (also in this case, Feil gives very precise indications). (Feil 2013).

1.2.4 Bientraitance

According to the High Authority for Healthcare, "well treatment" is a comprehensive approach to the care of patients, users and their families, aimed at promoting respect for the rights and freedoms of patients, users, their listening skills and their needs, while at the same time preventing abuse.

This global approach emphasises the role and interactions between different actors such as the professional, institutions the patient and their relatives. It requires both individual and collective questioning on the part of the actors.

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

According to the ANESM (Agence Nationale de l'Evaluation et de la qualité des établissements et Services sociaux et Médico-sociaux) Good Practice recommendations:

- Well treatment is a shared culture of respect for the individual and his or her history, dignity and uniqueness. For the professional, it is a way of being, saying and acting, caring for others, which is responsive to their needs and demands and respectful of their choices and refusals.
- Well treatment incorporates the desire to maintain a stable institutional framework, with clear rules that are known and secure for all, and an uncompromising refusal to accept any form of violence.
- The user's expression is valued. Well treatment is an approach that responds to the user's rights and choices.
- The process of well treatment is a permanent return trip between thinking and acting. It requires both collective reflection on the practices of professionals and the rigorous implementation of the measures recommended by collective reflection to improve them. From this point of view, it leads to the adoption of a permanent questioning culture.
- The search for well treatment is a continuous process of adaptation to a given situation. Essentially, it is never-ending: it implies the permanent reflection and collaboration between all the professionals involved in care.

2. The training programme and its implementation

| |
|---|
| MODULE 1 - CHANGING PARADIGMS ON THE BENEFICIARIES |
| Target |
| <i>Initial and in-service training</i> |
| Trainers |
| <i>Experts in geriatrics, neuropsychiatry, psychology.</i> |
| Learning contexts |
| <i>Vocational training, University - Adult education - In-service training.</i> |

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

| |
|---|
| <p>Purposes and goals</p> <ul style="list-style-type: none"> - Knowledge of the profiles of the beneficiaries; - Knowledge of the rights of beneficiaries; - Changing representations, paradigms and stereotypes to acquire a watchful and empathetic posture. |
| <p>Contents</p> <ul style="list-style-type: none"> - Ageing and/or disability: pathologies, cognitive disorders, physiological-psychological-social points of view, etc. - Impact on quality of life; - Legislation on the rights of frail and dependent persons; - Elderly or disabled people in other cultures - Anthropology; - History of ageing and people with disabilities (by territory); - Evolution of generational profiles in our territories. |
| <p>Methods and description of the activity Tools, no. of persons, spaces, etc.</p> <p>Brainstorming on ageing/disability (oral or written) Lessons with multi-media support Case studies in small or large groups Discussions in small or large groups Choice of inductive or deductive sequence: Either we can start from the analysis of cases or problems to arrive at the theory or we can present the theoretical elements and then cases and problems. Tools: computer, video projector, slides, internet, case to analyse, paperboard. Space: room with mobile chairs. no. of participants: max. 25 recommended duration: 4-16 hours</p> |
| <p>Methodological guidance for evaluation (diagnostic, formative and final evaluation tools)</p> <p>Diagnostic evaluation: Brain storming Formative evaluation: Observation of group activities. Discussion Final evaluation (of learning): Questionnaire/test on theoretical elements.</p> |

Elena Luppi – Training in non-pharmacological approaches to dementia and Alzheimer. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

Case study for the application of theory.

Starting from these premises, a training programme for professionals taking care of fragile elderly people was designed. The programme includes eight modules that can be applied all together in sequence or can be selected to build different training paths, according to the targeted learning needs. The programme can be addressed to students of care-related disciplines (in universities or vocational training programmes) or care professionals in service. Each module has different purposes, contents, methods and tools, a suggested minimum and a maximum length, different kinds of trainers and is conceived to be as adaptable as possible to the given training situation. A summary of the main characteristics of each module is provided below, each with a short description of:

- the target to which the module can be addressed.
- the trainers
- the learning context
- the purposes and goals
- the methods and description of activities
- the tools - no. of persons - spaces - time, etc.
- methodological suggestions for assessment (diagnostic, formative and summative)

MODULE 2 - NON-PHARMACOLOGICAL THERAPIES: A LEVERAGE FOR QUALITY OF LIFE

Target

Initial and in-service training

Trainers

Experts in education and social interventions, experts in innovative methodologies for AD (pet therapy, music therapy, theatre, etc.)

Learning context

Vocational Training Education, University, Adult training, Life-long education

Purposes and goals

PURPOSES

Learning approaches and methods of non-pharmacological ther-

Elena Luppi - *Training in non-pharmacological approaches to dementia and Alzheimer.* DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

| |
|--|
| <p><i>apies in order to apply them in a care context.</i></p> <p>GOALS</p> <ul style="list-style-type: none"> - <i>Organisation of spaces and atmospheres/settings/resources for well-being</i> - <i>Adoption of a relational, emphatic style of communication</i> - <i>Development of activities to promote the well-being and maintenance of personal resources.</i> - <i>Design, development and assessment of interventions based on social animation</i> |
| <p>Contents</p> <p><i>Organisation of spaces and atmospheres/settings/resources</i></p> <p><i>Communication</i></p> <p><i>Non-Violent Communication</i></p> <p><i>Validation Therapy</i></p> <p><i>Gentle care</i></p> <p><i>Sensory stimulation methods</i></p> <p><i>Cognitive stimulation methods</i></p> <p><i>Person-centred approach</i></p> <p><i>Occupational therapy</i></p> <p><i>Enabling Approach</i></p> <p><i>Psychomotor activity - Body stimulation</i></p> <p><i>Reorientation (RIOT) therapy in reality</i></p> <p><i>Reminiscence Method</i></p> <p><i>Use of new technologies for communication</i></p> <p><i>Person-centred project implementation and evaluation</i></p> <p><i>Montessori method for Alzheimer’s and dementia</i></p> |
| <p>Methods and description of the activities</p> <p>Tools - no. of persons, spaces, etc.</p> <p><i>Lessons with multi-media support</i></p> <p><i>Videos</i></p> <p><i>Simulations.</i></p> <p><i>Case studies</i></p> <p><i>External visits/activities.</i></p> <p>Space: <i>according to the planned activity.</i></p> <p>no. of participants: <i>max. 25</i></p> <p>recommended duration: <i>8-30 hours</i></p> |
| <p>Methodological guidance for evaluation</p> <p>(diagnostic, formative and final evaluation tools)</p> <p>Formative evaluation:</p> |

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer.* DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

| |
|---|
| <p><i>Observation of activities</i> <i>Discussions</i> Final evaluation (of learning): <i>Case study and project simulation.</i></p> |
|---|

| |
|---|
| MODULE 3 - THE RELATIONSHIP AND COMMUNICATION WITH THE BENEFICIARIES |
| Target |
| <i>Initial and in-service training</i> |
| Trainers |
| <i>Experts in communication (from a psycho-relational point of view) and/or psychology and/or education and/or social work.</i> |
| Learning context |
| <i>Vocational Training Education, University, Adult training, Life-long education</i> |
| Purposes and goals |
| <p>PURPOSES <i>Improving relationships and communication for a better quality of life.</i></p> <p>GOALS <i>Acquire skills for:</i></p> <ul style="list-style-type: none"> - <i>Listening and knowing how to communicate with beneficiaries in an empathetic manner</i> - <i>Taking into account verbal and non-verbal communication (Gentle Care)</i> - <i>Learning to know how to manage the reception phase and critical moments</i> <ul style="list-style-type: none"> - <i>Giving value to diversity</i> |
| Contents |
| <p><i>Empathic Communication - Non-Violent Communication (Rogers),</i> <i>Verbal and non-verbal communication (Gentle Care)</i> <i>Reception, daily life and critical moments</i> <i>Management of diversities - intersectionality (gender-ethnicity-age, etc.)</i> <i>Verbal and non-verbal communication</i> <i>Augmentative alternative communication (Use of new technologies for communication, etc.)</i></p> |
| Methods and description of the activities |

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer.* DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

| |
|---|
| <p>Tools - no. of persons, spaces, etc.</p> <p>Videos Simulation of typical or critical situations.. Simulations: putting oneself in the place of the elderly/disabled person. Workshops. Role-playing. Video analysis. Case studies Group work . Tools: computer, video projector, slides, internet, cases to analyse, paperboard, camera, etc. Space: room with mobile chairs, video. no. of participants: 6-15 max per trainer. recommended duration: 4-16 hrs</p> |
| <p>Methodological guidance for Evaluation (diagnostic, formative and final evaluation tools)</p> <p>Diagnostic evaluation: Brain storming on communication with the users (oral or written). Formative evaluation: Observation of activities Discussions Final evaluation (of learning): Questionnaire on theoretical elements. Simulations (role-playing, etc.)</p> |

| |
|--|
| <p>MODULE 4 - TEAM COMMUNICATION FOR THE QUALITY OF LIFE OF PROFESSIONALS</p> |
| <p>Target</p> <p>Initial and in-service training</p> |
| <p>Trainers</p> <p>Experts in communication (from a psycho-relational point of view) and/or psychology and/or education and/or social work.</p> |
| <p>Learning context</p> <p>Vocational Training Education, University, Adult training, Life-long education</p> |
| <p>Purposes and goals</p> <p><u>PURPOSES</u></p> |

Elena Luppi – Training in non-pharmacological approaches to dementia and Alzheimer. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

| |
|--|
| <p><i>Facilitating communication in teamwork for pursuing quality of life and preventing burnout.</i></p> <p><u>GOALS</u></p> <ul style="list-style-type: none"> - Improvement of listening and communication among colleagues; - Knowledge and recognition of the main group's dynamics; - Recognition and management of communication contexts and flows (informal, formal, etc.); - Prevention and conflict management. |
| <p>Contents</p> <p><i>Non-Violent Communication/Empathetic Communication; Group dynamics: interactions, roles, etc. Information flow management, critical analysis of information, collective decision-making Presentation skills Use of new technologies for communication</i></p> |
| <p>Methods and description of the activity Tools, no. of persons, spaces, etc.</p> <p><i>Videos Communicative situation simulations in the team. Workshops. Role-playing games - role playing. Video analysis. Case studies - Case studies Group work.</i></p> <p>Tools: computer, slides, internet, cases to analyse, paper-board, camera, etc. Space: room with mobile chairs, video and camera. no. of participants: 6-15 max per trainer. Recommended duration: 4-16 hours</p> |
| <p>Methodological guidance for Evaluation (diagnostic, formative and final evaluation tools)</p> <p>Diagnostic evaluation: <i>Brain storming on communication in the work team (oral or written)</i></p> <p>Formative evaluation: <i>Observation of activities Discussions</i></p> |

Elena Luppi – Training in non-pharmacological approaches to dementia and Alzheimer. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

Final evaluation (of learning):

Questionnaire on theoretical elements.

Simulations (role play, role-playing, role-playing, etc.)

MODULE 5 - THE INVOLVEMENT OF FAMILY AND RELATIVES

Target

Initial and in-service training

Trainers

Experts in psycho-relational communication and/or psychology and/or education and/or social work, experts in innovative methodologies.

Learning context

Vocational Training Education, University, Adult training, Life-long education

Purposes and goals

PURPOSES

Improving the empowerment of families and communication among the team and towards the families.

GOALS

- *Listening and understanding how to communicate with families in an empathetic manner (CNV);*
- *Promoting the training of families and volunteers;*
- *Involving the family in the daily life of the organisation (collaborative spaces);*
- *Involving the families in social activities;*
- *Integrating the volunteer dimension into the daily life of the structure.*

Contents

- *Active Listening (Rogers, Systemic Counselling)*
- *Empathetic communication (CNV)*
- *Organization of training activities for families and/or volunteers*
- *Active involvement of the family in key times of daily life (good practices: discussion groups, Alzheimer's coffee mornings, counselling, family involvement in programming activities, etc.)*
- *Social animation projects with families (good practices)*

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer.* DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

| |
|--|
| - <i>Use of new technologies for communication (Skype, etc.)</i> |
| Methods and description of the activity Tools, no. of persons, spaces, etc. |
| Workshops Simulations of communicative situations with families Role-playing games Video analysis Case studies Testimonials Analysis of good practices Group work Development of training projects for families and/or volunteers Tools: computer, video projector, slides, internet, case to analyse, paperboard, camera, etc. Space: room with mobile chairs, video, camera. no. of participants: 6-15 max per trainer. recommended duration: 4-16 hours |
| Methodological guidance for Evaluation (diagnostic, formative and final evaluation tools) |
| Diagnostic evaluation: Brain storming on communication with family/neighbours (oral or written) Formative evaluation: Observation of activities Situation analysis Discussions Final evaluation (of learning): Simulations of communicative situations (role-playing, situation settings, etc.). Project planning. |

| |
|---|
| MODULE 6 EMPOWERMENT OF BENEFICIARIES |
| Target |
| <i>Initial and in-service training</i> |
| Trainers |
| <i>Experts in socio-cultural animation, education, innovative methodologies (pet therapy, music therapy, theatre, etc.)</i> |
| Learning context |

Elena Luppi – Training in non-pharmacological approaches to dementia and Alzheimer. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

| |
|---|
| <i>Vocational Training Education, University, Adult training, Lifelong education</i> |
| Purposes and goals |
| <p>PURPOSES <i>Empowerment of beneficiaries</i></p> <p>OBJECTIVES</p> <ul style="list-style-type: none"> - <i>Recognition and highlighting of needs, abilities and interests of beneficiaries</i> - <i>Raising awareness of the relationships (social, emotional, etc.) among the beneficiaries</i> - <i>Involvement of beneficiaries in everyday life</i> - <i>Involvement of beneficiaries to put them at the centre of their life plans.</i> |
| Contents |
| <ul style="list-style-type: none"> - <i>Empowerment (notion of empowerment and related practical application)</i> - <i>Active citizenship (notion of active citizenship and related practical application)</i> - <i>Analysis of needs and interests</i> - <i>The person-centred approach</i> - <i>Empowerment projects (analysis of good practices)</i> - <i>Methodologies and strategies for empowerment</i> - <i>Use of new technologies for empowerment</i> |
| Methods and description of the activity |
| Tools, no. of persons, spaces, etc. |
| <p><i>Lessons with multimedia support</i></p> <p><i>Case studies in small or large groups</i></p> <p><i>Workshops</i></p> <p><i>Analysis of good practices</i></p> <p><i>External visits</i></p> <p><i>Testimonials</i></p> <p><i>Group work</i></p> <p><i>Development of projects for the empowerment of users / beneficiaries</i></p> <p>Tools: <i>computer, video projector, slides, internet, case to analyse, paperboard, camera, etc.</i></p> <p><i>Space: room with mobile chairs, video, camera.</i></p> <p>Participants no.: <i>25 max</i></p> <p>recommended duration: <i>4-16 h</i></p> |

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer.* DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

| |
|--|
| Methodological guidance for Evaluation (diagnostic, formative and final evaluation tools) |
| Formative Evaluation Project Analysis discussions |
| Final evaluation (learning): Questionnaires on key concepts Development of a project |

| |
|---|
| MODULE 7 - RELATIONSHIP WITH THE TERRITORY AND COMMUNITY |
| Target Initial and in-service training |
| Trainers Experts in socio-cultural animation, experts in education, psychology, social work, socio-cultural mediators, experts in innovative methodologies. |
| Learning context Vocational Training Education, University, Adult training, Life-long education |
| Purposes and goals |
| PURPOSES Integration of the social environment in order to promote active citizenship. |
| GOALS: <ul style="list-style-type: none"> - Knowledge of the territory and its resources/opportunities - Fostering connections between home and institutions - Developing partnerships with the territory - Promoting experiences of social inclusion (disability, intergenerational dialogue, inter-culturality, etc.) |
| Contents |
| Mapping key players in the territory (Integrated approach) Diversity in the community (social inclusion) Analysis of the relations between users and territory Creation of participatory projects - participatory planning (involving other organisations and/or the community) Networking (Project COMPARES) |

Elena Luppi - Training in non-pharmacological approaches to dementia and Alzheimer. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

| |
|--|
| <i>Taking into account the home in territorial anchoring</i> <i>Use of new technologies for the territorial network</i> |
| Methods and description of activities Tools - no. of persons, spaces, etc. |
| <i>Lessons with multi-media support</i> <i>Case studies in small or large groups</i> <i>Discussions in small or large groups</i> <i>Analysis of good practice</i> <i>External Visits</i> <i>Testimonials</i> <i>Group work</i> <i>Project work</i> Tools: <i>computer, video projector, slides, internet, case to analyse, paperboard, etc.</i> Space: <i>room with mobile chairs, video, camera.</i> no. of participants: <i>max. 25</i> recommended duration: <i>4-16 hrs</i> |
| Methodological guidance for Evaluation (diagnostic, formative and final evaluation tools) |
| Formative evaluation: <i>Mapping Analysis</i> <i>Project Analysis</i> <i>Discussions</i> Final evaluation (of learning): <i>Drawing up a cartography</i> <i>Elaboration of a project</i> |

| |
|--|
| MODULE + - DEVELOPMENT OF AN EDUCATIONAL PROJECT |
| Target <i>Initial and in-service training</i> |
| Trainers <i>Experts in socio-cultural animation, experts in education, psychology, social work, socio-cultural mediators, experts in innovative methodologies.</i> |
| Learning context <i>Vocational Training Education, University, Adult training, Life-long education</i> |
| Purposes and goals |

Elena Luppi - *Training in non-pharmacological approaches to dementia and Alzheimer.* DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

| |
|--|
| <ul style="list-style-type: none">- <i>Learning the principles of planning, implementation and evaluation of an educational project.</i>- <i>Needs' analysis for educational interventions in care contexts.</i>- <i>Development of an educational project according to the needs.</i>- <i>Assessment of the impact of an educational project.</i> |
| Contents |
| <ul style="list-style-type: none">- <i>Planning of a social educational project</i>- <i>Analysis of the situation and needs</i>- <i>Definition of objectives</i>- <i>Choice of educational methodology</i> |
| Methods and description of activities Tools - no. of persons, spaces, etc. |
| <i>Analysis of projects already developed.</i> <i>Group work for project planning.</i> <i>Simulations and risk analyses.</i> <i>Practical application of the project and impact assessment.</i> <i>Methodological guidance for Evaluation (diagnostic, formative and final evaluation tools)</i> Tools: <i>computer, video projector, slides, internet, cases to analyse, paperboard, etc.</i> Space: <i>room with mobile chairs, video, camera.</i> no. of participants: <i>max. 25</i> recommended duration: <i>8-40 hrs</i> |
| Methodological guidance for Evaluation (diagnostic, formative and final evaluation tools) |
| Formative evaluation: <i>Analysis of projects according to given indicators</i> <i>Discussions</i> Final evaluation (of learning): <i>Project Analysis</i> <i>Analysis of the results of the projects that have been developed.</i> <i>Assessment of risk analyses of project ideas.</i> |

Results

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer.* DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

The training activity was implemented in Spain, France, Italy and Croatia.

The results in the different countries involved are being analysed, but here we briefly present the results of the training delivered in Italy. This activity involved 56 long-term care organisations and 228 professionals (physicians, nurses, formal carers, social workers). The training lasted 50 hours, of which 28 dedicated to modules 1, 2, 3, 5 and 22 hours of training in the field dedicated to the application of module +.

To assess the impact of the training on professionals, the “Attitude towards dementia” scale (O’Connor, McFadden, 2010) was administered at the beginning of the training course (ex-ante) and at the end (ex-post). This scale consists of 20 items and investigates the attitude towards people with Alzheimer's or dementia, referring to the knowledge of AD and the feelings towards this kind of problems. The purpose of each item is to express the agreement/disagreement in relation to the statements given, according to a scale from 1 to 7 (1 corresponds to totally disagree and 7 to totally agree). The statements express both a favourable attitude (e.g. "It is rewarding to work with people with Alzheimer's or dementia") and an unfavourable attitude (e.g. "I'm scared of people with Alzheimer's or dementia"); in the latter the improvement was indicated by a decrease in the average value assigned to that item.

The following table present the pre-test and post-test results, with a comparison of each item of the scale.

Table 1: Attitude towards dementia scale: pre-test and post-test means

| Item | PRE-TEST | | POST-TEST | | t | p |
|--|----------|-------|-----------|-------|--------|-------|
| | M | STD. | M | STD. | | |
| 1. It is rewarding to work with people who have ADRD | 5,50 | 1,226 | 5,78 | 1,127 | -2,253 | ,048* |
| 2. I am afraid | 1,76 | 1,207 | 1,76 | 1,276 | -,004 | ,996 |

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

| | | | | | | |
|---|------|-------|------|-------|--------|--------|
| of people with ADRD. | | | | | | |
| 3. People with ADRD can be creative. | 6,09 | 1,139 | 6,27 | ,901 | -1,664 | ,190 |
| 4. I feel confident around people with ADRD. | 5,57 | 1,294 | 5,77 | 1,154 | -1,572 | ,014* |
| 5. I am comfortable touching people with ADRD. . | 5,82 | 1,201 | 5,87 | 1,155 | -,414 | ,537 |
| 6. I feel uncomfortable being around people with ADRD. | 2,01 | 1,396 | 1,92 | 1,388 | ,613 | ,951 |
| 7. Every person with ADRD has different needs. | 6,54 | ,971 | 6,72 | ,763 | -2,056 | ,006** |
| 8. I am not very familiar with ADRD. | 3,55 | 1,771 | 2,83 | 1,735 | 3,985 | ,680 |
| 9. I would avoid an agitated person with ADRD. | 2,94 | 1,802 | 2,50 | 1,615 | 2,524 | ,033* |
| 10. People with ADRD like having familiar things nearby. | 6,10 | 1,134 | 6,10 | 1,089 | ,013 | ,896 |
| 11. It is important to know the past history of people with ADRD. | 6,72 | ,875 | 6,82 | ,621 | -1,300 | ,026* |
| 12. It is possible to enjoy in- | 6,42 | ,715 | 6,42 | ,818 | ,021 | ,195 |

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

| | | | | | | |
|--|------|-------|------|-------|--------|---------|
| teracting with people with ADRD. | | | | | | |
| 13. I feel relaxed around people with ADRD. | 5,72 | 1,182 | 5,97 | 1,013 | -2,174 | ,002* |
| 14. People with ADRD can enjoy life. | 5,69 | 1,212 | 6,02 | 1,011 | -2,847 | ,000*** |
| 15. People with ADRD can feel when others are kind to them. | 6,45 | ,928 | 6,66 | ,763 | -2,458 | ,001** |
| 16. I feel frustrated because I do not know how to help people with ADRD. | 3,17 | 1,746 | 2,86 | 1,723 | 1,714 | ,417 |
| 17. I cannot imagine caring for someone with ADRD. | 1,87 | 1,332 | 1,67 | 1,210 | 1,577 | ,074* |
| 18. I admire the coping skills of people with ADRD. | 5,65 | 1,232 | 5,92 | 1,101 | -2,249 | ,001*** |
| 19. We can do a lot now to improve the lives of people with ADRD. | 6,52 | ,867 | 6,63 | ,701 | -1,360 | ,014* |
| 20. Difficult behaviors may be a form of communication for people with ADRD. | 6,03 | 1,483 | 6,46 | 1,090 | -3,218 | ,006** |

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

* $p < .05$. ** $p < .01$. *** $p < .001$.

The analysis and comparison of ex-ante and ex-post data indicates a general improvement in the knowledge and attitudes of the participants towards people with Alzheimer's or dementia. As shown in Summary Chart 1, there is an improvement in a series of items: of particular relevance: "It is rewarding to work with people who have ADRD", "I feel confident around people with ADRD", "Every person with ADRD has different needs.", "I would avoid an agitated person with ADRD" (decreased), "It is important to know the past history of people with ADRD.", "I feel relaxed around people with ADRD.", "People with ADRD can enjoy life.", "People with ADRD can feel when others are kind to them.", "I cannot imagine caring for someone with ADRD." (decreased), "I admire the coping skills of people with ADRD.", "We can do a lot now to improve the lives of people with ADRD", and "Difficult behaviors may be a form of communication for people with ADRD."

In conclusion, the analysis of the emerging mean and percentage values highlights a positive variation of knowledge attitudes towards the object of the training, both in relation to the items focusing on knowledge of problems related to dementia and Alzheimer's and towards the statements concerning attitudes towards users affected by these diseases. Therefore, the positive impact of the course is confirmed, in terms of training of the participants.

Conclusions

The project team includes researchers, trainers, social workers but also public authorities in charge of health and social work. This integrated team made it possible to design a training programme that enhances professional competences with innovative perspectives, methods and effective non-pharmacological answers to the needs of the elderly.

Elena Luppi – *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

The training had a positive impact on operators, first of all for its experience-based approach. The experience therefore represented an opportunity for discussion among operators with different professional skills, within the same structure and who often do not have the time to imagine non-pharmacological alternatives to Alzheimer's and dementia. All the participants in the training also expressed great satisfaction in acquiring competences and skills that can make their care intervention much more meaningful and focused on the needs of the elderly. As suggested by literature, this is also a way to prevent operators' burnout, and ensure the humanisation of the care that they provide on a daily basis.

Elena Luppi - *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

References

- Brune, K. B. (1995). *Eden Alternative certification, pilot group*. New Berlin, NY.
- Brune, K. B. (2011) *Culture Change in Long Term Care Services: Eden-Greenhouse-Aging in the Community*, Educational Gerontology, 37: 6, 506 — 525
- Calkins, M. P. (2002). *The nursing home of the future: Are you ready?* Nursing Homes Long-Term Care Management.
- Carbone G., Tonali A.P. (2007), *Invecchiamento cerebrale, demenze e Malattia di Alzheimer. Una guida informativa per i familiari e gli operatori con l'elenco delle Unità Valutative Alzheimer (UVA)*, Franco Angeli.
- Day C. R., *Validation Therapy: A Review of the Literature*, Journal of Gerontological Nursing. 1997; 23 (4): 29-34.
- Erikson E. H., Erikson J.M., Kivnick H.Q. (1986), *Vital Involvement in Old Age*, W. W. Norton & Co New York/London.
- Feil N. (1993) *Validation therapy with late-onset dementia populations. in Care-giving in dementia; research and applications*, Eds. Gamma & Miesan, New York: Tavis/Routledge, pp. 199-218.
- Feil N. (2003) *Validation: the Feil method. How to help disordered Old-Old* Edward Feil Productions.
- Formarier M., (2012), *Les concepts en sciences infirmières Edition association de recherche en soins infirmiers* ZRIBI et POUPEE FONTAINE Dictionnaire du handicap éditions aux presses de l'EHESP
- Hafskjold, L., Sundler, A. J., Holmström, I. K., Sundling, V., Van Dulmen, S., & Eide, H. (2015). A Cross-Sectional Study On Person-Centred Communication In The Care Of Older People: The Comhome Study Protocol. *Bmj Open*, 5(4), E007864.
- Jones M. (1996) *Gentle Care Changing the experience of Alzheimer's Disease in a positive way*. Moyra Jones Resources, Burnaby BC, Canada.
- Kitwood K., (1997), *Dementia reconsidered. The Person comes first*, Open University Press, Buckingham.

Elena Luppi - *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>

- Lloyd, B., & Stirling, C. (2015). *A Tool To Support Meaningful Person-Centred Activity For Clients With Dementia - A Delphi Study*. *Bmc Nursing*, 14(1), 10.
- O'Connor, M. L., & McFadden, S. H. (2010). *Development and Psychometric Validation of the Dementia Attitudes Scale*. *International Journal of Alzheimer's Disease*.
- Rahman, A. N., & Schnelle, J. F. (2008). *The nursing home culture change movement: recent past, present, and future directions for research*. *The Gerontologist*, 48, 142-148.
- Roberts, G., Morley, C., Walters, W., Malta, S., & Doyle, C. (2015). *Caring For People With Dementia In Residential Aged Care: Successes With A Composite Person-Centered Care Model Featuring Montessori-Based Activities*. *Geriatric Nursing*, 36(2), 106-110
- Rokstad, A. M. M., Vatne, S., Engedal, K., & Selbæk, G. (2015). *The Role Of Leadership In The Implementation Of Person-Centred Care Using Dementia Care Mapping: A Study In Three Nursing Homes*. *Journal Of Nursing Management*, 23(1), 15-26.
- Ross, H., Tod, A. M., & Clarke, A. (2015). *Understanding And Achieving Person-Centred Care: The Nurse Perspective*. *Journal Of Clinical Nursing*, 24(9-10), 1223-1233.
- Shura R., Siders R. A., Dannefer D. (2010), *Culture Change in Long-term Care: Participatory Action Research and the Role of the Resident*, *Gerontologist*. Apr 2011; 51(2): 212-225.
- Vikström, S., Sandman, P. O., Stenwall, E., Boström, A. M., Saarnio, L., Kindblom, K., & Borell, L. (2015). *A Model For Implementing Guidelines For Person-Centred Care In A Nursing Home Setting*. *International Psychogeriatrics*, 27(01), 49-59.
- World Health Organisation, (2015), *The European Health Report 2015: Targets and beyond - reaching new frontiers in evidence*, WHO Library Cataloguing in Publication Data, Copenhagen.

Ricerche di Pedagogia e Didattica - Journal of Theories and Research in Education 13, 3 (2018).
ISSN 1970-2221

Elena Luppi is Assistant Professor in Educational Research at the Department of Education, University of Bologna.

Contact: elena.luppi@unibo.it

Elena Luppi - *Training in non-pharmacological approaches to dementia and Alzheimer*. DOI: <https://doi.org/10.6092/issn.1970-2221/8678>