

IO 1- IO 3

Research report

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2. DOCUMENT HISTORY AND AUTHORSHIP

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3. INTRODUCTION

4. Aims and goals

Aim of A 1 was to carry out best practice in this field, which allows the care providers to use with confidence the tools techniques and methods relative to the needs of the person being cared for at their stage in the dementia cycle.

For conducting the research under IO1, the partnership used the following methods:

- Desktop research (IO1-3; A1)
- Analysis
- Data summarising

Guidelines for implementing the research were prepared by Lead partner to guide partners in conducting the research in their own countries.

The following templates were further on used to collect the data:

- Desktop research template questionnaire

The following countries were involved in the research: **Austria, Turkey, Italy, Northern Ireland (UK), Netherland, Sweden.**

The IO lead partner Austria collected all the results, processed, analysed and summarised the data.

5. Target groups

Target groups within the research were:

- Partners themselves

6. Reference documents

- Annex 1: IO1-Guidelines with annexes:
 - Annex 1: Desktop research template

7. Introduction into IO1-A1 Desktop research

Desktop research was one of the methods used within the project to carry out an exploratory study on existing good practices in the field of dementia care providers.

Desktop Research about examples, curricula's, handbooks, training descriptions for each stage to create a step by step guideline (which is the basis for the e-learning/blended learning materials) in three different stages.

- Summarizing of the findings and focus group discussions
- Discussions of the chosen contents and topics from the research phase with external stakeholders
- Final selection of contents – BFI is preparing a template about the scope.
- Topics and Contents –from the research phase as starting for the curricula.

The output of this research will serve as a starting point for the development of the curricula:

- “Dementia care curricula for informal caregivers with e-learning modules”

The curricula content will support informal caregivers and will center in practical caring skills and milestones of mobility changes for the person with dementia and the caregiver, resulting in the three levels of care intervention. The curricula will consider the disease progress and the changing and intensifying skills in each stage of dementia. It should include a therapeutic touch while engaging every day care tasks.

All project partners were involved in the study by trying to find relevant initiatives/projects/materials related to the needs of people suffering from dementia and the needs of their informal care givers.

Altogether, project partners from six countries (Austria, Turkey, Sweden, Netherland, Italy, Northern Ireland (UK), collected good practice examples, curricula's, handbooks, training descriptions in their countries.

8. REMARK and conclusions of each country

In order to design future support for informal carers in a sustainable but efficient way it is important to know more about the carers' situation, and what kind of support they receive currently and what their needs are. Support services for such carers, however, are different considerably throughout Europe, being virtually non-existent in several countries. In many European countries such services did not receive much attention until recently.

There are many reasons why health professionals need to focus on caregivers. Caregivers who have unmet needs or a high burden level may be impeded in their ability to function effectively, including in their role as an ongoing support system for the patients. Patients are more likely to have unmet needs if their caregiver has high degree of burden. Since a caregiver is a critical element of home care, if the burden on a caregiver becomes too great, the home care support may be seriously jeopardized. Increased caregiver burden increases the use of formal, paid helpers. Higher levels of burden can lead to an earlier institutionalization of the patient in a nursing home.

In **Sweden** several articles offer information about carers problems and their needs. Informal care givers find it difficult to react adequately in special situations, specially when the relative is showing difficult (aggressive) behaviour. It is also shown that the carers are distressed knowing that their lack of knowledge about dementia leads to late diagnose. In generally they aren't barely informed about they stages of dementia and the progress of the disease. Symptoms of dementia like wandering, agitation or the confusion isn't easy to handle for them.

In addition carers aren't aware of their own health, they are suffering from different issues like sleeping disorders, psychological problems and social problems. Feelings like guilt and obligation can sometimes worsen the care-situation at home.

- Behavior und memory difficulties-not being recognized by the relatives
- Information about the disease
- Information about social support
- Role shifting (from being a daughter to becoming the caregiver)
- Coping strategies (stress-distress)
- Neurological problems of informal caregivers
- Financial burdens in urban area

The research in **Turkey** shows that care givers are worried about their own future and the risk for dementia. They sacrifice the less time for themselves, further more they are neglecting their own health and are suffering from sleeping problems, social restrictions, stress and the social isolation. Many care givers have to leave their work to take care for their relatives and most of them are female.

The research made clear the concerns about the mental burden of taking care of someone and that informal care givers have barely knowledge of dementia, they early signs and the stages.

- Carers have barely education in the field
- Not many resources of help
- No knowledge about the disease
- Anxiety and concerns
- Reasons for caring relatives (guilt....)
- Physical as well neurological problems of informal care givers (depressions, sleep disorder,....)
- Economic problems
- Social isolation because of the full time caring
- Problems with behaviour of the relatives

The **Netherlands** research identifies that dementia caregiving has been associated with negative affects on caregivers health and early nursing home placement for dementia patients. An enclosed study shows that many citizens in the Netherlands are giving informal help, but also that there are limits. Those limits are related to the number of hours informal carers have available, their expertise and, for example, their ability to seek help in time if they are no longer able to cope.

Communication with other affected people could lead to a better understanding of dementia and could alleviate suffering.

- Information about disease
- Lack of communication with others
- Importance of nutrition for patients
- Taking care causes anxiety,

The **UK** research points out that dementia affects every aspect of the individuals daily living experience and their carers. Caregivers and people with dementia face psychological and emotional barriers in their home and in their community. It's an important point that caregivers know about the gradual process of dementia and the main symptoms. An appropriate and timely information/diagnose can make the difference between a positive caregiving experience and a distressing one.

Another report emphasises practical hints and checklists for cares that could lessen their burden. And it also presents the importance of coping strategies to find balance in their situation.

- Dementia symptoms
- Phases of the disease

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- Coping strategies – self care
- Safety
- Abilities
- Treatment (medication, validation,...)

The **Italian** research shows makes clear that informal caregivers need interventions in order to lighten the informal care burden, psychological help interventions, through individual counseling courses, designed to adress the depressive feelings related to caregiving and to encourage the mastery of the situation itself. Next tot that the literature presents the psychological distress and dysfunctional coping strategies of informal carers.

To receive satisfactory family caregivers need adequate inforamtion about dementia aswell avaiable support systems. It seems that caregivers live in situations of loneliness because of the lack of knowledge of voluntary associations in the community and little contact with the care services for elderly of local authorities.

- less knowledge about dementia and the symptoms
- psychological stress
- lack of support in communities
- need for adequate dementia care intervention

The needs caregivers express in the **Austrian** research are mainly relative to a better knowledge of the disease and better information about appropriate behavioral disorder managment skills and dementia specific care.

Despite the attention to the role families play in caring for patients with a diagnoses of moderate to severe dementia, caregivers still express low levels of illness-consciousness and high levels of psychological and social discomfort. They are suffering from the lack of free time and the social isolation.

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- Lack of knowledge of the disease itself
 - Early signs
 - Diagnosing and treatment
 - Loss of cognitive competences

- Change of behavior - how to deal with... (ex. aggression,..)
- Lack of knowledge in caring
- Social, physical and psychological problems of the care givers
 - Lack of free time (isolation,...)
 - Cardiovascular diseases, spinal problems, undefined pain, Sleeping disorders, depressions,...

9. Conclusions

In general, the collected articles of dementia care search do share many common features, on the basis of which we could form some suggestions regarding the content of the curricula.

The educational modules for informal caregivers, teachers/trainers should, thereafter, consist of a selection of best practices offered by partner countries – of course, with the addition of clear and distinctive guidelines for their implementation. Consequently, the curricula and the e-modules could include the following separate topics/units:

- General information about the disease
- Different stages of dementia and what to expect with main symptoms of each stage
- Change of behaviour and interventions (Aggression, agitation, wandering,...)
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It would be helpful for carers to know symptoms of dementia and that may include memory loss and difficulties with thinking, problem-solving or language. They should be aware that these changes are often small to start with, but become severe enough to affect daily life. Furthermore that a person with dementia may also experience changes in their mood or behaviour.

- Support opportunities in each country

The well-being of carers can be enhanced through strategies which lead to a reduced perception of burden, with respite services providing tangible relief from burden.

- Coping strategies – self-care management (lack of sleep, negative effects on physical and psychological condition....)

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Dementia caregiving has been associated with negative effects on health. Appropriately tailored interventions can improve the health and well-being of both caregiver and patient.

- Checklists for carers
- Practical hints (nutrition, mobility, incontinence,..)