



D2.3 PRE-GAME QUESTIONNAIRE

Deliverable 2.3

Project acronym:	POSTHCARD
AAL JP project number:	AAL-CALL-2017-045
Deliverable Id:	
Deliverable Name:	
Status:	final
Dissemination Level :	Public
Due date of deliverable:	M12
Actual submission date:	30-12-2018
Author(s):	
Lead partner for this deliverable:	HUG
Contributing partners:	

Version history

Version	Authors	Date	Description
0.1	Anna Laura	20-12-2018	Targeted on informal caregivers
0.2	Anna Laura	28-01-2019	Targeted on professional caregivers

Contents

Version history	1
Demographics	3
Patient Assessment	3
Evaluation of NPS and related distress	3
NPI-Questionnaire adapted short version for the simulation	4
Caregiver Assessment	5
The Brief COPE Inventory.	5
Brief COPE	6

Demographics

Demographics gather some information related to both caregivers and patients.

Other questions are made for research purpose and can be removed.

1. What's your gender?
2. What's your relation with the patient? Children/Spouse/other?
3. How long you have been caring for the patient?
 - a. I've just started
 - b. since 1-2 years
 - c. more than 2 years
4. In order to provide a good care for your patient do you use any of the following source :

Circle all that apply

1. Use of pet	4. Use of dools/toys
2. Music Therapy	5. Cinema/Theater/TV
3. Art Therapy	

Patient Assessment

Investigation will continue with the patient assessment, evaluating level of Alzheimer Disease (AD) on Presence of Neuropsychiatric symptoms (NPSs) with the NPI- Questionnaire.

Evaluation of NPS and related distress

Assessment of AD level will continue with the Neuropsychiatric Inventory Questionnaire (NPI-Q). The NPI-Q provides symptom Severity and Distress ratings for each symptom reported, and total Severity and Distress scores reflecting the sum of individual domain scores. NPI-Q is designed to be a self-administered questionnaire completed by informants about patients for whom they care. Each of the 8 NPI-Q domains contains a survey question that reflects cardinal symptoms of that domain. Initial responses to each domain questions are "Yes" (present) or "No" (absent). If the response to the domain question is "No", the informant goes to the next question. If "Yes", the informant then rates both the Severity of the symptoms present within

the last month on a 3-point scale and the associated impact of the symptom manifestations on them (i.e. Caregiver Distress) using a 5-point scale.

NPI-Questionnaire adapted short version for the simulation

Please answer the following questions based on changes that have occurred since the patient first began to experience memory problems.

Mark "Yes" only if the symptom(s) has been present in the last month. Otherwise, circle "No".

For each item marked "Yes":

Rate the SEVERITY of the symptom (how it affects the patient):

1. Mild (noticeable, but not a significant change)
2. Moderate (significant, but not a dramatic change)
3. Severe (very marked or prominent, a dramatic change)

Rate the DISTRESS you experience due to that symptom (how it affects you):

1. Not distressing at all
2. Minimal (slightly distressing, not a problem to cope with)
3. Mild (not very distressing, generally easy to cope with)
4. Moderate (fairly distressing, not always easy to cope with)
5. Severe (very distressing, difficult to cope with)
6. Extreme or Very Severe (extremely distressing, unable to cope with)

Please answer each question carefully.

1	Agitation	Does the patient become agitated? Does he/she have any signs of nervousness such as being unable to relax, or feeling excessively tense?
	Yes No	SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5
2	Agitation/Aggression	Is the patient aggressive either verbally or physically?
	Yes No	SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5
3	Agitation/Messiness	Does the patient tend to disorderly, keep the house untidy?

	Yes No	SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5
4	Sleeping disorder	Does the patient awaken you during the night, rise too early in the morning, or take excessive naps during the day?
	Yes No	SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5
5	Apathy	Does the patient seem less interested in his/her usual activities or in the activities and plans of others?
	Yes No	SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5
6	Repetition	Does the patient engage in repetitive communication such as asking or saying the same things repeatedly?
	Yes No	SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5
7	Resisting to the care	Is the patient resistive to help in daily activities such as bathing, toileting or dressing?
	Yes No	SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5
8	Wandering	Does the patient engage in wandering, pacing activities?
	Yes No	SEVERITY: 1 2 3 DISTRESS: 0 1 2 3 4 5

Caregiver Assessment

The Brief COPE Inventory.

This is a self-report questionnaire with 14 subscales describing different coping strategies, (two items per scale) with satisfactory psychometric properties (Carver, 1997). It takes from 2 to 5 minutes. It has been used previously in dementia caregivers (Crespo et al., 2005). Each subscale describes how caregivers normally react facing dementia problems. We employed each scale and integrated them in a narrative scenario.

The short version has 28 questions/items with the following ways of coping:

Self-distraction, items 1 and 19

Active coping, items 2 and 7

Denial, items 3 and 8

Substance use, items 4 and 11

Use of emotional support, items 5 and 15

Use of instrumental support, items 10 and 23

Behavioral disengagement, items 6 and 16

Venting, items 9 and 21

Positive reframing, items 12 and 17

Planning, items 14 and 25

Humor, items 18 and 28

Acceptance, items 20 and 24

Religion, items 22 and 27

Self-blame, items 13 and 26

Each coping strategies will be implemented in the scenario.

Brief COPE

These items deal with ways you've been coping with the stress in your life. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all

2 = I've been doing this a little bit

3 = I've been doing this a medium amount

4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."

4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

