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***The Ambient Assisted Living Joint Programme***

**understAID: a platform that helps informal caregivers to understand and aid their demented relatives**

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**Call: Ambient Assisted Living Joint Programme Call 5**

**WP2. Task 2.2. Final Report. Results section - Denmark**

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## Demographic data (Table 1)

The participants were recruited from The municipality of Skanderborg, and the final sample consisted of 39 people with a **mean age of 68,62 years** (range 38-85), among whom three quarters were female. All the caregivers were married, and the majority (N = 38) had no children below 14 years of age. Above eighty percent of the respondents had 9-12 years of education or more, and most of them were retired (65,8%). The mean household income was approximately a million Danish kroner - equal to 67.000 EURO.

Table 1. Caregivers: socio demographic data

|  |  |  |
| --- | --- | --- |
|  | **N** | **%** |
| **Gender** |  |  |
| Male | 10 | 25,0 |
| Female | 30 | 75,0 |
| **Marital status** |  |  |
| Single | 0 | 0,0 |
| Married | 40 | 100,0 |
| Separated/divorced | 0 | 0,0 |
| Widow/er | 0 | 0,0 |
| Cohabiting | 0 | 0,0 |
| **Number of children younger than 14 years of age** |  |  |
| 1 | 2 | 5,0 |
| 2 | 0 | 0,0 |
| 3 or more | 0 | 0,0 |
| No children | 38 | 95,0 |
| Disabled children | 0 | 0,0 |
| **Educational years** |  |  |
| 0-4 years | 0 | 0,0 |
| 5-8 years | 7 | 17,5 |
| 9-12 years | 17 | 42,5 |
| College or higher degree | 16 | 40,0 |
| **Occupation** |  |  |
| Physical labour | 8 | 21,1 |
| Intellectual labour | 5 | 13,2 |
| Student | 0 | 0,0 |
| Unemployed | 0 | 0,0 |
| Retired | 25 | 65,8 |
|  |  |  |
|  | **Mean** | **Standard deviation** |
| **Household income** | 502.083 | 212,38 |

## Caregiving situation (Table 2)

The mean time of the caregiver being in the caregiving role is between 4 and 5 years. Most of the caregivers (80%) are spouse of the demented person, some are an adult child (15%) and a few (5%) are daughter in laws. Most of them (65%) report spending more than 20 hours per week on caregiving, but only a few have lost work (N=3) or changed working shift (N=4) due to the caregiving.

Around three quarters received support from a dementia supervisor from the local municipality (75%) or relatives/friends (77,5%), while half of them received help from the home care services from the municipality or private firm (52,5%) and day care center (52,5%), and a fifth participated in self-help groups. Only around a one third (32,5%) take care of another relative in addition to the demented person, and 65% have either sometimes (45%) or frequently (20%) thought of institutionalizing them.

Table 2. Caregiving situation description

|  | **Mean** | **Standard deviation** |
| --- | --- | --- |
| **Caregiving time (months)** | 56,70 | 48,1 |
|  | **N** | **%** |
| **Family relationship** |  |  |
| Spouse | 32 | 80,0 |
| Adult child | 6 | 15,0 |
| Father/mother in law | 0 | 0,0 |
| Nephew/Niece | 0 | 0,0 |
| Sibling | 0 | 0,0 |
| Others (daughter in law) | 2 | 5,0 |
| **Hours per week of caregiving** |  |  |
| 1-5 | 1 | 2,5 |
| 6-10 | 4 | 10,0 |
| 11-15 | 6 | 15,0 |
| 16-20 | 3 | 7,5 |
| More than 20 | 26 | 65,0 |
| **Lost of work** | 3 | 7,5 |
| **Changed of working shift** | 4 | 10,0 |
| **Support** |  |  |
| Family doctors (GP) | 9 | 22,5 |
| Dementia supervisor from the municipality | 30 | 75,0 |
| Relatives/friends | 31 | 77,5 |
| Home support services from the municipality or private firm | 21 | 52,5 |
| Tele-care | 0 | 0,0 |
| Day centre | 21 | 52,5 |
| Respite care in an adult centre | 5 | 12,5 |
| Self-help groups | 8 | 20,0 |
| Local parish | 2 | 5,0 |
| Other | 6 | 15,0 |
| **Caring of other relative** | 13 | 32,5 |
| **Feelings of institutionalization** |  |  |
| Never | 14 | 35,0 |
| Sometimes | 18 | 45,0 |
| Frequently | 8 | 20,0 |

## Use of ICT (Table 3)

Approximately one third (32,5%) of the caregivers used internet once a week to search for information, while the use of social networks was scarcely with under 10% using social networks on a daily basis.

Table 3. Use of ICT

|  | **N** | **%** |
| --- | --- | --- |
| **Use Internet to search for information** | 19 | 47,5 |
| Several times a day | 0 | 0,0 |
| Approximately once a day | 0 | 0,0 |
| Several times a week | 1 | 2,5 |
| Approximately once a week | 13 | 32,5 |
| **Use of social networks** | 7 | 17,5 |
| Several times a day | 3 | 7,5 |
| Approximately once a day | 3 | 7,5 |
| Several times a week | 1 | 2,5 |
| Approximately once a week | 0 | 0,0 |

## Patient profile (Table 4)

Alzheimer disease counted for nearly half of the dementia diagnosis (45%), while around a fifth (17,5%) had a diagnosis of Vascular dementia. A few had either Fronto temporal dementia or Lewy bodies, 7,5% and 5% respectively. Other dementia diagnosis, which were mostly either Alzheimer dementia or Parkinson disease in combination with another dementia diagnosis, counted for 22,5% of the patients. Half of them had a GDS stage of 4, and the predominant FAST stage were 4 (32,5%) and 5 (25%).

Table 4. Patients profile

|  |  |  |
| --- | --- | --- |
| **Diagnosis** | **N** | **%** |
| Alzheimer disease | 18 | 45,0 |
| Vacular dementia | 7 | 17,5 |
| Fronto temporal dementia | 3 | 7,5 |
| Lewy bodies | 2 | 5,0 |
| Others | 9 | 22,5 |
| **GDS stage** |  |  |
| GDS 1 | 1 | 2,5 |
| GDS 2 | 1 | 2,5 |
| GDS 3 | 5 | 12,5 |
| GDS 4 | 20 | 50,0 |
| GDS 5 | 4 | 10,0 |
| GDS 6 | 7 | 17,5 |
| GDS 7 | 0 | 0,0 |
| **FAST stage** |  |  |
| FAST 4 | 13 | 32,5 |
| FAST 5 | 10 | 25,0 |
| FAST 6a | 2 | 5,0 |
| FAST 6b | 2 | 5,0 |
| FAST 6c | 3 | 7,5 |
| FAST 6d | 1 | 2,5 |
| FAST 6e | 4 | 10,0 |
| FAST 7a | 1 | 2,5 |
| FAST 7b | 1 | 2,5 |
| FAST 7d |  |  |
| FAST 7e |  |  |
| FAST 7f |  |  |

## Psychological and physical status of the caregiver

The mean level of the Zarit Scale was 39,8 indicating that the caregiver was burdened according to the cut-off score of Schreiner et al. (Schreiner A. S., Morimoto, T., Arai, Y. & Zarit, S. (2006). Assessing family caregiver’s mental health using a statistically derived cut-off score for the Zarit Burden Interview. Aging and Mental Health, 10 (2), 107-111). The mean of people whom the caregivers can count with is 2.2, with a mean value of 4.8 for satisfaction with this social support. The mean of CES-D expressing the depression symptomatology among caregivers were 14,1 with around 60% below the cut-off at 16 and approximately 40% above this level, indicating presence of depressive symptoms. The confidence with the caregiving was high with a mean of 13,6 at the CCS of a maximum at 16. The satisfaction with the caregiving, though, was moderate with a mean of 16,9 for RCSS of a maximum at 30. The majority never went to the general practitioner in the last month (61,5%), 30,8% went once and the rest (7,7%) went more than once (data not shown in table). The caregivers estimated their health status mostly as good or very good (55%), and only 15% used psychoactive drugs.

Table 5. Physical and psychological status of the caregiver

|  |  |  |
| --- | --- | --- |
|  | **Mean** | **Standard deviation** |
| **Zarit Scale** | 39,8 | 12,27 |
| **Social support** |  |  |
| Social support received | 2,2 | 0,97 |
| Satisfaction with social support received | 4,8 | 1,23 |
| **CES-D** | 14,1 | 10,08 |
| **CCS** | 13,6 | 1,88 |
| **RCSS** | 16,9 | 5,49 |
| **Self-estimation of health status** |  |  |
| Very good | 12 | 30,0 |
| Good | 10 | 25,0 |
| Fair | 12 | 30,0 |
| Poor | 6 | 15,0 |
| Very poor | 0 | 0,0 |
| **Psychoactive drugs intake** | 6 | 15,0 |

# INITIAL ASSESSMENT-QUESTIONNAIRE 1

The following section shows a series of tables analyzing the daily situations that the caregivers described during the Initial Assessment. These are common situations that usually arise during the care of the relative. Each table records the frequency of the behavior (how often the problem affects the caregiver’s daily live), the severity of the behavior (how the problem affects the caregiver’s and the patient’s daily life) and the discomfort this problem causes to the caregiver.

## Selection of tags

These tables contain the results collected during the Initial Assessment of the caregiver, and correspond to the Questionnaire 1 document. The tables are separated by the Main Categories used to classify the deficits of the patient: Table 6: Daily tasks, Table 7: Behavior, Table 8: Social activities and Table 9: Cognitive activities. These tables contain the number of caregivers that chose an answer (“n”) and also the percentage (“%”). In order to select those tasks or questions that will be included in the “UnderstAID Platform” Menu, it was taken into account the level of **discomfort** that every situation caused on the caregiver. There were discarded those questions in which the number of caregivers that chose the “Nothing” option was higher than the total number of caregivers that chose any of the three other options (Some, Quite a lot and A lot).

## Classification of tags

Once the question was selected, the answer was classified as “Highly relevant” tag, “Relevant” tag or “Not particular relevant” tag. To do that, it the number of caregivers that selected every answer was reviewed (“n”; Some, Quite a lot and A lot) and the more frequent answer was chosen. If the more frequent was “A lot”, it was considered as “Highly relevant” tag to be included in the platform (Table 10). If the more frequent answer was “Quite a lot” it was considered as “Relevant” tag to be included in the platform (Table 11). And finally, if the more frequent answer was “Some” it was considered as “Not particular relevant” tag to be included in the platform (Table 12). In the cases of several options with the same “n”, the “average” category was selected.

## Results: selection of tags

Table 6, Daily Tasks, records these sub-categories: Personal hygiene, Personal appearance, Household chores, Sleep behavior or disorders and Appetite and eating changes. After reviewing the data 14 items was discarded and only the items relating to “taking care of his/her personal hygiene” and “appears and the item on decrease in appetite” was passed on for further evaluation. This meaning that all the items in Personal appearance, Household chores, Sleep behavior were discarded.

Table 7, Behavior, records these sub-categories: Suspiciousness and false beliefs, General mood, Anxiety level, Indifference/Apathy/Motivation to act, Apprehension/Uneasiness and Agitation/Lack of inhibition/Aggressiveness. After applying the selection criteria, 15 items were discarded (not to be included in the platform content).The sub-categories in which all the items were discarded were “Suspiciousness and false beliefs” and “Anxiety level”. The rest qualified for further evaluation in the project.

Table 8, Social activities, records these sub-categories: Participation in conversation, Activities with family and friends, Engagement in hobbies and recreation and socially acceptable conduct. There were only discarded 2 items belonging to the sub-category “Socially acceptable conduct”, so the rest of categories should be included in the later analysis.

Table 9, Cognitive activities, contains these sub-categories: Name and event recollection, Finding appropriate words, Orientation, Awareness of the environment and Make decisions. 3 questions was discarded – 2 questions for the sub-category “Finding appropriate words” and 1 in the sub-category “Name and event recollection”. The rest of the items were passed on for further evaluation.

## Results: classification of tags

Tables 10, 11 and 12 content the selected items for “High relevant” tags, “Relevant” tags and “Not particular relevant” tags, respectively.

In the “High relevant” group there were 9 items selected. One from the “Daily task” category, 2 from the “behaviour” category, 1 from the “social activity” category and 5 from the “cognitive activities” category.

In the “Relevant” group there were 4 items selected, all belonging to the “cognitive activities” category.

In the “Not particular relevant” group there were the largest number present with 15 items selected for the 4 sub-categories. The majority with 7 items were in the category “behavior”. The sub-category “social activity” was present with 5 items and “cognitive activities” was present with 3 items. The sub-category “daily tasks” was not present in the “Not particular relevant” group at all.

In summery there were 28 item present in the High relevant, Relevant and Not particular relevant groups. The most distinguish observation is that only one “daily tasks” was found relevant for the platform, and it is present in the “highly relevant” group. The question is relating to the patient not caring as much about his/her personal hygiene and appearance.

Table 6. Q1. Daily tasks (n, %)

|  | **Frequency** | | | | | **Severity** | | | | **Discomfort** | | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Occasionally** | **Often** | **Frequently** | **Very frequently** | **NA** | **Mild** | **Moderate** | **Intense** | **NA** | **Nothing** | **Some** | **Quite a lot** | **A lot** | **NA** |
| Personal hygiene |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| The patient does not take as much care of his/her personal hygiene and appearance as usually | 16  (40,0) | 4  (10,0) | 3  (7,5) | 17  (42,5) |  | 17  (43,6) | 8  (20,5) | 14  (35,9) |  | 17  (43,6) | 6  (15,4) | 3  (7,7) | 13  (33,3) |  |
| The patient gets upset with those trying to care for him/her or resist activities such as bathing or changing clothes | 23  (57,5) | 6  (15,0) | 3  (7,5) | 8  (20,0) |  | 22  (57,9) | 7  (18,4) | 9  (23,7) |  | 22  (57,9) | 6  (15,8) | 2  (5,3) | 8  (21,1) |  |
| Personal appearance |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| You have to tell the patient that he/she should brush his/her teeth or comb his/her hair | 22  (55,0) | 1  (2,5) | 2  (5,0) | 15  (37,5) |  | 23  (59,0) | 8  (20,5) | 8  (20,5) |  | 25  (64,1) | 5  (12,8) | 2  (5,1) | 7  (17,9) |  |
| You have to assist the patient in brushing his teeth | 29  (74,4) | 2  (5,1) | 3  (7,7) | 5  (12,8) |  | 23  (63,9) | 6  (16,7) | 7  (19,4) |  | 24  (66,7) | 3  (8,3) | 2  (5,6) | 7  (19,4) |  |
| You have to assist the patient in combing his hair | 29  (72,5) | 4  (10,0) | 1  (2,5) | 6  (15,0) |  | 26  (72,2) | 6  (16,7) | 4  (11,1) |  | 26  (70,3) | 4  (10,8) | 2  (5,4) | 5  (13,5) |  |
| You have to assist the patient to get ready | 22  (56,4) | 3  (7,7) | 3  (7,7) | 11  (28,2) |  | 21  (58,3) | 10  (27,8) | 5  (13,9) |  | 24  (66,7) | 4  (11,1) | 4  (11,1) | 4  (11,1) |  |
| Household chores |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| You have to assist the patient in shopping | 7  (17,5) | 3  (7,5) | 4  (10,0) | 26  (65,0) |  | 15  (37,5) | 12  (30,0) | 13  (32,5) |  | 22  (55,0) | 5  (12,5) | 4  (10,0) | 9  (22,5) |  |
| You have to assist the patient in cooking | 8  (20,0) | 0  0,0 | 4  (10,0) | 28  (70,0) |  | 13  (33,3) | 11  (28,2) | 15  (38,5) |  | 20  (51,3) | 9  (23,1) | 3  (7,7) | 7  (17,9) |  |
| You have to assist the patient to use the electrical appliances | 8  (21,1) | 6  (15,8) | 4  (10,5) | 20  (52,6) |  | 15  (41,7) | 12  (33,3) | 9  (25,0) |  | 22  (59,5) | 7  (18,9) | 3  (8,1) | 5  (13,5) |  |
| Sleep behaviour or disorders |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| The patient has difficulty sleeping | 26  (66,7) | 5  (12,8) | 4  (10,3) | 4  (10,3) |  | 24  (64,9) | 6  (16,2) | 7  (18,9) |  | 20  (54,1) | 5  (13,5) | 4  (10,8) | 8  (21,6) |  |
| The patient wanders at night or get dressed | 30  (76,9) | 4  (10,3) | 4  (10,3) | 1  (2,6) |  | 23  (65,7) | 6  (17,1) | 6  (17,1) |  | 25  (71,4) | 1  (2,9) | 2  (5,7) | 7  (20,0) |  |
| The patient awakes you or any member of your family during the night | 25  (65,8) | 6  (15,8) | 2  (5,3) | 5  (13,2) |  | 22  (62,9) | 5  (14,3) | 8  (22,9) |  | 21  (60,0) | 3  (8,6) | 4  (11,4) | 7  (20,0) |  |
| Appetite and eating changes |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| The patient has some change in appetite, weight, or eating habits | 16  (41,0) | 3  (7,7) | 6  (15,4) | 14  (35,9) |  | 18  (48,6) | 10  (27,0) | 9  (24,3) |  | 22  (59,5) | 6  (16,2) | 4  (10,8) | 5  (13,5) |  |
| The patient has a change in the kind of food he/she likes | 22  (56,4) | 4  (10,3) | 4  (10,3) | 9  (23,1) |  | 21  (55,3) | 11  (28,9) | 6  (15,8) |  | 24  (63,2) | 6  (15,8) | 3  (7,9) | 5  (13,2) |  |
| The patient has an increase in appetite | 30  (81,1) | 1  (2,7) | 1  (2,7) | 5  (13,5) |  | 27  (77,1) | 5  (14,3) | 3  (8,6) |  | 28  (80,0) | 4  (11,4) | 1  (2,9) | 2  (5,7) |  |

Table 7. Q1. Behaviour (n, %)

|  | **Frequency** | | | | | | **Severity** | | | | | | | | **Discomfort** | | | | | | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Occasionally** | **Often** | | **Frequently** | **Very frequently** | **NA** | **Mild** | | **Moderate** | | **Intense** | | **NA** | | **Nothing** | | **Some** | | **Quite a lot** | | **A lot** | **NA** | |
| Suspiciousness and false beliefs |  |  | |  |  |  |  | |  | |  | |  | |  | |  | |  | |  |  | |
| The patient believes in things that you know are unreal | 19  (47,5) | 9  (22,5) | | 4  (10,0) | 8  (20,0) |  | 17  (43,6) | | 10  (25,6) | | 12  (30,8) | |  | | 20  (51,3) | | 6  (15,4) | | 4  (10,3) | | 9  (23,1) |  | |
| The patient has hallucinations such as seeing false visions or hearing false voices | 28  (73,7) | 5  (13,2) | | 3  (7,9) | 2  (5,3) |  | 28  (75,7) | | 5  (13,5) | | 4  (10,8) | |  | | 28  (75,7) | | 4  (10,8) | | 2  (5,4) | | 3  (8,1) |  | |
| General mood |  |  | |  |  |  |  | |  | |  | |  | |  | |  | |  | |  |  | |
| The patient loses their emotional responsiveness | 10  (26,3) | 7  (18,4) | | 9  (23,7) | 12  (31,6) |  | 13  (35,1) | | 9  (24,3) | | 15  (40,5) | |  | | 12  (32,4) | | 9  (24,3) | | 8  (21,6) | | 8  (21,6) |  | |
| The patient appears sad or depressed | 14  (36,8) | 9  (23,7) | | 13  (34,2) | 2  (5,3) |  | 13  (35,1) | | 15  (40,5) | | 9  (24,3) | |  | | 12  (32,4) | | 9  (24,3) | | 8  (21,6) | | 8  (21,6) |  | |
| The patient cries sometimes | 25  (65,8) | 12  (31,6) | | 1  (2,6) | 0  (0,0) |  | 23  (62,2) | | 9  (24,3) | | 5  (13,5) | |  | | 23  (62,2) | | 8  (21,6) | | 1  (2,7) | | 5  (13,5) |  | |
| The patient expresses feelings of sadness or depression | 18  (48,6) | 10  (27,0) | | 5  (13,5) | 4  (10,8) |  | 16  (44,4) | | 13  (36,1) | | 7  (19,4) | |  | | 15  (41,7) | | 9  (25,0) | | 6  (16,7) | | 6  (16,7) |  | |
| The patient comments about death of self or others (e.g. “Life isn´t worth living”, “I´d be better off dead”) | 30  (81,1) | 4  (10,8) | | 2  (5,4) | 1  (2,7) |  | 29  (80,6) | | 4  (11,1) | | 3  (8,3) | |  | | 27  (75,0) | | 6  (16,7) | | 1  (2,8) | | 2  (5,6) |  | |
| The patient comments about feeling worthless or being a burden to others | 26  (70,3) | 6  (16,2) | | 3  (8,1) | 2  (5,4) |  | 23  (63,9) | | 9  (25,0) | | 4  (11,1) | |  | | 23  (63,9) | | 8  (22,2) | | 3  (8,3) | | 2  (5,6) |  | |
| The patient comments about feeling like a failure or about not having any worthwhile accomplishments in life | 31  (83,8) | 1  (2,7) | | 3  (8,1) | 2  (5,4) |  | 30  (85,7) | | 3  (8,6) | | 2  (5,7) | |  | | 28  (80,0) | | 3  (8,6) | | 1  (2,9) | | 3  (8,6) |  | |
| The patient talks about feeling lonely | 30  (78,9) | 4  (10,5) | | 2  (5,3) | 2  (5,3) |  | 27  (73,0) | | 7  (18,9) | | 3  (8,1) | |  | | 24  (64,9) | | 9  (24,3) | | 1  (2,7) | | 3  (8,1) |  | |
| Anxiety level |  |  | |  |  |  |  |  | |  | |  | |  | |  | |  | |  | | |  |
| The patient appears to be anxious, worried or frightened for no apparent reason | 27  (67,5) | 7  (17,5) | | 5  (12,5) | 1  (2,5) |  | 24  (61,5) | 8  (20,5) | | 7  (17,9) | |  | | 22  (56,4) | | 8  (20,5) | | 3  (7,7) | | 6  (15,4) | | |  |
| The patient appears to be uneasy or nervous | 24  (63,2) | 8  (21,1) | | 5  (13,2) | 1  (2,6) |  | 22  (59,5) | 7  (18,9) | | 8  (21,6) | |  | | 22  (59,5) | | 5  (13,5) | | 3  (8,1) | | 7  (18,9) | | |  |
| Indifference/Apathy/Motivation to act | |  | |  |  |  |  |  | |  | |  | |  | |  | |  | |  | | |  |
| The patient has lack of initiative | 13  (33,3) | 5  (12,8) | | 5  (12,8) | 16  (41,0) |  | 11  (27,5) | 14  (35,0) | | 15  (37,5) | |  | | 13  (33,3) | | 8  (20,5) | | 7  (17,9) | | 11  (28,2) | | |  |
| The patient seems less spontaneous or less active than usual | 10  (25,0) | 4  (10,0) | | 7  (17,5) | 19  (47,5) |  | 8  (20,5) | 12  (30,8) | | 19  (48,7) | |  | | 12  (30,8) | | 8  (20,5) | | 5  (12,8) | | 14  (35,9) | | |  |
| The patient seems less interested in the activities and plans of others | 16  (41,0) | 1  (2,6) | | 9  (23,1) | 13  (33,3) |  | 14  (36,8) | 9  (23,7) | | 15  (39,5) | |  | | 13  (34,2) | | 11  (28,9) | | 6  (15,8) | | 8  (21,1) | | |  |
| Apprehension, uneasiness |  |  | |  |  |  |  |  | |  | |  | |  | |  | |  | |  | | |  |
| The patient feels uneasy or hyperactive | 20  (51,3) | 7  (17,9) | | 3  (7,7) | 9  (23,1) |  | 22  (56,4) | 8  (20,5) | | 9  (23,1) | |  | | 19  (48,7) | | 8  (20,5) | | 5  (12,8) | | 7  (17,9) | | |  |
| The patient does things over and over such as pace, opening closets or drawers, or repeatedly pick at things, etc. | 18  (46,2) | 2  (5,1) | | 4  (10,3) | 15  (38,5) |  | 20  (51,3) | 5  (12,8) | | 14  (35,9) | |  | | 21  (53,8) | | 6  (15,4) | | 2  (5,1) | | 10  (25,6) | | |  |
| The patient is irritable, argue or complain | 22  (56,4) | 6  (15,4) | | 3  (7,7) | 8  (20,5) |  | 18  (47,4) | 11  (28,9) | | 9  (23,7) | |  | | 17  (44,7) | | 9  (23,7) | | 4  (10,5) | | 8  (21,1) | | |  |
| Agitation, lack of inhibition, aggressiveness | |  |  | |  |  |  |  | |  | |  | |  | |  | |  | |  | | |  |
| The patient destroys the property | 35  (89,7) | 2  (5,1) | 2  (5,1) | | 0  (0,0) |  | 33  (86,8) | 3  (7,9) | | 2  (5,3) | |  | | 32  (84,2) | | 4  (10,5) | | 1  (2,6) | | 1  (2,6) | | |  |
| The patient does things that embarrass you | 27  (71,1) | 4  (10,5) | 5  (13,2) | | 2  (5,3) |  | 25  (67,6) | 3  (8,1) | | 9  (24,3) | |  | | 22  (59,5) | | 5  (13,5) | | 6  (16,2) | | 4  (10,8) | | |  |
| The patient talks loudly and rapidly | 33  (86,8) | 3  (7,9) | 0  (0,0) | | 2  (5,3) |  | 31  (83,8) | 2  (5,4) | | 4  (10,8) | |  | | 31  (83,8) | | 2  (5,4) | | 1  (2,7) | | 3  (8,1) | | |  |
| The patient engages in behaviour that is potentially dangerous to self or others | 33  (86,8) | 4  (10,5) | 0  (0,0) | | 1  (2,6) |  | 29  (78,4) | 4  (10,8) | | 4  (10,8) | |  | | 26  (70,3) | | 5  (13,5) | | 3  (8,1) | | 3  (8,1) | | |  |
| The patient threatened of hurting him/herself | 36  (94,7) | 1  (2,6) | 1  (2,6) | | 0  (0,0) |  | 35  (94,6) | 0  (0,0) | | 2  (5,4) | |  | | 33  (89,2) | | 2  (5,4) | | 1  (2,7) | | 1  (2,7) | | |  |
| The patient has been verbally aggressive to you or others | 17  (43,6) | 11  (28,2) | 8  (20,5) | | 3  (7,7) |  | 16  (42,1) | 13  (34,2) | | 9  (23,7) | |  | | 15  (39,5) | | 12  (31,6) | | 4  (10,5) | | 7  (18,4) | | |  |

Table 8. Q1. Social activities (n, %)

|  | **Frequency** | | | | | **Severity** | | | | **Discomfort** | | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Occasionally** | **Often** | **Frequently** | **Very frequently** | **NA** | **Mild** | **Moderate** | **Intense** | **NA** | **Nothing** | **Some** | **Quite a lot** | **A lot** | **NA** |
| Participating in conversation |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| The patient has the amount of speech significantly decreased | 9  (23,7) | 6  (15,8) | 6  (15,8) | 17  (44,7) |  | 8  (21,1) | 12  (31,6) | 18  (47,4) |  | 11  (28,9) | 12  (31,6) | 5  (13,2) | 10  (26,3) |  |
| The patient has lost the ability to converse | 14  (35,9) | 7  (17,9) | 4  (10,3) | 14  (35,9) |  | 10  (26,3) | 9  (23,7) | 19  (50,0) |  | 9  (23,7) | 13  (34,2) | 5  (13,2) | 11  (28,9) |  |
| Activities with family and friends |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| The patient lost interest in friends or daily activities | 19  (48,7) | 3  (7,7) | 4  (10,3) | 13  (33,3) |  | 15  (39,5) | 8  (21,1) | 15  (39,5) |  | 15  (39,5) | 11  (28,9) | 5  (13,2) | 7  (18,4) |  |
| The patient lost interest in friends or family members | 20  (51,3) | 7  (17,9) | 2  (5,1) | 10  (25,6) |  | 18  (47,4) | 7  (18,4) | 13  (34,2) |  | 18  (47,4) | 8  (21,1) | 5  (13,2) | 7  (18,4) |  |
|  | |  |  |  |  |  |  |  |  |  |  |  |  |  |
| The patient lost interest in doing things or lack motivation for starting new activities | 12  (30,8) | 3  (7,7) | 6  (15,4) | 18  (46,2) |  | 10  (26,3) | 10  (26,3) | 18  (47,4) |  | 13  (35,1) | 11  (29,7) | 3  (8,1) | 10  (27,0) |  |
| The patient is less enthusiastic about his/her usual interests | 10  (26,3) | 3  (7,9) | 7  (18,4) | 18  (47,4) |  | 10  (27,8) | 6  (16,7) | 20  (55,6) |  | 12  (32,4) | 8  (21,6) | 5  (13,5) | 12  (32,4) |  |
| Socially acceptable conduct |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| The patient do things outside what are acceptable | 19  (50,0) | 6  (15,8) | 6  (15,8) | 7  (18,4) |  | 25  (65,8) | 5  (13,2) | 8  (21,1) |  | 21  (55,3) | 6  (15,8) | 4  (10,5) | 7  (18,4) |  |
| The patient is rude, or childish | 25  (67,6) | 3  (8,1) | 5  (13,5) | 4  (10,8) |  | 25  (67,6) | 5  (13,5) | 7  (18,9) |  | 23  (62,2) | 4  (10,8) | 3  (8,1) | 7  (18,9) |  |

Table 9. Q1. Cognitive activities (n, %)

|  | **Frequency** | | | | | **Severity** | | | | **Discomfort** | | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Occasionally** | **Often** | **Frequently** | **Very frequently** | **NA** | **Mild** | **Moderate** | **Intense** | **NA** | **Nothing** | **Some** | **Quite a lot** | **A lot** | **NA** |
| Name and event recollection |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| The patient has trouble remembering the names of relatives or friends | 14  (36,8) | 3  (7,9) | 7  (18,4) | 14  (36,8) |  | 15  (41,7) | 8  (22,2) | 13  (36,1) |  | 18  (50,0) | 10  (27,8) | 3  (8,3) | 5  (13,9) |  |
| The patient has trouble remembering recent events (e.g. items in the newspaper or on TV) | 4  (11,1) | 2  (5,6) | 6  (16,7) | 24  (66,7) |  | 7  (20,0) | 10  (28,6) | 18  (51,4) |  | 13  (38,2) | 8  (23,5) | 5  (14,7) | 8  (23,5) |  |
| The patient asks the same question many times | 10  (26,3) | 2  (5,3) | 5  (13,2) | 21  (55,3) |  | 11  (29,7) | 6  (16,2) | 20  (54,1) |  | 13  (35,1) | 10  (27,0) | 5  (13,5) | 9  (24,3) |  |
| The patient has trouble remembering significant past events | 18  (48,6) | 6  (16,2) | 6  (16,2) | 7  (18,9) |  | 22  (61,1) | 8  (22,2) | 6  (16,7) |  | 20  (55,6) | 10  (27,8) | 3  (8,3) | 3  (8,3) |  |
| The patient loses or misplace things | 7  (18,9) | 7  (18,9) | 3  (8,1) | 20  (54,1) |  | 8  (22,9) | 10  (28,6) | 17  (48,6) |  | 10  (28,6) | 9  (25,7) | 4  (11,4) | 12  (34,3) |  |
| Finding appropriate words |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| The patient has trouble finding the appropriate word when trying to communicate | 14  (36,8) | 3  (7,9) | 6  (15,8) | 15  (39,5) |  | 13  (35,1) | 12  (32,4) | 12  (32,4) |  | 19  (51,4) | 7  (18,9) | 2  (5,4) | 9  (24,3) |  |
| The patient makes language or pronunciation errors | 26  (68,4) | 4  (10,5) | 1  (2,6) | 7  (18,4) |  | 24  (68,6) | 2  (5,7) | 9  (25,7) |  | 23  (65,7) | 4  (11,4) | 1  (2,9) | 7  (20,0) |  |
| Orientation |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| The patient loses his/her orientation in common places | 7  (17,9) | 2  (5,1) | 4  (10,3) | 26  (66,7) |  | 10  (26,3) | 8  (21,1) | 20  (52,6) |  | 12  (31,6) | 4  (10,5) | 6  (15,8) | 16  (42,1) |  |
| The patient does not know the date (month, day and time) | 11  (28,2) | 3  (7,7) | 6  (15,4) | 19  (48,7) |  | 14  (36,8) | 7  (18,4) | 17  (44,7) |  | 16  (42,1) | 6  (15,8) | 8  (21,1) | 8  (21,1) |  |
| Awareness of the environment |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| The patient has difficulty concentrating on a task | 5  (12,5) | 9  (22,5) | 9  (22,5) | 17  (42,5) |  | 10  (26,3) | 10  (26,3) | 18  (47,4) |  | 11  (28,9) | 11  (28,9) | 5  (13,2) | 11  (28,9) |  |
| The patient loses the interest in the world around him/her | 15  (38,5) | 6  (15,4) | 3  (7,7) | 15  (38,5) |  | 15  (39,5) | 9  (23,7) | 14  (36,8) |  | 15  (39,5) | 10  (26,3) | 3  (7,9) | 10  (26,3) |  |
| The patient is unaware of problems/changes or deny them when discussed | 10  (27,0) | 8  (21,6) | 9  (24,3) | 10  (27,0) |  | 9  (25,0) | 13  (36,1) | 14  (38,9) |  | 10  (27,8) | 13  (36,1) | 5  (13,9) | 8  (22,2) |  |
| The patient is not able to follow instructions | 11  (28,2) | 5  (12,8) | 7  (17,9) | 16  (41,0) |  | 8  (21,1) | 12  (31,6) | 18  (47,4) |  | 11  (28,9) | 10  (26,3) | 5  (13,2) | 12  (31,6) |  |
| Make decision |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| The patient is not able to make decisions about daily life (choosing clothes or food) | 15  (37,5) | 1  (2,5) | 12  (30,0) | 12  (30,0) |  | 14  (35,9) | 11  (28,2) | 14  (35,9) |  | 16  (41,0) | 9  (23,1) | 3  (7,7) | 11  (28,2) |  |
| The patient has been acting impulsively, irresponsibly, neglectfully or in poor judgment | 8  (21,6) | 8  (21,6) | 11  (29,7) | 10  (27,0) |  | 8  (21,6) | 13  (35,1) | 16  (43,2) |  | 8  (21,6) | 11  (29,7) | 4  (10,8) | 14  (37,8) |  |

Table 10. Q1. Selected items: Highly relevant tags (%)

|  | **Frequency** | | | | | **Severity** | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Occasionally** | **Often** | **Frequently** | **Very frequently** | **NA** | **Mild** | **Moderate** | **Intense** | **NA** |
| The patient does not take as much care of his/her personal hygiene and appearance as usually | 16  (40,0) | 4  (10,0) | 3  (7,5) | 17  (42,5) |  | 17  (43,6) | 8  (20,5) | 14  (35,9) |  |
| The patient has lack of initiative | 13  (33,3) | 5  (12,8) | 5  (12,8) | 16  (41,0) |  | 11  (27,5) | 14  (35,0) | 15  (37,5) |  |
| The patient seems less spontaneous or less active than usual | 10  (25,0) | 4  (10,0) | 7  (17,5) | 19  (47,5) |  | 8  (20,5) | 12  (30,8) | 19  (48,7) |  |
| The patient is less enthusiastic about his/her usual interests | 10  (26,3) | 3  (7,9) | 7  (18,4) | 18  (47,4) |  | 10  (27,8) | 6  (16,7) | 20  (55,6) |  |
| The patient loses or misplace things | 7  (18,9) | 7  (18,9) | 3  (8,1) | 20  (54,1) |  | 8  (22,9) | 10  (28,6) | 17  (48,6) |  |
| The patient loses his/her orientation in common places | 7  (17,9) | 2  (5,1) | 4  (10,3) | 26  (66,7) |  | 10  (26,3) | 8  (21,1) | 20  (52,6) |  |
| The patient is not able to follow instructions | 11  (28,2) | 5  (12,8) | 7  (17,9) | 16  (41,0) |  | 8  (21,1) | 12  (31,6) | 18  (47,4) |  |
| The patient is not able to make decisions about daily life (choosing clothes or food) | 15  (37,5) | 1  (2,5) | 12  (30,0) | 12  (30,0) |  | 14  (35,9) | 11  (28,2) | 14  (35,9) |  |
| The patient has been acting impulsively, irresponsibly, neglectfully or in poor judgment | 8  (21,6) | 8  (21,6) | 11  (29,7) | 10  (27,0) |  | 8  (21,6) | 13  (35,1) | 16  (43,2) |  |

Table 11.Q1. Selected items: Relevant tags (%)

|  | **Frequency** | | | | | **Severity** | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Occasionally** | **Often** | **Frequently** | **Very frequently** | **NA** | **Mild** | **Moderate** | **Intense** | **NA** |
| The patient has trouble remembering recent events (e.g. items in the newspaper or on TV) | 4  (11,1) | 2  (5,6) | 6  (16,7) | 24  (66,7) |  | 7  (20,0) | 10  (28,6) | 18  (51,4) |  |
| The patient does not know the date (month, day and time) | 11  (28,2) | 3  (7,7) | 6  (15,4) | 19  (48,7) |  | 14  (36,8) | 7  (18,4) | 17  (44,7) |  |
| The patient has difficulty concentrating on a task | 5  (12,5) | 9  (22,5) | 9  (22,5) | 17  (42,5) |  | 10  (26,3) | 10  (26,3) | 18  (47,4) |  |
| The patient loses the interest in the world around him/her | 15  (38,5) | 6  (15,4) | 3  (7,7) | 15  (38,5) |  | 15  (39,5) | 9  (23,7) | 14  (36,8) |  |

Table 12. Q1. Selected items: Not particular relevant tags (%)

|  | **Frequency** | | | | | **Severity** | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Occasionally** | **Often** | **Frequently** | **Very frequently** | **NA** | **Mild** | **Moderate** | **Intense** | **NA** |
| The patient loses their emotional responsiveness | 10  (26,3) | 7  (18,4) | 9  (23,7) | 12  (31,6) |  | 13  (35,1) | 9  (24,3) | 15  (40,5) |  |
| The patient appears sad or depressed | 14  (36,8) | 9  (23,7) | 13  (34,2) | 2  (5,3) |  | 13  (35,1) | 15  (40,5) | 9  (24,3) |  |
| The patient expresses feelings of sadness or depression | 18  (48,6) | 10  (27,0) | 5  (13,5) | 4  (10,8) |  | 16  (44,4) | 13  (36,1) | 7  (19,4) |  |
| The patient seems less interested in the activities and plans of others | 16  (41,0) | 1  (2,6) | 9  (23,1) | 13  (33,3) |  | 14  (36,8) | 9  (23,7) | 15  (39,5) |  |
| The patient feels uneasy or hyperactive | 20  (51,3) | 7  (17,9) | 3  (7,7) | 9  (23,1) |  | 22  (56,4) | 8  (20,5) | 9  (23,1) |  |
| The patient is irritable, argue or complain | 22  (56,4) | 6  (15,4) | 3  (7,7) | 8  (20,5) |  | 18  (47,4) | 11  (28,9) | 9  (23,7) |  |
| The patient has been verbally aggressive to you or others | 17  (43,6) | 11  (28,2) | 8  (20,5) | 3  (7,7) |  | 16  (42,1) | 13  (34,2) | 9  (23,7) |  |
| The patient has the amount of speech significantly decreased | 9  (23,7) | 6  (15,8) | 6  (15,8) | 17  (44,7) |  | 8  (21,1) | 12  (31,6) | 18  (47,4) |  |
| The patient has lost the ability to converse | 14  (35,9) | 7  (17,9) | 4  (10,3) | 14  (35,9) |  | 10  (26,3) | 9  (23,7) | 19  (50,0) |  |
| The patient lost interest in friends or daily activities | 19  (48,7) | 3  (7,7) | 4  (10,3) | 13  (33,3) |  | 15  (39,5) | 8  (21,1) | 15  (39,5) |  |
| The patient lost interest in friends or family members | 20  (51,3) | 7  (17,9) | 2  (5,1) | 10  (25,6) |  | 18  (47,4) | 7  (18,4) | 13  (34,2) |  |
| The patient lost interest in doing things or lack motivation for starting new activities | 12  (30,8) | 3  (7,7) | 6  (15,4) | 18  (46,2) |  | 10  (26,3) | 10  (26,3) | 18  (47,4) |  |
| The patient has trouble remembering the names of relatives or friends | 14  (36,8) | 3  (7,9) | 7  (18,4) | 14  (36,8) |  | 15  (41,7) | 8  (22,2) | 13  (36,1) |  |
| The patient asks the same question many times | 10  (26,3) | 2  (5,3) | 5  (13,2) | 21  (55,3) |  | 11  (29,7) | 6  (16,2) | 20  (54,1) |  |
| The patient is unaware of problems/changes or deny them when discussed | 10  (27,0) | 8  (21,6) | 9  (24,3) | 10  (27,0) |  | 9  (25,0) | 13  (36,1) | 14  (38,9) |  |

# CAREGIVERS DIARY-QUESTIONNAIRE 2

The following part of this result section shows a series of tables analyzing the daily situations that arise during the care of the relative. The situations were collected on a daily basis for seven consecutive days. Each table records the frequency of the behavior (how often the problem affects the caregiver’s daily life), the severity for the behavior (how the problem affects the caregiver’s and the patient´s daily life) and the discomfort this problem causes to the caregiver.

## Selection of tags

These tables contain the results collected from the Caregivers Diary, and correspond to the Questionnaire 2 document. The tables are separated by the Main Categories used to classify the behavior of the patient: Table 13: Daily tasks, Table 14: Social activities, Table 15: Behavior and Table 16: Cognitive activities. Firstly the **mean** and standard deviation (SD) of the frequency, severity and discomfort was calculated for every question. The tables therefore record the mean and the standard deviation for every answer. In order to select those questions to be included in the “UnderstAID Platform” Menu, it was taken into account the level of discomfort that every situation caused on the caregiver. For every question, the means of the seven days collection were calculated. If the number of “0” answers was higher than the rest, that question was discarded (Not to be included as a tag).

## Classification of tags

Once the question was selected, the answer was classified as “Highly relevant” tag, “Relevant” tag or “Not particular relevant” tag. To do that, the means for every answer were reviewed again. The “0” or “missing” answers were discarded and the rest were selected. The selected items were classified in three equal groups by using the “Percentile Values” option in SPSS. Consequently, the group in the upper range (higher values) was composed by the “High relevant” answers, the one in the medium range (medium values) was composed by the “Relevant” answers and finally the group in the lower range was composed by the “Not particular relevant” answers. Afterwards the number of cases “n” in each group was counted up (Highly relevant, Relevant Not particular relevant). The range with the higher n determines the category of that item. The selected items were classified in the Tables 17, 18 and 19.

## Results: selection of tags

Table 13, Daily Tasks, records these sub-categories: Personal hygiene, Personal appearance, Household chores, Sleep behavior or disorders and Appetite and eating changes. Only one item was chosen according to the exclusion criteria and that were in the sub-categories “household chores” and the question about assisting the patient to use the electrical appliances.

Table 14, Social activities, records these sub-categories: Participation in conversation, Activities with family and friends, Engagement in hobbies and recreation and Socially acceptable conduct. Six items was selected according to the election process and 2 were excluded. The 2 excluded were both from the “Socially acceptable conduct” so all the items in Participation in conversation, Activities with family and friends, Engagement in hobbies and recreation is past on in the evaluation.

Table 15, Behavior, records these sub-categories: Suspiciousness and false beliefs, General mood, Anxiety level and Agitation/Lack of inhibition/Aggressiveness. Only 4 items were qualified for further evaluation. All 3 items from the sub-category “Indifference /Apathy/Motivation to act” were selected and 1 item form the sub-category “general mood” was also selected.

Table 16, Cognitive activities, contains these sub-categories: Name and event recollection, Finding appropriate words, Orientation, Awareness of the environment and Make decisions. Only two items were excluded from the items in Table 16. One item in “name and event recollection” and one item in “finding appropriate words”. The remaining 13 items were past on in the process, and the sub-categories “orientation”, “awareness of the environment” and “make decisions” were all past on with all the items included.

## Results: classification of tags

Tables 17, 18 and 19 contains the selected items for “Highly relevant”, “Relevant” and “Not particular relevant” tags.

In Table 17 we found 4 items with sufficient score to get the “highly relevant” tagging. One from each of the sub-categories “behavior” and “social activities” and two from the “cognitive activities” category.

In Table 18 we found 7 items with sufficient score to get the “relevant” tagging. Two from the sub-category “behavior”, one from the “Social activities” and four from the “Cognitive activities” category.

In table 19 we found 13 items with sufficient score to get the “not particular relevant” tag. One item from the category “daily tasks” and relating to assisting the patient with electric appliances. One item was related to “behavior” , on less spontaneous activities. Four items were related to the tag “Social activities” and 7 items were related to “Cognitive activities”.

To summarize, there were selected 24 items to be evaluated in different levels of importance in relation to the platform building. The most relevant finding is the many items was given the tag “not particular relevant” witch is something needed to be taken in consideration when designing and building the understAID platform.

Table 13. Q2. Daily tasks

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Frequency** | | **Severity** | | **Discomfort** | |
| **Mean** | **SD** | **Mean** | **SD** | **Mean** | **SD** |
| Personal hygiene |  |  |  |  |  |  |
| The patient does not take as much care of his/her personal hygiene and appearance as usually | 3,67 | 3,29 | 1,00 | 0,90 | 0,75 | 0,97 |
| The patient gets upset with those trying to care for him/her or resist activities such as bathing or changing clothes | 2,59 | 3,29 | 1,02 | 1,86 | 0,71 | 1,00 |
| Personal appearance |  |  |  |  |  |  |
| You have to tell the patient that he/she should brush his/her teeth or comb his/her hair | 2,13 | 3,18 | 0,56 | 0,90 | 0,47 | 0,90 |
| You have to assist the patient in brushing his teeth | 1,16 | 2,61 | 0,23 | 0,50 | 0,23 | 0,50 |
| You have to assist the patient in combing his hair | 1,16 | 2,61 | 0,26 | 0,59 | 0,26 | 0,64 |
| You have to assist the patient to get ready | 1,74 | 2,93 | 0,45 | 0,75 | 0,40 | 0,85 |
| Household chores |  |  |  |  |  |  |
| You have to assist the patient in shopping | 3,81 | 3,27 | 1,47 | 1,19 | 0,70 | 0,99 |
| You have to assist the patient in cooking | 3,93 | 3,31 | 1,52 | 1,22 | 0,79 | 1,03 |
| You have to assist the patient to use the electrical appliances | 4,23 | 3,21 | 1,38 | 1,11 | 0,83 | 1,00 |
| Sleep behaviour or disorders |  |  |  |  |  |  |
| The patient has difficulty sleeping | 1,92 | 2,92 | 0,54 | 0,82 | 0,37 | 0,72 |
| The patient wanders at night or get dressed | 1,35 | 2,47 | 0,51 | 0,87 | 0,48 | 0,86 |
| The patient awakes you or any member of your family during the night | 2,58 | 3,12 | 0,83 | 1,05 | 0,72 | 0,97 |
| Appetite and eating changes |  |  |  |  |  |  |
| The patient has any change in appetite, weight, or eating habits | 3,12 | 3,30 | 0,94 | 1,03 | 0,63 | 0,91 |
| The patient has a change in the kind of food he/she likes | 2,01 | 3,07 | 0,63 | 0,95 | 0,47 | 0,85 |
| The patient has an increase in appetite | 1,48 | 2,62 | 0,58 | 0,97 | 0,27 | 0,63 |
| The patient has a decrease in appetite\* |  |  |  |  |  |  |

\*Missing data

Table 14. Q2. Social activities

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | **Frequency** | | **Severity** | | **Discomfort** | |
| **Mean** | **SD** | **Mean** | **SD** | **Mean** | **SD** |
| Participating in conversation |  |  |  |  |  |  |
| The patient has the amount of speech significantly decreased | 4,25 | 3,11 | 1,50 | 1,12 | 1,37 | 1,11 |
| The patient has lost the ability to converse | 4,82 | 2,73 | 1,74 | 1,00 | 1,44 | 1,12 |
| Activities with family and friends |  |  |  |  |  |  |
| The patient lost interest in friends or daily activities | 5,06 | 2,84 | 1,41 | 1,00 | 1,34 | 1,04 |
| The patient lost interest in friends or family members | 4,72 | 3,07 | 1,23 | 0,85 | 1,41 | 1,00 |
| Engagement in hobbies and recreation |  |  |  |  |  |  |
| The patient lost interest in doing things or lack motivation for starting new activities | 5,62 | 2,50 | 1,60 | 0,89 | 1,30 | 0,93 |
| The patient is less enthusiastic about his/her usual interests | 4,58 | 3,05 | 1,44 | 1,06 | 1,13 | 1,03 |
| Socially acceptable conduct |  |  |  |  |  |  |
| The patient do things outside what are acceptable | 2,38 | 3,15 | 0,68 | 0,88 | 0,74 | 0,98 |
| The patient is rude, or childish | 2,23 | 3,03 | 0,57 | 0,73 | 0,62 | 0,82 |

Table 15. Q2. Behaviour

|  | **Frequency** | | | | **Severity** | | | | **Discomfort** | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Mean** | | **SD** | | **Mean** | | **SD** | | **Mean** | | **SD** | |
| Suspiciousness and false beliefs |  | |  | |  | |  | |  | |  | |
| The patient believes in things that you know are unreal | 2,34 | | 2,93 | | 0,85 | | 0,96 | | 0,66 | | 1,03 | |
| The patient has hallucinations such as seeing false visions or hearing false voices | 1,58 | | 2,73 | | 0,47 | | 0,76 | | 0,40 | | 0,86 | |
| General mood |  | |  | |  | |  | |  | |  | |
| The patient loses their emotional responsiveness | 4,50 | | 3,23 | | 1,10 | | 0,97 | | 0,97 | | 0,96 | |
| The patient appears sad or depressed | 3,31 | | 3,48 | | 0,80 | | 0,95 | | 0,70 | | 0,93 | |
| The patient cries sometimes | 1,84 | | 2,90 | | 0,54 | | 0,81 | | 0,62 | | 1,02 | |
| The patient expresses feelings of sadness or depression | 3,50 | | 3,45 | | 0,88 | | 0,88 | | 0,81 | | 0,99 | |
| The patient comments about death of self or others (e.g. “Life isn´t worth living”, “I´d be better off dead”) | 1,38 | | 2,77 | | 0,32 | | 0,65 | | 0,34 | | 0,72 | |
| The patient comments about feeling worthless or being a burden to others | 1,91 | | 2,99 | | 0,40 | | 0,66 | | 0,44 | | 0,76 | |
| The patient comments about feeling like a failure or about not having any worthwhile accomplishments in life | 0,47 | | 1,61 | | 0,18 | | 0,52 | | 0,18 | | 0,52 | |
| The patient talks about feeling lonely | 1,09 | | 2,35 | | 0,31 | | 0,69 | | 0,32 | | 0,74 | |
| Anxiety level |  | |  | |  | |  | |  | |  | |
| The patient appears to be anxious, worried or frightened for no apparent reason | 1,82 | | 2,91 | | 0,49 | | 0,83 | | 0,51 | | 0,88 | |
| The patient appears to be uneasy or nervous | 2,55 | | 3,19 | | 0,59 | | 0,73 | | 0,48 | | 0,72 | |
| Indifference/Apathy/Motivation to act | |  | |  | |  | |  | |  | |  |
| The patient has lack of initiative | 5,47 | | 2,50 | | 1,60 | | 0,96 | | 1,32 | | 1,07 | |
| The patient seems less spontaneous or less active than usual | 5,19 | | 2,80 | | 1,64 | | 1,06 | | 1,38 | | 1,11 | |
| The patient seems less interested in the activities and plans of others | 4,77 | | 3,00 | | 1,47 | | 1,02 | | 1,16 | | 1,15 | |
| Apprehension, unaesiness | |  | |  | |  | |  | |  | |  |
| The patient feels uneasy or hyperactive | 3,03 | | 3,22 | | 0,78 | | 0,85 | | 0,67 | | 0,88 | |
| The patient does things over and over such as pace, opening closets or drawers, or repeatedly pick at things, etc. | 3,10 | | 3,40 | | 0,88 | | 1,06 | | 0,68 | | 0,99 | |
| The patient is irritable, argue or complain | 2,94 | | 3,32 | | 0,79 | | 0,88 | | 0,83 | | 1,00 | |
| Agitation, lack of inhibition, aggressiveness | |  | |  | |  | |  | |  | |  |
| The patient destroys the property | 0,94 | | 2,36 | | 0,26 | | 0,63 | | 0,21 | | 0,53 | |
| The patient does things that embarrass you | 1,81 | | 2,86 | | 0,50 | | 0,66 | | 0,53 | | 0,87 | |
| The patient talks loudly and rapidly | 0,97 | | 2,39 | | 0,18 | | 0,45 | | 0,17 | | 0,49 | |
| The patient engages in behaviour that is potentially dangerous to self or others | 1,09 | | 2,58 | | 0,24 | | 0,59 | | 0,32 | | 0,80 | |
| The patient threatened of hurting him/herself | 0,47 | | 1,72 | | 0,09 | | 0,30 | | 0,16 | | 0,57 | |
| The patient has been verbally aggressive to you or others | 2,53 | | 2,87 | | 0,85 | | 1,20 | | 0,60 | | 0,84 | |

Table 16. Q2. Cognitive activities

|  | **Frequency** | | **Severity** | | **Discomfort** | |
| --- | --- | --- | --- | --- | --- | --- |
| **Mean** | **SD** | **Mean** | **SD** | **Mean** | **SD** |
| Name and event recollection |  |  |  |  |  |  |
| The patient has trouble remembering the names of relatives or friends | 4,28 | 3,02 | 1,31 | 0,91 | 0,89 | 0,90 |
| The patient has trouble remembering recent events (e.g. items in the newspaper or on TV) | 5,56 | 2,34 | 1,72 | 0,87 | 1,22 | 0,95 |
| The patient asks the same question many times | 4,56 | 3,13 | 1,45 | 1,09 | 1,01 | 1,05 |
| The patient has trouble remembering significant past events | 3,53 | 3,37 | 1,01 | 1,14 | 0,80 | 1,01 |
| The patient loses or misplace things | 4,90 | 2,90 | 1,46 | 0,95 | 1,17 | 0,96 |
| Finding appropriate words |  |  |  |  |  |  |
| The patient has trouble finding the appropriate word when trying to communicate | 4,50 | 2,98 | 1,49 | 1,13 | 0,97 | 1,01 |
| The patient makes language or pronunciation errors | 2,69 | 3,23 | 0,79 | 1,07 | 0,54 | 0,81 |
| Orientation |  |  |  |  |  |  |
| The patient loses his/her orientation in common places | 4,22 | 3,08 | 1,69 | 1,46 | 1,23 | 1,10 |
| The patient does not know the date (month, day and time) | 4,70 | 2,98 | 1,62 | 1,42 | 1,01 | 0,95 |
| Awareness of the environment |  |  |  |  |  |  |
| The patient has difficulty concentrating on a task | 5,74 | 2,21 | 1,60 | 0,89 | 1,17 | 0,99 |
| The patient loses the interest in the world around him/her | 3,68 | 3,33 | 1,16 | 1,03 | 1,10 | 1,12 |
| The patient is unaware of problems/changes or deny them when discussed | 4,97 | 2,89 | 1,56 | 1,08 | 1,48 | 1,15 |
| The patient is not able to follow instructions | 5,45 | 2,54 | 1,61 | 0,99 | 1,27 | 1,01 |
| Make decision |  |  |  |  |  |  |
| The patient is not able to make decisions about daily life (choosing clothes or food) | 3,81 | 3,23 | 1,19 | 1,07 | 0,87 | 1,08 |
| The patient has been acting impulsively, irresponsibly, neglectfully or in poor judgment | 3,81 | 3,22 | 1,11 | 1,05 | 1,01 | 1,07 |

Table 17. Q2. Selected items: Highly relevant tags

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Frequency** | | **Severity** | |
|  | **Mean** | **SD** | **Mean** | **SD** |
| The patient has trouble remembering the names of relatives or friends | 4,28 | 3,02 | 1,31 | 0,91 |
| The patient has lost the ability to converse | 4,82 | 2,73 | 1,74 | 1,00 |
| The patient is unaware of problems/changes or deny them when discussed | 4,97 | 2,89 | 1,56 | 1,08 |
| The patient is not able to make decisions about daily life (choosing clothes or food) | 3,81 | 3,23 | 1,19 | 1,07 |

Table 18. Q2. Selected items: Relevant tags

|  | **Frequency** | | **Severity** | |
| --- | --- | --- | --- | --- |
|  | **Mean** | **SD** | **Mean** | **SD** |
| The patient loses his/her orientation in common places | 4,22 | 3,08 | 1,69 | 1,46 |
| The patient loses or misplace things | 4,90 | 2,90 | 1,46 | 0,95 |
| The patient lost interest in friends or family members | 4,72 | 3,07 | 1,23 | 0,85 |
| The patient loses their emotional responsiveness | 4,50 | 3,23 | 1,10 | 0,97 |
| The patient has lack of initiative | 5,47 | 2,50 | 1,60 | 0,96 |
| The patient asks the same question many times | 4,56 | 3,13 | 1,45 | 1,09 |
| The patient loses the interest in the world around him/her | 3,68 | 3,33 | 1,16 | 1,03 |

Table 19. Q2. Selected items: Not particular relevant tags

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Frequency** | | **Severity** | |
|  | **Mean** | **SD** | **Mean** | **SD** |
| You have to assist the patient to use the electrical appliances | 4,23 | 3,21 | 1,38 | 1,11 |
| The patient has the amount of speech significantly decreased | 4,25 | 3,11 | 1,50 | 1,12 |
| The patient lost interest in friends or daily activities | 5,06 | 2,84 | 1,41 | 1,00 |
| The patient lost interest in doing things or lack motivation for starting new activities | 5,62 | 2,50 | 1,60 | 0,89 |
| The patient is less enthusiastic about his/her usual interests | 4,58 | 3,05 | 1,44 | 1,06 |
| The patient expresses feelings of sadness or depression | 3,50 | 3,45 | 0,88 | 0,88 |
| The patient seems less interested in the activities and plans of others | 4,77 | 3,00 | 1,47 | 1,02 |
| The patient has trouble remembering recent events (e.g. items in the newspaper or on TV) | 5,56 | 2,34 | 1,72 | 0,87 |
| The patient has trouble finding the appropriate word when trying to communicate | 4,50 | 2,98 | 1,49 | 1,13 |
| The patient does not know the date (month, day and time) | 4,70 | 2,98 | 1,62 | 1,42 |
| The patient has difficulty concentrating on a task | 5,74 | 2,21 | 1,60 | 0,89 |
| The patient is not able to follow instructions | 5,45 | 2,54 | 1,61 | 0,99 |
| The patient has been acting impulsively, irresponsibly, neglectfully or in poor judgment | 3,81 | 3,22 | 1,11 | 1,05 |

# PROFESSIONAL ASSESSMENT-QUESTIONNAIRE 3

The following part of this result section shows a series of tables that record the point of view of the professional caregivers with regard to the daily situations that may arise during the care of the patient. Each table records the frequency of the behavior (how often the problem affects the caregiver’s daily life) and the severity of the behavior (how the problem affects the caregiver’s and the patient´s daily life).

## Selection of tags

These tables contain the results collected during the Professional Assessment of the patient, and correspond to the Questionnaire 3 document. The tables are separated by the Main Categories used to classify the deficits of the patients: Table 20: Daily tasks, Table 21: Social activities, Table 22: Behavior and Table 23: Cognitive activities. These tables contain the number of professional caregivers that chose an answer (“n”) and the percentage (“%”). In order to select those questions that will be included in the “UnderstAID Platform” Menu, the **frequency** of every situation was taken into account. There were discarded those questions in which the number of caregivers that chose the “Occasionally” option was higher than the total number of caregivers that chose any of the three other options (Often, Frequently, Very frequently).

## Classification of tags

Once the questions were selected, the items were classified as “Highly relevant” tags, “Relevant” tags or “Not particular relevant” tags. To do that, it was reviewed the number of professional caregivers that selected every answer (“n”; Often, Frequently, Very frequently) and the more frequent answer was chosen. If the more frequent was “Very frequently”, it was considered as “Highly relevant” tag to be included in the platform (Table 24). If the more frequent answer was “Frequently” it was considered as “Relevant” tag to be included in the platform (Table 25). And finally, if the more frequent answer was “Often” it was considered as “Not particular relevant” tag to be included in the platform (not included due to no items tagged). In the cases of several options with the same “n”, the “average” category was selected.

## Results: selection of tags

Table 20, Daily Tasks, records these sub-categories: Personal hygiene, Personal appearance, Household chores, Sleep behavior or disorders and Appetite and eating changes. Following the instructions explained before, 10 items were discarded, and 7 of them belonged to the sub-categories of “Sleep behavior or disorders” and “Appetite and eating changes”. Household are the only sub-category where all the items were regarded as relevant by the professionals.

Table 21, Social activities, records these sub-categories: Participation in conversation, Activities with family and friends, Engagement in hobbies and recreation and Socially acceptable conduct. In table 22 only 2 items were discarded, and they both belonged to the sub-category “social acceptable conduct” and that category will therefore not be included in the further analysis.

Table 22, behavior, records these sub-categories: Suspiciousness and false beliefs, General mood, Anxiety level, Indifference/Apathy/Motivation to act, Apprehension/Uneasiness and Agitation/Lack of inhibition/Aggressiveness. After applying the selection criteria 23 items were discarded, leveeing only 2 items for further analysis. Therefore no items from the sub-categories; “Suspiciousness and false beliefs”, “General mood”, “Anxiety level”, “Apprehension/Uneasiness” and “Agitation/Lack of inhibition/Aggressiveness” are included for further analysis. The only questions found relevant to include were about lack of initiative and being less spontaneous.

Table 23, Cognitive activities, contains these sub-categories: Finding appropriate words, Name and event recollection, Orientation, Awareness of the environment and Make decisions. Only 1 item was excluded and that was about the patient asking the same question many times. The sub-categories “finding appropriate words”, “orientation”, “awareness of the environment” and “make decisions” came out with all the items selected for further processing.

## Results: classification of tags

The items passed on from the initial screening process was evaluated according to instructions above, and revealed the following distribution among the tags “Highly relevant” and “Relevant”. No items were placed in the category “Not particularly relevant”.

Table 24 reveals 25 items with “highly relevant” tag. Six items from the sub-category “daily tasks”, 5 items from “social activities”, 2 items on “behaviour” and 12 items from “Cognitive activities”.

In table 25 only 3 items were given the tag “relevant” and they were one in “behaviour” and 2 in “Cognitive activities”.

In total, 28 items were selected to be included in different levels of importance of the platform the majority in the “highly relevant” category witch I to be taken in to special consideration when designing a building the content for the for the understAID platform.

Table 20. Q3. Daily task (n, %)

|  | **Frequency** | | | | | **Severity** | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Occasionally** | **Often** | **Frequently** | **Very frequently** | **NA** | **Mild** | **Moderate** | **Intense** | **NA** |
| Personal hygiene |  |  |  |  |  |  |  |  |  |
| The patient does not take as much care of his/her personal hygiene and appearance as usually | 11  (50,0) | 4  (18,2) | 1  (4,5) | 6  (27,3) |  | 8  (40,0) | 7  (35,0) | 5  (25,0) |  |
| The patient gets upset with those trying to care for him/her or resist activities such as bathing or changing clothes | 17  (77,3) | 4  (18,2) | 1  (4,5) | 0  (0,0) |  | 16  (80,0) | 3  (15,0) | 1  (5,0) |  |
| Personal appearance |  |  |  |  |  |  |  |  |  |
| You have to tell the patient that he/she should brush his/her teeth or comb his/her hair | 8  (50,0) | 1  (6,3) | 3  (18,8) | 4  (25,0 |  | 8  (61,5) | 5  (38,5) | 0  (0,0) |  |
| You have to assist the patient in brushing his teeth | 8  (53,3) | 1  (6,7) | 2  (13,3) | 4  (26,7) |  | 8  (61,5) | 5  (38,5) | 0  (0,0) |  |
| You have to assist the patient in combing his hair | 8  (53,3) | 1  (6,7) | 2  (13,3) | 4  (26,7) |  | 8  (61,5) | 5  (38,5) | 0  (0,0) |  |
| You have to assist the patient to get ready | 7  (50,0) | 1  (7,1) | 2  (14,3) | 4  (28,6) |  | 7  (58,3) | 5  (41,7) | 0  (0,0) |  |
| Household chores |  |  |  |  |  |  |  |  |  |
| You have to assist the patient in shopping | 2  (11,1) | 1  (5,6) | 0  (0,0) | 15  (83,3) |  | 6  (35,3) | 2  (11,8) | 9  (52,9) |  |
| You have to assist the patient in cooking | 2  (10,5) | 1  (5,3) | 0  (0,0) | 16  (84,2) |  | 4  (23,5) | 1  (5,9) | 12  (70,6) |  |
| You have to assist the patient to use the electrical appliances | 5  (27,8) | 1  (5,6) | 0  (0,0) | 12  (66,7) |  | 7  (43,8) | 1  (6,3) | 8  (50,0) |  |
| Sleep behaviour or disorders |  |  |  |  |  |  |  |  |  |
| The patient has difficulty sleeping | 6  (60,0) | 1  (10,0) | 1  (10,0) | 2  (20,0) |  | 7  (77,8) | 2  (22,2) | 0  (0,0) |  |
| The patient wanders at night or get dressed | 8  (80,0) | 0  (0,0) | 1  (10,0) | 1  (10,0) |  | 7  (87,5) | 0  (0,0) | 1  (12,5) |  |
| The patient awakes you or any member of your family during the night | 6  (60,0) | 2  (20,0) | 1  (10,0) | 1  (10,0) |  | 7  (77,8) | 1  (11,1) | 1  (11,1) |  |
| Appetite and eating changes |  |  |  |  |  |  |  |  |  |
| The patient has any change in appetite, weight, or eating habits | 13  (68,4) | 2  (10,5) | 1  (5,3) | 3  (15,8) |  | 13  (72,2) | 4  (22,2) | 1  (5,6) |  |
| The patient has a change in the kind of food he/she likes | 15  (83,3) | 0  (0,0) | 1  (5,6) | 2  (1,11) |  | 15  (88,2) | 1  (5,9) | 1  (5,9) |  |
| The patient has an increase in appetite | 16  (88,9) | 0  (0,0) | 0  (0,0) | 2  (11,1) |  | 16  (94,1) | 0  (0,0) | 1  (5,9) |  |
| The patient has a decrease in appetite\* |  |  |  |  |  |  |  |  |  |

\*Missing data

Table 21. Q3. Social activities (n, %)

|  | **Frequency** | | | | | **Severity** | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Occasionally** | **Often** | **Frequently** | **Very frequently** | **NA** | **Mild** | **Moderate** | **Intense** | **NA** |
| Participating in conversation |  |  |  |  |  |  |  |  |  |
| The patient has the amount of speech significantly decreased | 8  (40,0) | 3  (15,0) | 4  (20,0) | 5  (25,0) |  | 9  (45,0) | 7  (35,0) | 4  (20,0) |  |
| The patient has lost the ability to converse | 7  (33,3) | 1  (4,8) | 2  (9,5) | 11  (52,4) |  | 8  (38,1) | 6  (28,6) | 7  (33,3) |  |
| Activities with family and friends |  |  |  |  |  |  |  |  |  |
| The patient lost interest in friends or daily activities | 10  (43,5) | 3  (13,0) | 3  (13,0) | 7  (30,4) |  | 14  (63,6) | 3  (13,6) | 5  (22,7) |  |
| The patient lost interest in friends or family members | 10  (47,6) | 2  (9,5) | 5  (23,8) | 4  (19,0) |  | 13  (65,0) | 2  (10,0) | 5  (25,0) |  |
| Engagement in hobbies and recreation | |  |  |  |  |  |  |  |  |
| The patient lost interest in doing things or lack motivation for starting new activities | 9  (39,1) | 1  (4,3) | 1  (4,3) | 12  (52,2) |  | 7  (35,0) | 4  (20,0) | 9  (45,0) |  |
| The patient is less enthusiastic about his/her usual interests | 9  (42,9) | 2  (9,5) | 1  (4,8) | 9  (42,9) |  | 8  (42,1) | 3  (15,8) | 8  (42,1) |  |
| Socially acceptable conduct |  |  |  |  |  |  |  |  |  |
| The patient do things outside what are acceptable | 18  (78,3) | 1  (4,3) | 2  (8,7) | 2  (8,7) |  | 17  (81,0) | 2  (9,5) | 2  (9,5) |  |
| The patient is rude, or childish | 15  (71,4) | 3  (14,3) | 2  (9,5) | 1  (4,8) |  | 13  (68,4) | 4  (21,1) | 2  (10,5) |  |

Table 22. Q3. Behaviour (n, %)

|  | **Frequency** | | | | | | **Severity** | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Occasionally** | **Often** | | **Frequently** | **Very frequently** | **NA** | **Mild** | **Moderate** | **Intense** | **NA** |
| Suspiciousness and false beliefs |  |  | |  |  |  |  |  |  |  |
| The patient believes in things that you know are unreal | 14  (66,7) | 5  (23,8) | | 1  (4,8) | 1  (4,8) |  | 11  (61,1) | 6  (33,3) | 1  (5,6) |  |
| The patient has hallucinations such as seeing false visions or hearing false voices | 18  (90,0) | 2  (10,0) | | 0  (0,0) | 0  (0,0) |  | 17  (100,0) | 0  (0,0) | 0  (0,0) |  |
| General mood |  |  | |  |  |  |  |  |  |  |
| The patient loses their emotional responsiveness | 13  (61,9) | 1  (4,8) | | 3  (14,3) | 4  (19,0) |  | 12  (60,0) | 4  (20,0) | 4  (20,0) |  |
| The patient appears sad or depressed | 12  (52,2) | 5  (21,7) | | 5  (21,7) | 1  (4,3) |  | 13  (56,5) | 6  (26,1) | 4  (17,4) |  |
| The patient cries sometimes | 17  (81,0) | 0  (0,0) | | 3  (14,3) | 1  (4,8) |  | 17  (81,0) | 0  (0,0) | 4  (19,0) |  |
| The patient expresses feelings of sadness or depression | 16  (69,6) | 2  (8,7) | | 5  (21,7) | 0  (0,0) |  | 15  (68,2) | 3  (13,6) | 4  (18,2) |  |
| The patient comments about death of self or others (e.g. “Life isn´t worth living”, “I´d be better off dead”) | 19  (95,0) | 1  (5,0) | | 0  (0,0) | 0  (0,0) |  | 19  (95,0) | 1  (5,0) | 0  (0,0) |  |
| The patient comments about feeling worthless or being a burden to others | 21  (100,0) | 0  (0,0) | | 0  (0,0) | 0  (0,0) |  | 18  (90,0) | 2  (10,0) | 0  (0,0) |  |
| The patient comments about feeling like a failure or about not having any worthwhile accomplishments in life | 19  (95,0) | 1  (5,0) | | 0  (0,0) | 0  (0,0) |  | 18  (94,7) | 1  (5,3) | 0  (0,0) |  |
| The patient talks about feeling lonely | 17  (85,0) | 0  (0,0) | | 2  (10,0) | 1  (5,0) |  | 16  (84,2) | 1  (5,3) | 2  (10,5) |  |
| The patient change significantly his/her mood | 17  (77,3) | 0  (0,0) | | 1  (4,5) | 4  (18,2) |  | 15  (75,0) | 3  (15,0) | 2  (10,0) |  |
| Anxiety level |  |  | |  |  |  |  |  |  |  |
| The patient appears to be anxious, worried or frightened for no apparent reason | 18  (81,8) | 1  (4,5) | | 1  (4,5) | 2  (9,1) |  | 20  (90,9) | 1  (4,5) | 1  (4,5) |  |
| The patient appears to be uneasy or nervous | 15  (68,2) | 8  (13,6) | | 1  (4,5) | 3  (13,6) |  | 18  (81,8) | 2  (9,1) | 2  (9,1) |  |
| Indifference/Apathy/Motivation to act | |  | |  |  |  |  |  |  |  |
| The patient has lack of initiative | 8  (34,8) | 2  (8,7) | | 4  (17,4) | 9  (39,1) |  | 10  (43,5) | 7  (30,4) | 6  (26,1) |  |
| The patient seems less spontaneous or less active than usual | 8  (34,8) | 4  (17,4) | | 3  (13,0) | 8  (34,8) |  | 10  (43,5) | 5  (21,7) | 8  (34,8) |  |
| The patient seems less interested in the activities and plans of others | 12  (54,5) | 1  (4,5) | | 3  (13,6) | 6  (27,3) |  | 14  (63,6) | 2  (9,1) | 6  (27,3) |  |
| Apprehension, uneasiness |  |  | |  |  |  |  |  |  |  |
| The patient feels uneasy or hyperactive | 17  (81,0) | 1  (4,8) | | 1  (4,8) | 2  (9,5) |  | 17  (81,0) | 3  (14,3) | 1  (4,8) |  |
| The patient does things over and over such as pace, opening closets or drawers, or repeatedly pick at things, etc. | 15  (65,2) | 3  (13,0) | | 3  (13,0) | 2  (8,7) |  | 16  (69,6) | 4  (17,4) | 3  (13,0) |  |
| The patient is irritable, argue or complain | 17  (77,3) | 3  (13,6) | | 2  (9,1) | 0  (0,0) |  | 18  (81,8) | 2  (9,1) | 2  (9,1) |  |
| Agitation, lack of inhibition, aggressiveness | |  |  | |  |  |  |  |  |  |
| The patient destroys the property | 21  (100,0) | 0  (0,0) | 0  (0,0) | | 0  (0,0) |  | 21  (100,0) | 0  (0,0) | 0  (0,0) |  |
| The patient does things that embarrass you | 19  (90,5) | 1  (4,8) | 0  (0,0) | | 1  (4,8) |  | 19  (90,5) | 1  (4,8) | 1  (4,8) |  |
| The patient talks loudly and rapidly | 18  (90,0) | 0  (0,0) | 0  (0,0) | | 2  (10,0) |  | 19  (100,0) | 0  (0,0) | 0  (0,0) |  |
| The patient engages in behaviour that is potentially dangerous to self or others | 17  (85,0) | 2  (10,0) | 1  (5,0) | | 0  (0,0) |  | 17  (89,5) | 2  (10,5) | 0  (0,0) |  |
| The patient threatened of hurting him/herself | 20  (100,0) | 0  (0,0) | 0  (0,0) | | 0  (0,0) |  | 20  (100,0) | 0  (0,0) | 0  (0,0) |  |
| The patient has been verbally aggressive to you or others | 18  (85,7) | 3  (14,3) | 0  (0,0) | | 0  (0,0) |  | 18  (90,0) | 2  (10,0) | 0  (0,0) |  |

Table 23. Q3. Cognitive activities (n, %)

|  | **Frequency** | | | | | **Severity** | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **Occasionally** | **Often** | **Frequently** | **Very frequently** | **NA** | **Mild** | **Moderate** | **Intense** | **NA** |
| Finding appropriate words |  |  |  |  |  |  |  |  |  |
| The patient has trouble finding the appropriate word when trying to communicate | 11  (47,8) | 2  (8,7) | 3  (13,0) | 7  (30,4) |  | 10  (43,5) | 6  (26,1) | 7  (30,4) |  |
| The patient makes language or pronunciation errors | 14  (70,0) | 1  (5,0) | 2  (10,0) | 3  (15,0) |  | 14  (70,0) | 2  (10,0) | 4  (20,0) |  |
| Name and event recollection |  |  |  |  |  |  |  |  |  |
| The patient has trouble remembering the names of relatives or friends | 11  (50,0) | 4  (18,2) | 3  (13,6) | 4  (18,2) |  | 12  (54,5) | 7  (31,8) | 3  (13,6) |  |
| The patient has trouble remembering recent events (e.g. items in the newspaper or on TV) | 7  (30,4) | 4  (17,4) | 2  (8,7) | 9  (39,1) | 1  (4,3) | 7  (30,4) | 8  (34,8) | 7  (30,4) | 1  (4,3) |
| The patient asks the same question many times | 13  (59,1) | 2  (9,1) | 3  (13,6) | 3  (13,6) | 1  (4,5) | 15  (68,2) | 3  (13,6) | 3  (13,6) | 1  (4,5) |
| The patient has trouble remembering significant past events | 10  (45,5) | 4  (18,2) | 4  (18,2) | 3  (13,6) | I  (4,5) | 11  (50,0) | 6  (27,3) | 4  (18,2) | 1  (4,5) |
| The patient loses or misplace things | 7  (35,0) | 4  (20,0) | 3  (15,0) | 5  (25,0) | 1  (5,0) | 8  (40,0) | 7  (35,0) | 4  (20,0) | 1  (5,0) |
| Orientation |  |  |  |  |  |  |  |  |  |
| The patient loses his/her orientation in common places | 9  (39,1) | 2  (8,7) | 1  (4,3) | 11  (47,8) |  | 9  (42,9) | 3  (14,3) | 9  (42,9) |  |
| The patient does not know the date (month, day and time) | 8  (36,4) | 3  (13,6) | 0  (0,0) | 11  (50,0) |  | 9  (45,0) | 2  (10,0) | 8  (40,0) | 1  (5,0) |
| Awareness of the environment |  |  |  |  |  |  |  |  |  |
| The patient has difficulty concentrating on a task | 11  (50,0) | 2  (9,1) | 4  (18,2) | 5  (22,7) |  | 11  (52,4) | 7  (33,3) | 3  (14,3) |  |
| The patient loses the interest in the world around him/her | 10  (50,0) | 2  (10,0) | 4  (20,0) | 4  (20,0) |  | 9  (47,4) | 5  (26,3) | 5  (26,3) |  |
| The patient is unaware of problems/changes or deny them when discussed | 5  (22,7) | 3  (13,6) | 2  (9,1) | 12  (54,5) |  | 3  (13,6) | 8  (36,4) | 11  (50,0) |  |
| The patient is not able to follow instructions | 7  (35,0) | 0  (0,0) | 5  (25,0) | 8  (40,0) |  | 10  (50,0) | 4  (20,0) | 6  (30,0) |  |
| Make decision |  |  |  |  |  |  |  |  |  |
| The patient is not able to make decisions about daily life (choosing clothes or food) | 6  (27,3) | 4  (18,2) | 3  (13,6) | 9  (40,9) |  | 8  (36,4) | 5  (22,7) | 9  (40,9) |  |
| The patient has been acting impulsively, irresponsibly, neglectfully or in poor judgment | 8  (33,3) | 4  (16,7) | 4  (16,7) | 8  (33,3) |  | 11  (45,8) | 7  (29,2) | 6  (25,0) |  |

Table 24. Q3. Selected items: Highly relevant tags (%)

|  | **Severity** | | | |
| --- | --- | --- | --- | --- |
|  | **Mild** | **Moderate** | **Intense** | **NA** |
| The patient does not take as much care of his/her personal hygiene and appearance as usually | 40,0 | 35,0 | 25,0 |  |
| You have to tell the patient that he/she should brush his/her teeth or comb his/her hair | 61,5 | 38,5 | 0,0 |  |
| You have to assist the patient to get ready | 58,3 | 41,7 | 0,0 |  |
| You have to assist the patient in shopping | 35,3 | 11,8 | 52,9 |  |
| You have to assist the patient in cooking | 23,5 | 5,9 | 70,6 |  |
| You have to assist the patient to use the electrical appliances | 43,8 | 6,3 | 50,0 |  |
| The patient has the amount of speech significantly decreased | 45,0 | 35,0 | 20,0 |  |
| The patient has lost the ability to converse | 38,1 | 28,6 | 33,3 |  |
| The patient lost interest in friends or daily activities | 63,6 | 13,6 | 22,7 |  |
| The patient lost interest in doing things or lack motivation for starting new activities | 35,0 | 20,0 | 45,0 |  |
| The patient is less enthusiastic about his/her usual interests | 42,1 | 15,8 | 42,1 |  |
| The patient has lack of initiative | 43,5 | 30,4 | 26,1 |  |
| The patient seems less spontaneous or less active than usual | 43,5 | 21,7 | 34,8 |  |
| The patient has trouble finding the appropriate word when trying to communicate | 43,5 | 26,1 | 30,4 |  |
| The patient makes language or pronunciation errors | 70,0 | 10,0 | 20,0 |  |
| The patient has trouble remembering recent events (e.g. items in the newspaper or on TV) | 30,4 | 34,8 | 30,4 | 4,3 |
| The patient loses or misplace things | 40,0 | 35,0 | 20,0 | 5,0 |
| The patient loses his/her orientation in common places | 42,9 | 14,3 | 42,9 |  |
| The patient does not know the date (month, day and time) | 45,0 | 10,0 | 40,0 | 5,0 |
| The patient has difficulty concentrating on a task | 52,4 | 33,3 | 14,3 |  |
| The patient loses the interest in the world around him/her | 47,4 | 26,3 | 26,3 |  |
| The patient is unaware of problems/changes or deny them when discussed | 13,6 | 36,4 | 50,0 |  |
| The patient is not able to follow instructions | 50,0 | 20,0 | 30,0 |  |
| The patient is not able to make decisions about daily life (choosing clothes or food) | 36,4 | 22,7 | 40,9 |  |
| The patient has been acting impulsively, irresponsibly, neglectfully or in poor judgment | 45,8 | 29,2 | 25,0 |  |

Table 25. Q3. Selected items: Relevant tags (%)

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **Severity** | | | |
|  | **Mild** | **Moderate** | **Intense** | **NA** |
| The patient lost interest in friends or family members | 65,0 | 10,0 | 25,0 |  |
| The patient has trouble remembering the names of relatives or friends | 54,5 | 31,8 | 13,6 |  |
| The patient has trouble remembering significant past events | 50,0 | 27,3 | 18,2 | 4,5 |

# CONCLUSSIONS

## Selection of tags

All selected items from every questionnaire were compiled in a new table (Table 26) recording not only the importance for the tag (High relevant; HR, Relevant; R, Not particular relevant; NPR) but also the Questionnaire of origin (Questionnaire 1; Q1, Questionnaire 2; Q2, Questionnaire 3; Q3). The most relevant data is that in general the selected items by the informal caregivers are relatively different from that chosen by the professional.

From Questionnaire 1, 28 items were passed on with different relevance. For questionnaire 2 the numbers of items were 24 and for questionnaire 3 the numbers of items were 28.

In conclusion, a total of 42 items were selected in different levels of importance and from different questionnaires. It is recommended to take into account not only this level but also who selected the item (informal or professional caregiver) in order to adapt the UnderstAID platform to the user.

Table 26. Items selected

|  | **Q1** | | | **Q2** | | | **Q3** | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | **NPR** | **R** | **HR** | **NPR** | **R** | **HR** | **NPR** | **R** | **HR** |
| **DAILY TASKS** | | | | | | | | | |
| The patient does not take as much care of his/her personal hygiene and appearance as usually |  |  | **x** |  |  |  |  |  | **x** |
| The patient gets upset with those trying to care for him/her or resist activities such as bathing or changing clothes |  |  |  |  |  |  |  |  |  |
| You have to tell the patient that he/she should brush his/her teeth or comb his/her hair |  |  |  |  |  |  |  |  | **x** |
| You have to assist the patient in brushing his teeth |  |  |  |  |  |  |  |  |  |
| You have to assist the patient in combing his hair |  |  |  |  |  |  |  |  |  |
| You have to assist the patient to get ready |  |  |  |  |  |  |  |  | **x** |
| You have to assist the patient in shopping |  |  |  |  |  |  |  |  | **x** |
| You have to assist the patient in cooking |  |  |  |  |  |  |  |  | **x** |
| You have to assist the patient to use the electrical appliances |  |  |  | **x** |  |  |  |  | **x** |
| **BEHAVIOR** | | | | | | | | | |
| The patient loses their emotional responsiveness | **x** |  |  |  | **x** |  |  |  |  |
| The patient appears sad or depressed | **x** |  |  |  |  |  |  |  |  |
| The patient expresses feelings of sadness or depression | **x** |  |  | **x** |  |  |  |  |  |
| The patient has lack of initiative |  |  | **x** |  | **x** |  |  |  | **x** |
| The patient seems less spontaneous or less active than usual |  |  | **x** | **x** |  |  |  |  | **x** |
| The patient seems less interested in the activities and plans of others | **x** |  |  |  |  | **x** |  |  |  |
| The patient feels uneasy or hyperactive | **x** |  |  |  |  |  |  |  |  |
| The patient has been verbally aggressive to you or others | **x** |  |  |  |  |  |  |  |  |
| The patient does things over and over such as pace, opening closets or drawers, or repeatedly pick at things, etc. |  |  |  |  |  |  |  |  |  |
| The patient is irritable, argue or complain | **x** |  |  |  |  |  |  |  |  |
| The patient does things that embarrass you |  |  |  |  |  |  |  |  |  |
| **SOCIAL ACTIVITIES** | | | | | | | | | |
| The patient has the amount of speech significantly decreased | **x** |  |  | **x** |  |  |  |  | **x** |
| The patient has lost the ability to converse | **x** |  |  |  |  | **x** |  |  | **x** |
| The patient lost interest in friends or daily activities | **x** |  |  | **x** |  |  |  |  | **x** |
| The patient lost interest in friends or family members | **x** |  |  |  | **x** |  |  | **x** |  |
| The patient lost interest in doing things or lack motivation for starting new activities | **x** |  |  | **x** |  |  |  |  | **x** |
| The patient is less enthusiastic about his/her usual interests |  |  | **x** | **x** |  |  |  |  | **x** |
| The patient believes in things that you know are unreal |  |  |  |  |  |  |  |  |  |
| **COGNITIVE ACTIVITIES** | | | | | | | | | |
| The patient has trouble remembering the names of relatives or friends | **x** |  |  | **x** |  |  |  | **x** |  |
| The patient has trouble remembering recent events (e.g. items in the newspaper or on TV) |  | **x** |  | **x** |  |  |  | **x** |  |
| The patient asks the same question many times | **x** |  |  |  | **x** |  |  |  |  |
| The patient has trouble remembering significant past events |  |  |  |  |  |  |  |  | **x** |
| The patient loses or misplace things |  |  | **x** |  | **x** |  |  |  | **x** |
| The patient has trouble finding the appropriate word when trying to communicate |  |  |  | **x** |  |  |  |  | **x** |
| The patient makes language or pronunciation errors |  |  |  |  |  |  |  |  | **x** |
| The patient loses his/her orientation in common places |  |  | **x** |  | **x** |  |  |  | **x** |
| The patient does not know the date (month, day and time) |  | **x** |  | **x** |  |  |  |  | **x** |
| The patient has difficulty concentrating on a task |  | **x** |  | **x** |  |  |  |  | **x** |
| The patient loses the interest in the world around him/her |  | **x** |  |  | **x** |  |  |  | **x** |
| The patient is unaware of problems/changes or deny them when discussed | **x** |  |  |  |  | **x** |  |  | **x** |
| The patient is not able to follow instructions |  |  | **x** | **x** |  |  |  |  | **x** |
| The patient is not able to make decisions about daily life (choosing clothes or food) |  |  | **x** |  |  | **x** |  |  | **x** |
| The patient has been acting impulsively, irresponsibly, neglectfully or in poor judgment |  |  | **x** | **x** |  |  |  |  | **x** |