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SOUND

TRAINING SOCIAL AND HEALTH CARE PROFESSIONALS IN MUSIC-BASED THERAPEUTIC INTERVENTIONS TO SUPPORT OLDER PEOPLE WITH DEMENTIA

D1 - SOUND Handbook on the co-design process in brief

SOUND CONSORTIUM

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INDEX

1. Introduction: what is SOUND and aim of this handbook

The SOUND project wants to develop a curriculum of active and passive music activities for dementia care professionals (DCPs) and informal caregivers (ICGs) and to design and test a music-based intervention targeted to older people with dementia (OPDs).
To gather data and information on the educational needs of DCPs and ICGs, and on care needs of OPDs, in Summer 2022, a co-design study, based on the Experience-Based Co-Design (EBCD) method, was carried out in Italy, Portugal and Romania.
This Handbook wants to report a list of recommendations for planning SOUND sessions and its aim is to provide a step by step guide for an optimal organisation of SOUND activities.

2. What the SOUND methodology includes

SOUND adopted a methodology that would put all participants at ease, especially the OPDs, that would be fun and enjoyable and, at the same time, observable. The choice fell on Circleactivities (CATS) developed by Albert Hera and tested in 2018 for the first time with OPDs by himself, Giorgia Caldini and Claudia Bernardi. CATS, that is inspired by the «Circlesongs»[1], allow the facilitator to be flexible and to include variations to the planned activities because its final aim is to increase the wellbeing of participants rather than to deliver a perfect performance. CATS is not «therapy» but rather a means of "care", because it wants to empower the overall wellbeing of beneficiaries rather than to fight a disease.

SOUND consists in a set of activities, called SOUND Activities (SA), that take place in a circle, based on:

-vocal emissions of syllables associated with sounds often on a rhythmic basis

-body movements

-facial expressions

-materials such as cloths or sound tubes

-some percussion instruments.

The activities are led by a facilitator who stands mostly in the middle of the circle and who proposes vocal and/or rhythmic activities and invites the participants to repeat them. Each SOUND session may have between 3 and 5 SA for a total duration of 45-60 minutes depending on the group participants (OPDs with major impairment generally need a shorter session).

The SOUND strength rests essentially on three CATS fundamental pillars:

[1] a choral singing performance developed by Bobby McFerrin based on improvisation, influenced by Jazz music, and led by professional singers and artists

a) the circle (the setting);

b) the voice / song (as facilitating instrument)

c) the presence of “bridging activities” or “gluing activities”, which have the specific task of making the use of the voice / singing instrument more effective.

The SOUND approach foresees three pivotal roles: a) the facilitator; b) the internal observers; the external observers.

The facilitator leads the activities. S/he can be a care professional preferably with basic music knowledge and trained to the SOUND method. The facilitator is required to have not only professional skills, but also creativity, empathy and flexibility. S/he has to be able to be non-judgemental, to govern the unexpected and to welcome the emerging ones that generate discontinuity as an opportunity to deviate from the plan.

The internal observers (about four depending on the circle size) remain in the circle, participate actively and emotionally in the experience and help the facilitator leading the activities e.g., by distributing materials and doing all is needed for putting participants at ease.

The internal observers focus their attention on the behaviour of the OPDs in order to capture any signal of disappointment, tiredness, anxiety etc. as result of the stimulation given during the activities or coming from other sources. Should have noticed any of these “negative” reactions which they think have not been captured by the facilitator, they send an alert to the facilitator through a conventional sign such as for example a clap on the leg so that the facilitator has one more chance to focus his/her attention on the person who felt uncomfortable. For example, if a participant looks annoyed, the internal observer signals this to the facilitator who then invites the participant to do the exercise together or to create a new one that may be more interesting.

The external observers (one or more depending on the size of the circle) pay attention to all patients involved in the circle and examine their affects during the workshop by using the Apparent Affects Rating Scale (AARS). After the workshops, external observers may analyse the videos of the circles to obtain a more detailed observation.

The external observer has to observe one person at a time for 5 minutes in order to capture their feelings and fill the AARS, therefore s/he needs to change position after observing 3 or 4 participants so that they s/he can observe the other participants. For this reason, it is important to set the room with four chairs in four different corners so that the external observer can move in silence and without disturbing the circle from one observation point to the next.

3. How to prepare a SOUND co-design session

SOUND is a methodology that can be employed in healthcare/dementia day centres and residential care settings. It is highly recommended for the health care team to have a SOUND co-design session for informing the setup of future SOUND Activities (SA) to use with their service users. Moreover, if the healthcare institute allows it, it is

possible to involve family/informal caregivers to the SA, therefore it is important to involve them since the co-design phase.

The steps to take for implementing the SOUND co-design are as follows:

a. To profile each potential participant through the use of a biographic tool, focus-group and interviews
b. To assign roles within the team
c. To choose the objectives for each SA
d. To plan an activity for each objective and to prepare the materials
e. To set the SOUND environment

a. Profiling participants

A SOUND co-design session should include at least:

- Five dementia care professionals (DCPs)
- Five informal caregivers (ICGs)
- Five older people with dementia (OPDs)

The profiling of participants take place in three steps:

i. Collecting background information for ensuring that participants meet the inclusion criteria
ii. Collecting further information on music preferences and attitudes
iii. Gathering information pre and post SOUND co-design session through focus-group

i. DCPs can take part if they are: a) health professionals working in a dementia service and b) interested and motivated to take part in the project.

ICGs can be included in the co-design if they: a) are the primary caregivers of OPDs, i.e. family members, neighbours or friends looking after the OPDs on a daily basis, preferably living with them; b) provide medium or intensive care i.e. between 14 and 20 hours of care per week.

Professionals need to collect some data on ICGs through a questionnaire including questions on: gender, age, relationship with OPD, cohabitation issues, years of assistance, working caregiver, informal support received and list of supporters, formal support addressed to OPDs (e.g., day-care centre, nursing home) and list of services, formal support addressed to ICGs (e.g., psychological help, respite care, self-help groups) and list of services.

OPDs can be included in the co-design if they: a) do not present hearing and sight impairment nor motor problems; b) have a diagnosis of dementia/MCI (preferably a MMSE score of 15 and over); c) do not present major language deficits; d) are able to understand and perform simple activities. In light of the above, the inclusion of each participant depends first and foremost, but not exclusively, on an in-depth assessment of his/her cognitive functions by psychologists or neurologists/psychiatrists familiar with each clinical case, particularly considering the overall level of impairment, the level of language and motor difficulties and of sight and hearing impairment. Together with cognition, motor and sensory aspects, it is important to assess the behavioural and psychological symptoms of dementia (BPSD) and what can cause/trigger fear responses and distress e.g., sensitivity to light or noises. Tools like the

Neuropsychiatric Inventory (NPI), the patients' biography and life story can be useful for this purpose.

ii. Once the above is assessed, the healthcare staff can work on completing a profile of each patient based on the OPD's biography (Annex 1), music preferences and eventual music competences (Annex 2). Furthermore, information on care professionals need to be collected through a questionnaire asking about gender, age, profession(s), workplace(s), years of experience, music knowledge and competences.

iii. The participants' perspective can be captured before and after the SOUND co-design session by using different qualitative tools, namely: focus-groups with DCPs ICGs and individual interviews or focus-groups with OPDs. The focus-group/interviews consists of specific topic-guide questions for each group of participants (Annex 3).

b. To assign roles within the team

At least two of the professionals involved need to complete the SOUND training, the ones who do not participate need to complete the SOUND online training and to gain further practical learning from their fully trained colleagues. This means that the team needs to identify the most suitable staff member to play the facilitator role in advance for them to receive the whole training.

Post training, the team will need to identify the internal observers and external observers. Therefore, the three roles of facilitator, internal observers and external observers will be assigned based on DCPs' attitude, empathy, music knowledge and skills, and knowledge of the SOUND intervention.

c. The SAs objectives

Each SA within a SOUND session is structured for reaching the general objective of enhancing the wellbeing of all participants and specific objectives for stimulating OPDs cognition such as language fluency, memory, coordination (Annex 4).

Every SAs is aimed at reaching one, two or more objectives. They can be divided in primary and secondary objectives. The primary ones are about cognitive stimulation whilst the secondary ones are about the group and socialisation of participants. For instance, activity n.1 objectives may be to stimulate listening skills, attention and motor coordination (primary) and activity n. 2 objectives may be to boost the group cohesion and adapt to enhance socialisation (secondary).

d. SAs planning and materials preparation

The choice of the goals to address is up to the care staff according to the users' needs. Therefore, it is very important that the SAs proposed during the SOUND session are planned in details according to the following factors:

- the physical and cognitive condition of the OPDs and the characteristics of their family relationships and social life;
- the motivation and the level of knowledge of the SOUND method of the care professionals;
- the support and the willingness to participate of the informal caregivers;
- the cooperation with other healthcare professionals (e.g., gerontologists and psychologists) who would monitor the neuropsychological, health and social outcomes of the SOUND approach with appropriate tools;
- the environment hosting the SAs.

The SAs can also take into consideration the resources offered by the dementia service (in terms of materials available and funding to use for buying new tools) and the talents and competencies of the facilitator. For instance, if the facilitator is a piano player the activities can be set up differently compared to a group in which the facilitator is a singer or a guitar player.

It is important to plan each SA and to prepare or ensure that the material is available in advance so that the welcoming in the SOUND session is not rushed. To help with the planning of each SA it is recommended to use the table in Annex 5.

A SOUND co-design session with DCPs and OPDs should be planned as below:

- SOUND team briefing
- Pre-workshop interviews/focus-group with OPDs
- Welcome the OPDs in the circle
- SAs delivery
- Closure with final «ritual» and feedback question to the OPDs
- SOUND team debriefing

A SOUND co-design session with DCPs, OPDs and ICGs should be planned as below:

- Focus-group with ICGs
- Welcome of DCP, ICGs and OPDs in the circle
- SAs delivery
- Closure with final «ritual» and focus-group with ICGs
- SOUND team debriefing

e. Setting up the SOUND environment

The environment where SOUND sessions take place is very important because people with dementia are more sensitive to beauty, light, colours and objects standing in the room than people without dementia.

In light of the above, the SOUND team need to prepare the setting appropriately.

The chairs need to be arranged in a circle with assigned seats (each chair has one participant's name affixed to it) for OPDs participants taking into account:

- interpersonal dynamics (e.g., putting a distance between OPD and their caregiver (during the SOUND session with them);

- visual/auditory difficulties;

- need for proximity to the care staff;

- chairs outside the circle for external observers.

As mentioned above, all materials that can be used in the activity need to be listed and prepared. Additionally, technologies for video recordings (two video cameras are recommended) need to be installed before the start of the SOUND session.

Finally, special attention needs to be paid to the microclimate i.e. curtains, noise, light such that everything can help OPDs have a good and pleasant experience, without disturbing their perceptions. It is recommended to use a large room that is tidy and rumble-free.

4. How to monitor SOUND sessions

A SOUND co-design session needs to foresee a "live" observation, i.e. external observers who observe the participants' reactions and behaviour while the SAs are carried out, and an "ex-post" observation, i.e. the SOUND team that watches and analyses the video recordings of the sessions.

Since both the facilitator and the internal observers participate in the circle, they cannot be equipped with observational sheets, instead they can fill the "Emotions thermometer" tool immediately after the end of the SOUND session (Annex 6).

External observers stay out of the circle to observe the OPDs without disturbing the circle interactions in any way. They observe each participant for five minutes and fill the AARS (Annex 7) recording the feelings of OPDs and for how long such feelings are experienced. They can also take notes on further observations they deem relevant.

The SOUND team or part of it, e.g., the facilitator and external observers, can analyse the video recordings ex-post in order to integrate the live observation. For this purpose, it is recommended to follow specific "Observational guidelines" (Annex 8).

A SOUND team debriefing is important to share and integrate observations and discuss any relevant issue, such as disruptions, emerged during the session.

The feedback question to OPDs and the focus-group with ICGs can also provide relevant data for the monitoring of SAs.

Annex 9 provides a list of OPDs' behaviours that can be observed during a SOUND session. They are listed as a glossary.

ANNEXES

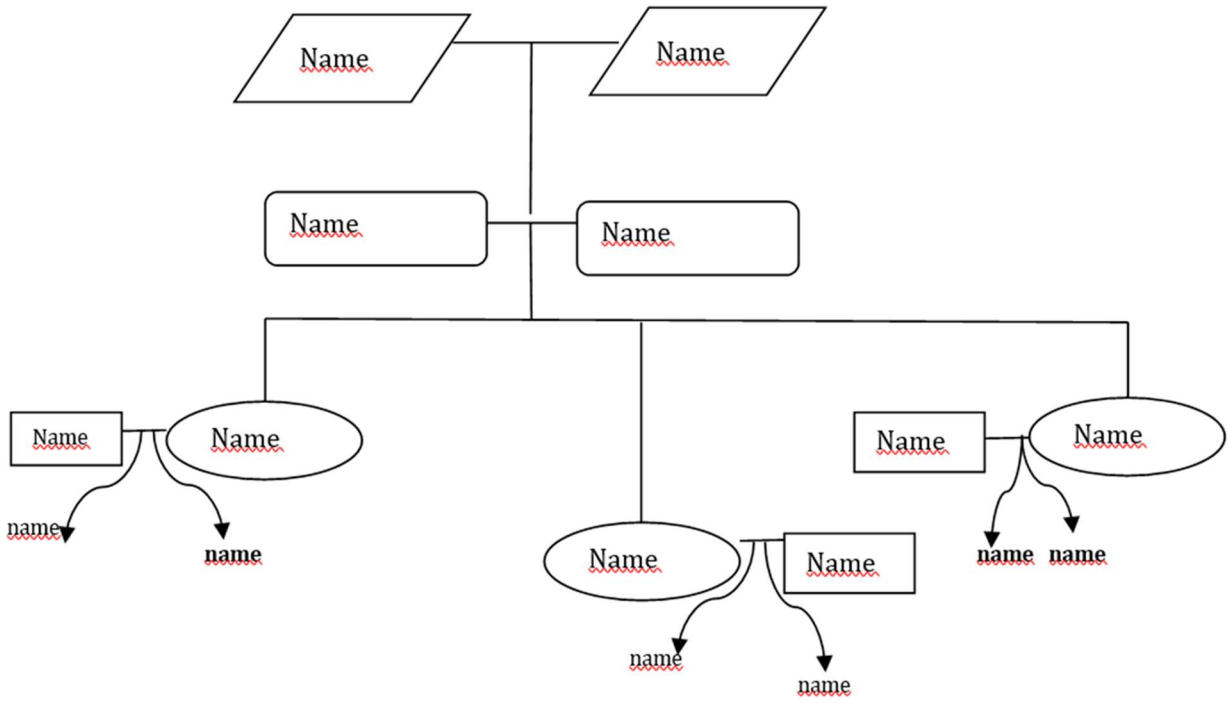
ANNEX 1. BIOGRAPHY OF THE PERSON WITH DEMENTIA

Instrument kindly delivered by Giorgia Caldini and Claudia Bernardi, A.P.S.P. Civica di Trento – Centro Diurno Alzheimer

Mr./Mrs./Ms. _____

Place and day of birth: _____

Description of the family unit with genealogical tree:



News from the past, before the onset of the disease (relationship with family, significant events, schools attended, professions held, places where he/she lived, important relationships, etc.)

CHILDHOOD:

ADOLESCENCE:

MATURITY:

OLD AGE:

Onset of the disease (how it manifested itself, what relevant problems arised, etc.):

News on current interests (how time is spent in the last period: listening to music, reading, watching TV, walking, etc.):

Current social relations:

Specific objects that he/she always has with him/her:

Relation to corporeality (does he/she accept physical contact, etc.):

Particular fears (darkness, noise, etc.) **detected by family members**:

Description of behavioural manifestations and effective strategies to deal with them:

Life habits (rest in the afternoon, what time does he/she go to bed in the evening, what time does he/she get up, sleep/wake rhythm, etc.):

Other remarks:

Signature of the operator who filled out the form

_____

_____(_____), ____/____/ _____

Place (Country), date *dd / mm / aaaa*

ANNEX 2. ASSESSMENT OF INDIVIDUALIZED (PERSONAL) MUSIC PREFERENCE - 2nd EDITION

Care Recipient Version

Familiar music is often a very important part of people's lives. Please complete the questionnaire based on your knowledge of your family member's music preferences.

Please put a check (X) beside the most correct choice to the following questions.

Historically, before the onset of the disease, how important was the music in this person's life?

____1. Very Important

____2. Moderately Important

____ 3. Slightly Important

____ 4. Not Important

Does/did this person play a musical instrument? ____1. Yes ____0. No

If yes, please specify (examples: piano, guitar, etc) _____

Does/did this person enjoy singing? ____1. Yes ____0. No

If yes, please specify (examples: around-the house, church choir, etc)_____

Does/did this person enjoy dancing? ____1. Yes ____0. No

If yes, please specify (examples: attended dance lessons, participate in square dancing, etc.)

_____

The following is a list of different types of music. Please indicate the individual's three (3) most favourite types with 1 being the most favourite, 2 the next, and 3 the third favourite.

____ Popular

____ Classical

____ Spiritual /Religious

____ Music for dancing (i.e. ballroom dancing)

____ Blues /Rhythm and Blues/ Soul

____ Jazz

____ Country

____ Rock and Roll

____ Pop music (from national language)

____ Other (specify) _____

What form does the individual's favourite music take?

____ Vocal

____ Instrumental

____ Both

Which specific songs/musical selections (album) make this person feel happy? _____

Which specific artist(s)/compositor(s)/performers(s) does this person enjoy listening to the most? _____

Which specific playlists, compact discs, audio-cassette tapes, or vinyl records are contained in this individual's personal music library? _____

ANNEX 3. TOPIC-GUIDES

The topic-guide of the focus-group with DCPs asked the following questions.

Before the workshop:

1. Which are the main difficulties you encounter as health care professionals in the field of dementia?
2. How do you feel at the end of a work shift?
3. What is missing in the care of the elderly with dementia?
4. Which are the greatest satisfactions you find in your work?

After the workshop:

1. How did you feel during the workshop?
2. How would you define the Circleactivities?
3. Do you think it is possible to apply the Circleactivities to the service/day-care centre where you are working and with patients you are caring for?
4. Which obstacles and barriers do you see to use the Circleactivities to your daily work with OPDs?
5. Which opportunities do you see in using the Circleactivities in your daily work with OPDs?
6. How can Circleactivities help you in your job?
7. How should Circleactivities be designed and thought about in order to contribute to your well-being?
8. How should Circleactivities be designed and conceived in order to positively influence the team?

The topic-guide of the focus-group with ICGs included the following questions.

Before the workshop:

1. How do you feel at the end of the day?
2. Which are the main difficulties you encounter in caring for your family members with dementia?
3. Are there any positive aspects of taking care of your loved one? If so, which ones?
4. What is your relationship with music? May you describe it briefly??
5. What is your loved one's relationship with the music? May you describe it briefly?
6. Do you use music as a strategy to handle your relative's mood and behaviour in your daily care?

After the workshop:

1. How did you feel during the workshop?

2. How can Circleactivities help you in your daily routine with your loved-one?
3. Which opportunities do you think there could be in using Circleactivities with your relatives?

Before the workshop was performed, either individual interviews or focus-group with OPDs were performed in this phase, by using the following questions:

1. What is music for you?
2. What music was there in the most beautiful moments of your life?
3. Which music do you prefer?

The discussion with OPDs has been stimulated with:

- Music, both used during the workshop and others: the mimic and behaviours of OPDs were observed while listening to the music.
- Photographs were shown of people with different moods for grasping the OPDs' feelings.

After the workshop just a question was asked to the OPDs i.e., How did you feel during the workshop?

ANNEX 4. LIST OF OBJECTIVES FOR EVERY TARGET TYPE

The following table shows the objectives chosen for every target type in the two co-design sessions i.e., one with OPDs and care professionals and another one with OPDs, care professionals and informal caregivers. Every country team chooses the Circleactivities to be performed to reach the objectives based on the tools, talents, resources available at country level.

<table>
<tr><th colspan="7">OBJECTIVES AND CIRCLEACTIVITIES PER TARGET TYPES</th></tr>
<tr><th colspan="3">CO-DESIGN SESSION N. 1

WITH CARE PROFESSIONALS AND OPDS</th><th colspan="4">CO-DESIGN SESSION N. 2

WITH CARE PROFESSIONALS, OPDs AND INFORMAL CAREGIVERS</th></tr>
<tr><td colspan="7">COMMON GENERAL OBJECTIVE: IMPROVING WELLBEING AND SOCIALIZATION</td></tr>
<tr><td>Care professionals</td><td>OPDs</td><td>Number/ Name of the activity</td><td>Care professionals</td><td>OPDs</td><td>Informal caregivers</td><td>Number/Name of the activity</td></tr>
</table>

Improving the capability of capturing verbal and non-verbal OPDs' messages in the Circle	Short term memory		Improving the capability of capturing verbal and non-verbal OPDs' messages in the Circle	Short term memory	Improving the communication with the care recipient (listening, speaking, understanding)	
Reducing the work-related stress	Improving voice/Speech/Language (cognitive health)		Reducing the work-related stress	Voice/Speech (cognition)	Improving the relationship with the care recipient	
Improving the cooperation within the team	Movement/coordination (physical health)		Improving the cooperation within the team	Movement/coordination	Reducing the caregiving stress	

ANNEX 5. PLANNING OF SAs

The following is an example of a filled working table used to plan each SOUND Activity: report the name of the activity and its objectives; the materials and the equipment needed to perform it; the procedure i.e. how to develop the activity and its length; possible changes due to encountered difficulties.

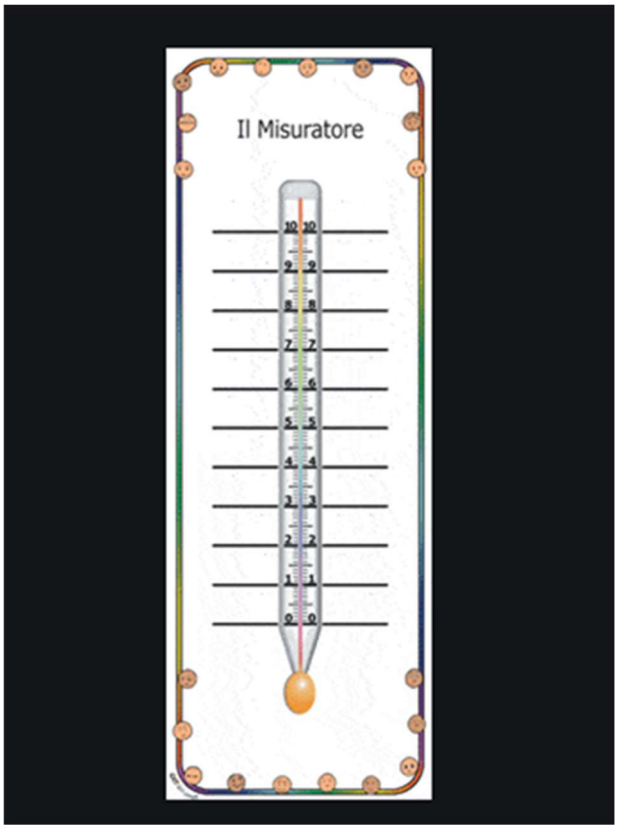
CIRCLE ACTIVITY SHEET		
COUNTRY-ORGANIZATION		
Number of the activity	1	
Name of the activity	**Story (with names)**	
Circle participants	Older people with dementia (OPDs) Care professionals Informal caregivers	
Activity main objective	Direct objective: OPDs: Care professionals	Indirect objective: OPDs Care professionals
Materials needed	e.g. little coloured balls	
Equipment/setting	e.g. chairs	

Activity procedure (development)	Here we describe what participants and facilitators have to do e.g. every participant is asked to sing his/her name.
Extension of the activity	Here we describe if and how we can further develop the activity e.g. every participant is asked to call the name of another circle participant by singing his/her name
Changes to the activity	Here we can write how we want to change the activity in case of difficult groups with older people with more problems, e.g. we can decide that the facilitator sings the name of every participant and then the circle repeats.

ANNEX 6. EMOTIONS' THERMOMETER

Assessment tool for OPD _____ Date _____

Emotions' Thermometer (to measure: anger-irritation, anxiety-fear, happyness-cheerfulness, sadness, shame-embarrassment, guilt) – INDICATE THE SCORE

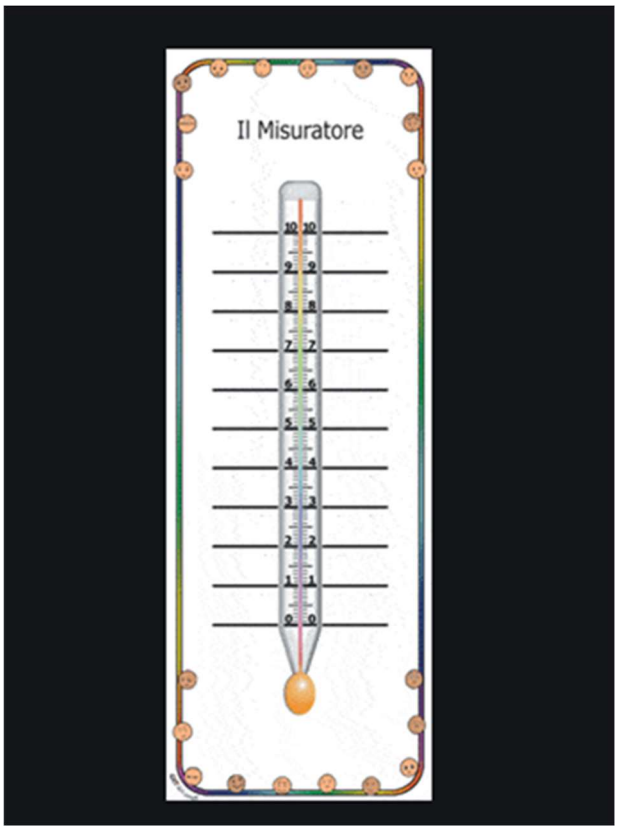


Write the user's emotions and behaviors and the activity that he/she was doing at that moment

i.e. Mary: anxiety 7, foot movement and labored breathing, cognitive stimulation activity

Assessment tool for professional _____ Date _____

Emotions' Thermometer (to measure: anger-irritation, anxiety-fear, happyness-cheerfulness, sadness, shame-embarrassment, guilt) – INDICATE THE SCORE



Write near the thermometer the emotions you experienced with respect to the episodes reported in the user's thermometer, thoughts and behaviours adopted.

Sense of perceived effectiveness: i.e. Anxiety 6.

Thought: if I can't calm him/her down he/she will ruin the group climate;

Behaviour: I will increase my closeness, I will give him/her my hand;

Sense of perceived effectiveness of my intervention: I did my best, the behaviour decreased only a little.

ANNEX 7. APPARENT AFFECT RATING SCALE (AARS) (By Lawton et al)*

PARTNER: _____ PLACE: _____ DATE: _____ TIME: _____

ID OPD: _____ OBSERVER'S NAME: _____

	0	1	2	3	4	5
Observation period: 5 minutes	Can't tell	Never	Less than 16 secs	16-59 secs	1-2 mins	More than 2 mins
PLEASURE Signs: laughing; singing; smiling; kissing; stroking or gently touching other; reaching out warmly to other; responding to music (only counts as pleasure if in combination with another sign). Statements of pleasure.						
ANGER Signs: physical aggression; yelling; cursing; berating; shaking fist; drawing eyebrows together; clentching teeth; pursing lips; narrowing eyes; making distancing gesture. Statements of anger.						

ANXIETY/FEAR Signs: shrieking; repetitive calling out; restlessness; wincing; grimacing; repeated or agitated movement; lines between eyebrows; lines across forehead; hand wringing; tremor; leg jiggling; rapid breathing; eyes wide; tight facial muscles. Statements of anxiety/fear.						
DEPRESSION/SADNESS Signs: Cry; frowning; eyes drooping; moaning; sighing; head in hand; eyes/head turned down and face expression less (only counts as sadness if paired with another sign). Statements of sadness.						
INTEREST Signs: participating in a task, maintaining eye contact; eyes following objects or persons; looking around room; responding by moving or saying something; turning body or moving toward person or object.						

* Lawton MP, Van Haitsma K, Perkinson MA, Ruckdeschel K (1999). Observed Affect and Quality of Life in Dementia: Further Affirmations and Problems. Aging and Mental Health, 5(1):69-81.

ANNEX 8. OBSERVATION GUIDELINES

1. First step: video-recording workshop sessions

The recordings have to be re-watched by the facilitator(s), and the external observers (it is better if the observers are both musicians and social researchers: psychologists, sociologists, gerontologists, educators, etc).

2. Observation instructions

Possibly the observation should be given separately for the two workshop sessions and for each activity performed.

Every observer must observe:

- Older People with Dementia (OPD)
- Dementia care professionals (DCPs)
- Informal caregivers (ICGs)
- Facilitator
- All participants
- The environment

3. What to observe?

3.1 Observe OPDs' movements of the hands, the movement of the body, the facial expression, the level of participation to the activities, and replay to the following questions for every workshop session.

OLDER PEOPLE WITH DEMENTIA		
	Workshop with DCPs and OPDs	Workshop with DCPs, OPDs and ICGs
Which is the activity that triggered/motivated the patients more than others?		
Did anybody feel uncomfortable? If so, who? And during which activity especially?		
Can you find a behaviour that all or most the older participants had, and during what activities?		

3.2 Observe DCPs and ICGs' movements of the hands, the movement of the body, the facial expression, the level of participation to the activities, and replay to the following questions for every workshop session.

DEMENTIA CARE PROFESSIONALS INFORMAL CAREGIVERS

	Workshop with DCPs and OPDs	Workshop with DCPs, OPDs and ICGs
Which facial expressions do you notice in every or in most care professional and informal caregivers' face?		
Did they feel uncomfortable? Nervous? Good? Relaxed?		
How many times did they laugh or smile and for which activities?		
Did you observe any interaction between care professionals and OPDs, and between informal caregivers and OPDs?		
Had OPDs a different behavior in presence of their informal caregivers?		

3.3 Observe what the Facilitator' behaviour and how s/he did during every exercise. Then, answer to the following questions.

FACILITATOR(S)

	Workshop with DCPs and OPDs	Workshop with DCPs, OPDs and ICGs
Which music elements did she/he use? For example, did she/he use intervals of third major or minor?		
Which was the Facilitator behavior/attitude i.e. which movement did she/he do?		
What position did the facilitator take in relation to the circle?		
What posture did he/she use?		
What body movements did he/she assume?		
Which was the basic element of every exercise? E.g. the use of the voice? The use of the movement? The language? The music?		
What do you think about how the facilitator carried on the CAs?		
What went wrong? Did she/he forget something or someone during the exercises facilitation?		

What went well? Which were the strengths of the Facilitator during the activities?		
What about the speed of execution of every activity?		

3.4 Facilitator's self-reflection

The facilitator observes him/her self and answers the following questions.

FACILITATOR(S)		
	Workshop with DCPs and OPDs	Workshop with DCPs, OPDs and ICGs
How did you feel during the activity (n. 1/2/3/4 etc.)?		
What did you like?		
What got you in trouble?		
What would you suggest to another facilitator conducting a Circleactivities session with a group of OPDs?		

3.5 Music analysis

If you have musicians in your team, you may also carry out a deeper music analysis of the workshops, by paying attention to the following aspects and replaying the corresponding questions.

PARTICIPANTS		
	Workshop with DCPs and OPDs	Workshop with DCPs, OPDs and ICGs
Did the members of the circle exactly copy the activities proposed by the Facilitator (mirroring melody)? E.g., in the exercise of the “names” (when older people were asked to sing/say their names to present to the circle), did they repeat the same melody proposed by the Facilitator or did they interrupt the melody by introducing verbal replay?		
Did the members of the circle copy the Facilitator’ movements (body mirroring)?		
Did the members of the circle maintain the same prosodic rhythm		

(isochrony) proposed by the Facilitator?		
Which feelings did you observe?		

3.6 The environment

Briefly describe the environment where the co-design sessions took place. Then, write your answers here below.

a) Was it appropriate? Please describe it either if it was or if it was not.

b) What was the light like?

c) Was the room welcoming and beautiful to see and stay in?

d) Were there objects you would like to remove?

e) What would you like to change?

3.7 The activities

Observe the activities carried out during the workshops to answer the following questions:

ACTIVITIES		
	Workshop with DCPs and OPDs	Workshop with DCPs, OPDs and ICGs
Which were the activities that worked better i.e. made the OPDs feel good and triggered their participation? Why?		
Which were the activities that did not work? Why?		
What would you like to change?		
What was missing?		
How is the speed of execution? Too fast? Too slow? Right?		
What impressed you the most? That is, what surprised you the most?		

ANNEX 9. SMALL GLOSSARY OF BEHAVIOURS THAT CAN BE DETECTED AND OBSERVED DURING A SOUND SESSION

Agnosia: condition in which a person is unable to recognise an object through a sensory channel, in the absence of deficits in perceptual abilities

Amnesia: memory disorder, which may occur in a global or partial form, characterised by the inability to recall past experiences (retrograde a.) and/or to acquire new information (anterograde a.)

Aphasia: total or partial loss of the ability to express and/or understand words and speech

Apraxia: Inability to perform gestures, caused by a specific disturbance of motor programming, in the absence of perceptual disturbances or physical strength disturbances.

Disorientation: disorientation - spatial, temporal, personal - characterises the whole course of the disease, initially it may be episodic (the patient cannot find his/her way home, does not know what time of year it is, etc.), but with the passage of time disorientation is increasingly frequent and disabling. In the advanced stages, the patient is constantly disorientated, being able to have only a few moments of good orientation. Amnesia contributes above all to disorientation, but other disorders also come into play (for spatial disorientation).

Emotions: complex organic responses to internal or external stimuli, characterised by certain subjective experiences and a physiological reaction. Emotions (fear, joy, sadness, anger, disgust), unlike moods or feelings (e.g. serenity, discomfort), are intense and short-lived responses.

Frontal syndrome: a clinical picture that manifests itself in the presence of damage to the frontal lobes and that may manifest itself: on a behavioural level with disinhibition, perseveration, lack of spontaneity; on an emotional level with changes in personality and mood (manic or apathetic); on a cognitive level with easy distractibility, deficits in planning, abstraction and logical reasoning, language difficulties.

Personality: an organisation of ways of being, knowing and acting that ensures unity, coherence and continuity, stability and planning to the individual's relations with the world; e.g.: meek, grumpy, reserved, irascible, extroverted, punctilious, ...

Relationship: the bond existing between two or more persons, characterised by manifestations, acts and/or feelings that characterise the interpersonal relationship.

Behavioural and Psychological Symptoms of Dementia (BPSD)

Aggressiveness: verbal (shouting, insults, ...) or physical (punches, shoving, ...); there may be a refusal to cooperate or to proposed help

Agitation: anxiety, fear, restlessness with inability to sit still, continuous demands for attention

Apathy: lack of initiative, motivation and interest in daily activities, emotional detachment and imperturbability in the face of any stimulus, even affective.

Busyness: indicates repetitive gestures and behaviour performed without an apparent purpose

Delusions: the person believes that things are happening that are not true (e.g. the person may be convinced that someone has stolen personal belongings). To be distinguished from delirium, which is instead characterised by a cluster of cognitive-behavioural symptoms, including delirium or hallucinations, and is often caused by acute illnesses, including infections of various kinds, or by drug intoxication.

Depression/dysphoria: is a mood disorder. Those with depressive symptoms experience frequent moments of sadness and have negative and pessimistic thoughts about themselves and the world around them, as well as lack of or increased appetite, sleep disturbances, fatigue, deterioration of attention and memory, and muscle aches.

Hallucinations: seeing or hearing things that do not exist and being convinced of the real presence of what is perceived (e.g., the person can see other people in the room)

Inappropriate sexual behaviour: is characterised by a verbal or physical act of an explicit or perceived sexual nature that is considered unacceptable within the social context in which it is manifested.

Sleep disorders: sleep is shallow or short in duration either due to difficulty falling asleep, premature awakening or repeated awakenings during the night; the person may lie awake, wander around the house and/or sleep excessively during the day.

Wandering: the person keeps walking without a clear goal or purpose.