

NPT-ES: A MEASURE OF THE EXPERIENCE OF PEOPLE WITH DEMENTIA DURING NON- PHARMACOLOGICAL INTERVENTIONS

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Abstract

Introduction. The non-pharmacological therapy (NPT) field lacks an easy-to-use instrument that measures the experience of people with dementia (PWD) while undergoing non-pharmacological interventions. The NPT Experience Scale (NPT-ES) was designed and validated to cover this need.

Methods. A multi-disciplinary team developed 15 candidate items of which five items were selected on the basis of objectivity, emotional valence, complementarity and inter-rater reliability. The properties of NPT-ES were studied in people with Alzheimer's disease (AD) receiving several NPTs at two day-care centers. Scale validation was conducted via administration of NPT-ES by independent raters in four successive steps: I. Rating by two external observers. II. Rating by one external observer and one therapist. III. Rating by two internal observers and one therapist. IV. Rating by one internal observer and one therapist that alternated roles.

Results. NPT-ES internal consistency was good or excellent (Cronbach α ranged from 0.68 to 0.88). Good inter-rater agreement was attained by internal observers (intra-class correlation coefficient [ICC] 0.83) and by external observers (ICC 0.79). Fair-moderate agreement was obtained between observers and therapists (ICC 0.49-0.69), but almost excellent agreement was achieved when therapist and internal observer alternated roles (ICC 0.90). Properties of the scale improved with frequent use and with increased evaluator's acquaintance of the assessed PWD.

Conclusion. NPT-ES is an adequate and easy-to-use instrument to measure the affective and social experience of people with dementia while receiving non-pharmacological interventions. The scale displayed good properties under varied testing conditions. Best results were obtained when therapists were trained as internal observers.

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Introduction

The increase in prevalence of Alzheimer's disease and related dementias (ADRD) and the lack of curative therapies is fuelling the development of non-pharmacological therapies (NPT) to improve quality of life of both people with dementia (PWD) and their caregivers (Woods 2003). Offering NPTs to PWD has two main objectives: a) convey as many positive experiences as possible while minimizing the negative ones whilst the PWD is in a session, and b) provide clinically relevant carryover effects in domains like cognition, function, behaviour or mood, amongst other.

A positive affective and social experience is possibly the main objective in dementia care, particularly for those persons in advanced stages of the disease (Kitwood 1997a). However, people from moderate dementia onwards have increasing difficulties expressing their likes and dislikes about NPTs or the care they receive. For this reason, the immediate experience of PWD has to be induced from careful observation of patients. Although several instruments have been utilized, some were too narrowly focused (Lee and Kieckhefer 1989; Hurley et al., 1992; Kovach and Henschel 1996; Lawton et al., 1996; Holliman et al., 2001), other required high expertise (Kitwood 1997b), or were time-consuming (Baker and Dowling, 1995). Moreover, some of the scales were not designed for the evaluation of discrete interventions (Lee and Kieckhefer 1989; Hurley et al., 1992; Kitwood 1997b).

The Philadelphia Geriatric Center Affect Rating Scale was designed to measure the affect of PWD in an Alzheimer special care unit. It contains six items, three of them measuring positive affect and the other three measuring negative affect (Lawton et al., 1996). This simple and easy to use instrument would appear to be adequate to evaluate PWD experience during non-pharmacological interventions, but it was not designed for that purpose, and relevant items related to participation and relation with others are not included. The Copper Ridge Activities Index was specifically designed to measure the success of activity therapy sessions. It included participation (1–6 points), cueing (1–3 points), and enjoyment (1–5 points). Interrater reliability of these subscales, when administered independently after session by two 'therapists' was, respectively, 0.69, 0.78 and 0.92, but details about the roles of these two 'therapists' were not given. The properties of the scale under other testing conditions (e.g. evaluation by external observer) were also not investigated (Politis et al., 2004).

We developed a brief scale to measure the immediate affective and social effect of any kind of discrete non-pharmacological intervention delivered to people with ADRD. The feasibility and validity of this NPT Experience Scale (NPT-ES) was tested under different rating conditions. We analysed the properties of the scale when administered by out-of-session observers (i.e., external video observers), in-session observers (i.e., internal observers) and therapists at the end of sessions. The hypothesis was that the NPT-ES would work well in those three key settings. By doing so, the scale could help to improve the design of NPTs and monitor therapist skills in both daily-care and research settings.

Method

1) Development of the NPT-ES

a) Selection of items by multi-disciplinary team

Candidate items were elaborated from observations and in-depth interviews (Ibáñez 1985) run by the first author (RM) with PWD and Maria Wolff staff of two day care centres (four occupational therapists, two psychomotor-therapists, one music-therapist [PL], one social worker, one geriatrician and one general physician). After discussion of the multi-disciplinary team, 15 items were pre-selected (Table 1). Pre-selected items should help inferring affective experience and social interaction of PWD during sessions of NPTs.

Pre-selected items were piloted by two independent observers using video-recorded sessions of different kinds of NPT sessions. Raters were instructed to take notes and score every item at the end of the observation period. Items were initially scored on a five-point basis, according to the percentage of time that PWD manifested those items.

After piloting, five items were selected on the basis of objectiveness of the measure, emotional valence, lack of redundancy and inter-rater reliability. For instance, items like “smiles”, “frowns”, “relaxed face muscles”, etc., were difficult to observe and interpret, and their inter-rater reliability was low. Other items (“time patient participates” and “time patient does not participate”) were too concordant and therefore redundant. Inadequate items were dropped or reformulated to yield the final 5 item scale presented here. In addition, a simpler four-level grading of items was chosen to facilitate a potential use of the scale by therapists after group interventions. Therefore, the total score of the final NPT-ES ranged from zero to 15, higher scores indicating more positive experience.

b) Translation and back-translation

The Spanish scale was translated to English and then back-translated to Spanish by two independent translators. Only minor discrepancies emerged between the original and final Spanish versions, which were analyzed and resolved with the help of a third translator (Appendix 1 and 2).

2) Validation of NPT-ES

The validation of NPT-ES was performed in four steps that are described in Table 2. Steps I and II were planned to assess NPT-ES' properties in the most differing testing conditions: external observers that did not know the participants and watched the sessions on video versus therapists that were familiar with participants. Stages III and IV were designed *post-hoc* to investigate the reasons of discrepancy between external observers and therapists found at stage II. The evaluators received 10-minute training of NPT-ES rationale, objectives and use. The study design, however, was not disclosed. They were just requested to complete the NPT-ES for each participating PWD at the end of session. Taking notes during sessions was not permitted. When several raters had to be together in

the same sessions (Stages III and IV) they were instructed to use the NPT-ES independently of each other.

Therapy sessions were conducted at two Maria Wolff day-care centers. Sessions of cognitive stimulation, use of music, psychomotor exercises, training of activities of daily living and massage were conducted following a pseudo-random sequence. Session duration was 45 minutes. Patients were people with moderate or moderately severe Alzheimer's disease (AD) that attended Maria Wolff day-care centers regularly. Both patients and their caregivers were informed about the study and asked consent to participate.

Internal consistency of NPT-ES was analysed using Cronbach α coefficient. This indicator gives an estimate of global correlation among the different items of the scale. Since all scale items are targeted at the same concept, a high α (desirably ranging between 0.70 and 0.95) would support face validity. Inter-rater reliability was assessed using intra-class correlation coefficient (ICC). This is the most appropriate indicator of agreement when dealing with quantitative variables. An ICC between 0.7 and 1 is desirable (Argimón & Jiménez, 1998).

Table. Process of validation of NPT-ES

Stage (rater characteristics)*	Sample description	Number of sessions, number of observations	Internal consistency (α)	Inter-rater reliability (ICC)
I. Two psychologists (A,B) after watching videos of sessions	45 AD, 60% Female Mean age 78, SD 7 FAST 5-6a	45, 385	0.81 (A) 0.77 (B)	0.79 (A-B)
II. Therapist (C) after conducting sessions and psychologist (A) after watching videos of those sessions	11 AD, 82% female Mean age 78, SD 5 FAST 5-6a	5, 55	0.82 (C) 0.63 (A)	0.49 (A-C)
III. Therapist (D) and two raters (C,E) that were present but not involved in sessions	10 AD, 70% female Mean age 79, SD 5 FAST 5-6a	5, 50	0.88 (E) 0.86 (C) 0.73 (D)	0.83 (C-E) 0.69 (C-D) 0.61 (D-E)
IV. Two raters (C,E) that alternated roles of therapist and internal observer every session	Same as above	8, 80	0.86 (E) 0.84 (C)	0.88 (C-E)

*Raters completed NPT-ES for each PWD at the end of intervention session.

A and B were psychologists with neither knowledge of PWDs nor experience as therapist. C,D and E were therapists that knew PWDs and had similar working experience.

α : Cronbach coefficient (> 0'70, good; > 0'80, excellent); ICC: intra-class correlation coefficient (< 0'30, bad; 0'31-0'50, fair; 0'51-0'70, moderate; 0'71-0'90, good; >0'91, excellent).

AD: Alzheimer's disease; FAST: Functional Assessment Staging (Reisberg 1988); NPT-ES: non-pharmacological therapies experience scale; PWD: person with dementia.

Results

Internal consistency of NPT-ES was good or excellent in virtually all testing conditions (α 0.73-0.88). Internal consistency was slightly inferior in one instance that involved relatively few observations of new patients by external observer (stage II, α 0.63) (Table

2). In the majority of instances, the elimination of the different items of the scale reduced α coefficient (data of α coefficients if the individual items are eliminated are not shown).

Inter-rater agreement between raters that watched videos of sessions was good (ICC 0.79, step I) but agreement between video assessment and assessment by therapist was fair (ICC 0.49, step II). After these results, validation stage III was designed to assess a hypothetical effect of being out of sessions in NPT-ES reliability. Agreement between observers present during sessions and therapist reached the moderate range (ICC 0.61 and 0.69, step III) but agreement between those two internal observers was still superior (ICC 0.83, step III). After these results, it was hypothesized that acting as an evaluator would train and improve the therapist's rating capacity. This hypothesis was confirmed at step IV, where the highest inter-rater agreement was attained by internal observers and therapists that changed their roles on every session (ICC 0.88) (Table 2).

Discussion

Several instruments have been used to measure the effects of non-pharmacological interventions in PWD. In most instances these instruments were not specifically designed to measure the effect of interventions. Typically, existing scales were adapted to evaluate specific intervention targets, particularly agitation (Gerdner 2000; Sloane et al., 2004) or affect (Sloane et al., 2004). When reported, psychometric characteristics of these scales were usually good (Lawton et al., 1996; Mitchell and Maercklein 1996; Vogelpohl and Beck, 1997; Politis et al., 2004; Sloane et al., 2004).

In contrast, our NPT-ES was specifically designed to measure the immediate affective and social effect of discrete non-pharmacological interventions in PWD. The NPT-ES was well accepted and easily used by different kind of professionals in various settings, evaluating a variety of non-pharmacological interventions. The high internal consistency of NPT-ES indirectly supports content validity of the selected five items.

In addition, to the authors' knowledge, this is the first time that properties of a scale of this kind were measured and compared under different rating conditions. Consistency and reliability of NPT-ES when used by observers that watched videos of sessions were good (Table, step I). Moreover, these external observers were neither therapists nor familiar with non-pharmacological interventions for dementia. However, agreement between intervening therapist and external observer was fair (Table, step II). This result, possibly due to missing information of PWD characteristics and responses by external observer, do not permit to conclude on the adequacy of NPT-ES in research contexts where intervention sessions should ideally be evaluated at minimal costs by raters that are neither present in the sessions nor aware of study design.

Results obtained when NPT-ES was rated by an internal observer (i.e., a therapist present, but not involved in the sessions) were better than those obtained by external observers. However, agreement between intervening therapist and internal observers were just moderate (Table, step III). This could be due to lack of rater experience or missing information of PWD responses by therapist. This explanation was confirmed in our validation step IV, when agreement between internal observers and therapists clearly

improved after therapists also acted as internal observers. In other words, step IV results suggest that acting as an internal observer for several sessions train and improve the therapist's observational skills. This training, later qualifies the therapist to rate his or her own sessions.

This study bears some limitations. Only group sessions of AD PWDs at moderate or moderately severe stages of dementia were analysed. Our data do not allow us to extrapolate the performance of the scale with severe stages, where patients' behavioural or psychological signs might be less apparent. We also have not measured the scale in individual settings where expressivity might be different than in a group.

In conclusion, the NPT-ES emerges as a feasible and reliable tool to measure the experiences of PWD during NPT. It is particularly adequate to be used by therapists trained also as internal observers. This instrument has several immediate applications. It allows therapists to evaluate their own sessions, it may facilitate the adjustment of interventions to improve patient's experience (satisfaction) with NPTs, and it may be used to compare patient response to different NPTs (e.g., Music Therapy vs. Cognitive Stimulation). More research is needed to further ascertain the use of NPT-ES in research settings, either in its present, or modified form, (e.g.: some added items). An instrument like the NPT-ES for research use is needed, since poor response to NPTs might be associated to poor clinical prognosis.

Appendix 1. Non-pharmacological Therapy Experience Scale (NPT-ES): English Version

Instructions

The NPT-ES seeks to measure aspects of patients' experience at the time of intervention. Experience is awareness of the present moment, conditioned by the possibilities of each patient. Some of the observable consequences of a this experience are expressed through behaviour and social relationships.

The scale consists of five items, which must be scored as per the guidelines included below. In the case of ambiguous or dubious answers, the evaluator has to make a judgement call according to his/her knowledge of the patient, without losing sight of the aim of the scale outlined above.

The time used for evaluation must be the entire period required for the target intervention. In other words, the evaluation period may be a complete session, from the first to the last therapeutic element (e.g., from greeting to closure, both inclusive), or only a part of the session (e.g., psychomotor activity).

Item scores will be allocated at the end of the intervention. The use of watches or other aids (notes, etc.) is not permitted. One item may possibly determine the scoring of another: for instance, if a patient has abandoned the session, any time that he/she spends out of the room will be counted as "rejection" as well as "non-participation", though not necessarily as "displeasure". 'Not assessable' will be endorsed when information is not available for more than half of the evaluation period.

A. Participation

The patient shows signs of paying attention and responding to the therapists' indications, through his/her posture, looks, gestures, words or actions. Should the patient not understand or be unable to perform the task, his/her efforts to collaborate will be viewed positively for scoring purposes. Spontaneous responses as well as responses to the therapist's indications are all scored.

- 3. Always
 - 2. Frequently
 - 1. Sometimes
 - 0. Never
- Not assessable

B. Pleasure

The patient shows signs of wellbeing and pleasure, through smiles, other gestures and expressions, posture, words or actions. Please note that participation does not necessarily mean pleasure.

- 3. Always
 - 2. Frequently
 - 1. Sometimes
 - 0. Never
- Not assessable

C. Relationship with others

The patient communicates positively (respectfully, in a friendly manner, etc.) or neutrally with other patients in the session or with the therapist, through looks, gestures, words or actions, whether spontaneously or at the therapist's indication.

- 3. Always
 - 2. Frequently
 - 1. Sometimes
 - 0. Never
- Not assessable

D. Displeasure

The patient displays negative feelings, such as uneasiness, anxiety, sadness, discomfort, shame, boredom, through posture, gestures and expressions, or words. Motor and other more complex actions will only be scored as displeasure if accompanied by some other indication of negative mood (e.g., leg tremble accompanied by tense posture or facial expression of anxiety, or drumming of the fingers accompanied by facial expression of boredom). Likewise, actions of rejection (question E) will only be included here if accompanied by signs of displeasure.

- 0. Always
 - 1. Frequently
 - 2. Sometimes
 - 3. Never
- Not assessable

E. Rejection

The patient actively rejects the therapist's indications. This includes gestures (e.g., shaking his/her head), postures (e.g., folding arms and staring at the floor), words, motor actions (e.g., pushing away or throwing objects), and more complex actions (e.g., pacing about, retreating, leaving). Should the patient leave, the length of time he/she is out of the room is also counted as rejection. To qualify as rejection, there is no need for displeasure to be present.

- | | |
|---------------|-----------------|
| 0. Always | |
| 1. Frequently | |
| 2. Sometimes | |
| 3. Never | .Not assessable |

Appendix 2. Non-pharmacological Therapy Experience Scale (NPT-ES): Spanish Version

Instrucciones

La NPT-ES pretende medir aspectos de la experiencia del paciente en el momento de la intervención. La experiencia es la vivencia del momento presente, condicionada por las posibilidades de cada paciente. Algunas de las consecuencias observables de esta experiencia se expresan en la conducta y en las relaciones sociales.

El tiempo de evaluación ha de ser todo el que abarque la intervención que se quiera puntuar. Por tanto, el tiempo de evaluación puede ser una sesión completa, desde el primer elemento terapéutico hasta el último (p.e., desde la acogida hasta la despedida, incluyendo ambas), o bien sólo una parte de la sesión (p.e., la psicomotricidad).

Las puntuaciones en cada ítem se realizarán al finalizar la intervención. No se permite el uso de reloj ni de otras ayudas (notas, etc.). Es posible que un ítem condicione la puntuación en otros. Por ejemplo, si un paciente ha abandonado la sesión, el tiempo que permanece fuera de la sala se contabilizará como "rechazo" además de "no participación", aunque no necesariamente como "displacer". La respuesta 'no valorable' se aplicará cuando no se disponga de información para más de la mitad del tiempo de evaluación.

A. Participación

El paciente da muestras de atender y de responder a las indicaciones del terapeuta, a través de la postura, la mirada, los gestos, las palabras o las acciones. En caso de que el paciente no comprenda o no sea capaz de realizar la tarea, se valoran positivamente sus intentos de colaborar. Se puntúa tanto la respuesta espontánea como la respuesta a indicación del terapeuta.

3. Siempre
2. A menudo
1. Alguna vez

0. Nunca No valorable

B. Disfrute

El paciente expresa bienestar y placer, a través de la sonrisa, de otros gestos, de la postura, de las palabras o de las acciones. Debe advertirse que la participación no necesariamente conlleva disfrute.

3. Siempre
2. A menudo
1. Alguna vez
0. Nunca No valorable

C. Relación con otros

El paciente se comunica de forma positiva (respetuosa, amigable, etc.) o neutra con otros pacientes presentes en la sesión o con el terapeuta, mediante miradas, gestos, palabras o acciones, ya sea de forma espontánea o a indicación del terapeuta.

3. Siempre
2. A menudo
1. Alguna vez
0. Nunca No valorable

D. Displacer

El paciente da muestras de sentimientos negativos tales como malestar, ansiedad, tristeza, incomodidad, vergüenza, aburrimiento, a través de la postura, los gestos o las palabras. Los actos motores y las acciones más complejas sólo se puntuarán como displacer si se acompañan de algún otro dato que indique un humor negativo (p.e. un temblor en una pierna que se acompañe de una postura tensa o de un aspecto facial de ansiedad, o un tamborilear con los dedos con cara de aburrimiento). De igual modo, las acciones de rechazo (pregunta E) sólo se incluirán aquí si se acompañan de signos de displacer.

0. Siempre
1. A menudo
2. Alguna vez
3. Nunca No valorable

E. Rechazo

El paciente rechaza de forma activa las indicaciones del terapeuta. Se incluyen gestos (p.e., negación con la cabeza), posturas (p.e., cruzar los brazos y mirar hacia el suelo), palabras, actos motores (p.e. apartar o tirar objetos), y acciones más complejas (p.e. deambulación, alejarse, irse). En caso de irse, el tiempo que el paciente permanece fuera de la sala se contabiliza también como rechazo. Para puntuar como rechazo, no es necesario que exista displacer.

0. Siempre

- | | |
|---------------|--------------|
| 1. A menudo | |
| 2. Alguna vez | |
| 3. Nunca | No valorable |

References

- [1] Argimón, JM; Jiménez, J. Diseño de estudios descriptivos (III): estudios sobre fiabilidad de una medida. Diseño y validación de cuestionarios. In: Argimón JM, Jiménez J. Diseño de investigaciones en ciencias de la salud. Barcelona: Signo, 1998.
- [2] Baker, R; Dowling, Z. INTERACT: a new measure of response to multi-sensory environments. Research Publication. Research and Development Support Unit, Poole Hospital, Dorset; 1995.
- [3] Gerdner, LA. Effects of individualized versus classical “relaxation” music on the frequency of agitation in elderly persons with Alzheimer’s disease and related disorders. *Int Psychogeriatr* 2000; 12: 49-65.
- [4] Holliman, DC; Orgassa, UC; Forney, JP. Developing an interactive physical activity group in a Geriatric Psychiatry facility. *Activities, Adaptation and Aging* 2001; 26: 57-69.
- [5] Hurley, AC; Volicer, BJ; Hanrahan, PA; Houde, S; Volicer, L. Assessment of discomfort in advanced Alzheimer patients. *Res Nurs Health* 1992; 15:369-77.
- [6] Ibáñez, J; (1985). Del algoritmo al sujeto. Madrid: Siglo XXI.1985
- [7] Kitwood T. Dementia reconsidered: the person comes first. Buckingham: Open University Press; 1997a.
- [8] Kitwood, T. Dementia Care Mapping: the DCM method (7th ed.). Bradford: 1997b; Bradford Dementia Group, University of Bradford.
- [9] Kovach, CR; Henschel, H. Planning activities for patients with dementia: a descriptive study of therapeutic activities on special care units. *J Gerontolog Nurs* 1996; 22: 33-8.
- [10] Lawton, MP; Van Haitsma, K; Klapper, J. Observed affect in nursing home residents with Alzheimer’s disease. *J Gerontol Psychol Sci* 1996; 51B: P3-P14.
- [11] Lee KA, Kieckhefer GM. Measuring human responses using visual analogue scales. *West J Nurs Res* 1989; 11:128-32.
- [12] Mitchell, LA; Maercklein, G. The effect of individualized special instruction on the behaviors of nursing home residents diagnosed with dementia. *Am J Alzheimer Dis* 1996; January/February: 23-31.
- [13] Politis, AM; Vozzella, S; Mayer, LS; Onyike, CU; Baker, AS; Lyketsos, CG. A randomized, controlled, clinical trial of activity therapy for apathy in patients with dementia residing in long-term care. *Int J Geriatr Psychiatry* 2004; 19: 1087-94.
- [14] Reisberg, B. Functional Assessment Staging (FAST). *Psychopharmacol Bull* 1988; 24: 653-9.
- [15] Sloane, PD; Hoeffler, B; Mitchell, CM; McKenzie, DA; Barrick, AL; Rader, J; et al., Effect of person-centered showering and the towel bath on bathing-associated

aggression, agitation, and discomfort in nursing home residents with dementia: a randomized, controlled trial. *J Am Geriatr Soc* 2004; 52: 1795-804.

- [16] Vogelpohl, TS; Beck, CK. Affective responses to behavioral interventions. *Sem Clin Neuropsychiatry* 1997; 2: 102-112.
- [17] Woods, RT. Non-pharmacological techniques. In: Qizilbash N, Schneider LS, Chui H, Tariot P, Broday H, Kaye J, Erkinjuntti T, editors. Evidence-based dementia practice. Oxford: Blackwell; 2003: 428-446.