Neuropsychiatric Inventory

Comprehensive Assessment of Psychopathology in Patients with Dementia

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INTRODUCTION

The Neuropsychiatric Inventory (NPI) was developed to provide a means of assessing neuropsychiatric symptoms and psychopathology of patients with Alzheimer's disease and other neurodegenerative disorders. The NPI has been used to characterize the neuropsychiatric symptom profiles in a variety of neurological diseases. It has proven to be sensitive to change and has been employed to capture treatment related behavioral changes in patients receiving cholinesterase inhibitors, antipsychotic agents, melatonin and a variety of other antidementia and psychotropic compounds. The NPI is available in many languages, has been shown to be reliable in cross-cultural studies, and allows study of neuropsychiatric symptoms of dementia patients in different countries and cultures.

The NPI is valid and reliable. It has been integrated into studies with neuroimaging techniques (magnetic resonance imaging, single photon emission computed tomography, and positron emission tomography) to help explicate the neuroimaging correlates of behavioral changes in patients with Alzheimer's disease and other dementias, and to explore the relationship between treatment-related changes in regional brain function and altered behavior. Autopsy studies provide further convergent validity of the NPI.

This manual provides administration and scoring instructions for the NPI. It contains the standardized script for administering the questions to be asked of patients when performing the NPI. The background articles that establish the psychometric properties of the NPI and of the related caregiver distress scale are referenced. Master copies of the worksheets and scoring summaries that can be copied for your convenience are provided. This material constitutes the administration manual for the NPI.

A version of the NPI has been developed and validated for use in nursing homes (the NPI-NH), where information is collected from professional caregivers. The NPI-Questionnaire (NPI-Q) version of the NPI has been developed and cross-validated with the standard NPI to provide a brief assessment of neuropsychiatric symptomatology in clinical practice settings.

Thank you for your interest in the NPI. I hope that these instruments and their manuals and related information prove to be helpful to you in characterizing behavioral and neuropsychiatric symptoms in your patients, understanding the distress experienced by caregivers, and following treatment related changes in behavior. Neuropsychiatric symptoms are a key manifestation of dementias, and understanding and treating them is a major advance in improving the quality of lives of patients and their caregivers.

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NPI Neuropsychiatric Inventory (NPI): INSTRUCTIONS FOR USE AND ADMINISTRATION

I. Purpose of the NPI

The purpose of the Neuropsychiatric Inventory (NPI) is to obtain information on the presence of psychopathology in patients with brain disorders. The NPI was developed for application to patients with Alzheimer's disease and other dementias, but it may be useful in the assessment of behavioral changes in other conditions. Ten behavioral and two neurovegetative areas are included in the NPI:

Delusions
Hallucinations
Agitation/Aggression
Depression/Dysphoria
Anxiety
Elation/Euphoria
Apathy/Indifference
Disinhibition
Irritability/Lability
Aberrant motor behavior

Sleep and Nighttime Behavior Disorders
Appetite and Eating Disorders

II. Administration of the NPI

A. NPI Interview

The NPI is based on responses from an informed caregiver, preferably one living with the patient. A caregiver can be defined as a person spending at least 4 hours per day at least 4 days per week with the patient and who is knowledgeable about the patient's daytime and nighttime behaviors. If an informed observer is not available, this instrument cannot be used or must be modified. The interview is best conducted with the caregiver in the absence of the patient to facilitate an open discussion of behaviors that may be difficult to describe with the patient present. Several points should be made when you introduce the NPI interview to the caregiver:

- Purpose of the interview
- Ratings - frequency, severity, distress
- Answers apply to behaviors that are new since the onset of the disease and have been present for the past four weeks or other defined period
- Questions can usually be answered with "Yes" or "No" and responses should be brief

When beginning the inventory, say to the caregiver "These questions are designed to evaluate your (husband's/wife's/etc) behavior. They can usually be answered "yes" or "no" so please try to be brief in your responses." If the caregiver lapses into elaborate responses that provide little useful information, he/she may be reminded of the need to be brief. Some of the issues raised with this scale are very emotionally disturbing to caregivers and the interviewer should reassure the caregiver that they will discuss the problems in more detail after completion of the inventory.

Questions should be asked exactly as written. Clarification should be provided if the caregiver does not understand the question. Acceptable clarifications are restatements of the questions in alternate terms.

B. Changes in Behavior

The questions pertain to changes in the patient's behavior that have appeared since the onset of the illness. Behaviors that have been present throughout the patient's life and have not changed in the course of the illness are not scored even if they are abnormal (e.g., anxiety, depression). Behaviors that have been present throughout life but have changed since the illness are scored (e.g., the patient has always been apathetic but there has been a notable increase in apathy during the period of inquiry).

The NPI is typically used to assess changes in the patient's behavior that have appeared in a defined period of time (e.g., in the past four weeks or other defined interval). In some studies, the NPI may be used to address changes occurring in response to treatment or that have changed since the last clinic visit. The reliability and validity studies of the NPI were conducted using the 4-week time frame. The time frame of the question would then be revised to reflect this interest in recent changes. Emphasize to the caregiver that the questions pertain to behaviors that have appeared or changed since the onset of the illness. For example, the questions might be phrased "Since he/she began treatment with the new medications..." or "Since the dosage of _____ was increased ...."

C. Screening Questions and Subquestions

The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, mark "No" and proceed to the next screening question without asking the subquestions. If the answer to the screening question is positive or if there are any uncertainties in the caregiver's response or any inconsistencies between the response and other information known by the clinician (e.g., the caregiver responds negatively to the euphoria screening question but the patient appears euphoric to the clinician), the category is marked "Yes" and is explored in more depth with the subquestions. If the subquestions confirm the screening question, the severity and frequency of the behavior are determined according to the criteria provided with each behavior (below).

In some cases, the caregiver will provide a positive response to the screening question and a negative reply to all subquestions. If this happens, ask the caregiver to expand on why he/she responded affirmatively to the screen. If he/she provides information relevant to the behavioral domain but in different terms, the behavior should be scored for severity and frequency as usual. If the original affirmative response was erroneous, leading to a failure to endorse any subquestions, then the behavior is changed to "No" on the screen.

Some sections such as the questions pertaining to appetite are framed so as to capture whether there is an increase or decrease in the behavior (increased or decreased appetite or weight). If the caregiver answers "Yes" to the first member of the paired questions (such as has the patient's weight decreased?), do not ask the second question (has the patient's weight increased?) since the answer to the second question is contained in the answer to the first. If the caregiver answers "No" to the first member of the pair of questions, then the second question must be asked.

D. Frequency and Severity Ratings

When determining frequency and severity, use the behaviors identified by the subquestions as most aberrant. For example, if the caregiver indicates that resistive behavior is particularly problematic when you are asking the subquestions of the agitation section, then use resistive behavior to prompt judgments regarding the frequency and severity of agitation. If two behaviors are very problematic, use the frequency and severity of both behaviors to score the item. For example, if the patient has two or more types of delusions, then use the severity and the frequency of all delusional behaviors to phrase the questions regarding severity and frequency.

When assessing frequency, say to the person being interviewed "Now I want to find out how often these things (define using the description of the behaviors noted as most problematic on the subquestions) occur. Would you say that they occur less than once per week, about once per week, several times per week but not every day, or every day?" Some behaviors such as apathy eventually become continuously present, and then "are constantly present" can be substituted for "every day."

When determining severity, tell the person being interviewed "Now I would like to find out how severe these behaviors are. By severity, I mean how disturbing or disabling they are for the patient. Would you say that (the behaviors) are mild, moderate, or severe?" Additional descriptors are provided in each section that may be used to help the interviewer clarify each grade of severity. In each case, be sure that the caregiver provides you with a definite answer as to the frequency and severity of the behaviors. Do not guess what you think the caregiver would say based on your discussion.

We have found it helpful to provide the caregiver with a piece of paper on which is written the frequency and severity descriptions (less than once per week, about once per week, several times per week, and once or more per day for frequency; and mild, moderate, and severe for severity) to allow him/her to visualize the response alternatives. This also saves the examiner from reiterating the alternatives with each question.

E. "Not Applicable" Designations

In very impaired patients or in patients with special medical circumstances, a set of questions may not be applicable. For example, bed-bound patients may exhibit hallucinations or agitation but are unable to exhibit aberrant motor behavior. If the clinician or the caregiver believes that the questions are inappropriate, then the section should be marked "NA" (upper right corner of each section), and no further data are recorded for that section. Likewise, if the clinician feels that the responses are invalid (e.g., the caregiver did not seem to understand the particular set of questions asked),"NA" should be marked. Analytically, "NA" responses must be treated as missing values.

F. Neurovegetative Changes

Items 11 (sleep) and 12 (appetite) were added after the original publication of the NPI (Cummings et al, 1994). They were included because they are common problem areas in Alzheimer's disease and other dementias. They form part of the depression syndrome in some patients and were specifically excluded from the dysphoria subscale of the NPI in order to allow that subscale to focus on mood symptoms. These two symptoms may not be included in all protocols.

G. Caregiver Distress (NPI-D)

When each domain is completed and the caregiver has completed the frequency and severity rating, ask the associated caregiver distress question if your protocol includes the distress assessment. To do this, ask the caregiver how much, if any, "emotional or psychological" distress the behavior he/she just discussed causes him/her (the caregiver). The caregiver must rate his/her own distress on a five point scale from 0 - not at all, 1- minimal, 2 - mildly, 3 - moderately, 4 - severely, 5 - very severely or extremely. The distress scale of this instrument was developed by Daniel Kaufer, M.D. (Kaufer et al., 1998).

III. Scoring the NPI

Frequency is rated as:

☐ 1. Rarely – less than once per week
☐ 2. Sometimes – about once per week
☐ 3. Often – several times per week but less than every day
☐ 4. Very often – once or more per day

Severity is rated as:
☐ 1. Mild – produces little distress in the patient
☐ 2. Moderate – more disturbing to the patient but can be redirected by the caregiver
☐ 3. Severe – very disturbing to the patient and difficult to redirect

The score for each domain is: domain score = frequency x severity

Distress is scored as:
☐ 0. Not at all
☐ 1. Minimally (almost no change in work routine)
☐ 2. Mildly (some change in work routine but little time rebudgeting required)
☐ 3. Moderately (disrupts work routine, requires time rebudgeting)
☐ 4. Severely (disruptive, upsetting to staff and other residents, major time infringement)
☐ 5. Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

Thus, for each behavioral domain there are four scores:
• Frequency
• Severity
• Total (frequency x severity)
• Caregiver distress

A total NPI score can be calculated by adding the scores of the first 10 domain scores together. If the two neurovegetative items are included, specify that the 12 item score is being used rather than the 10 item score. The distress score is not included in the total NPI core.

The total distress score is generated by adding together the scores of the individual NPI distress questions; specify whether the 10 or 12 item score is being used.

IV. NPI-NH and NPI-Q

A nursing home version of the NPI (the NPI-NH) has been developed for use with professional caregivers in institutional settings. The instrument is identical to the original NPI but the questions have been rephrased to reflect the fact that the professional caregiver will not have known the patient prior to the onset of the illness and cannot know if the current behaviors represent changes from premorbid behaviors. The caregiver distress questions have been rephrased to assess the "occupational disruptiveness" of the behaviors. The NPI-Q version of the NPI has been developed and cross-validated with the standard NPI to provide a brief assessment of neuropsychiatric symptomatology in clinical practice settings. The NPI, NPI-NH, and NPI-Q are all available through the website (NPItest.net).

V. Translations

The NPI is available in a variety of languages for Asia, Europe, and the Americas and more translated versions are currently being developed. These are available through the MAPI Institute Nice, France.

VI. Copyright and Use of the NPI

It is requested that a copy of all published papers and abstracts using the NPI or NPI-NH be provided to Dr. Cummings at the address shown above. This allows construction of a comprehensive bibliography of studies and investigators using these instruments.

VII. Key References

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