GUIDELINES FOR APATHY EVALUATION SCALE

I. Definition and measurement of apathy:

The Apathy Evaluation Scale (AES) was developed to provide global measures of apathy in adults and elderly individuals[1]. Reliability and validity data are available for middle aged and older adults (2). Examination of individual items also provides qualitative information which may be of use in clinical assessments. The conceptual, clinical, and empirical background for the AES is presented in several publications (2-7). This background, along with descriptions of other applications of apathy and the AES, is summarized in more recent work (8-10). Essential aspects of this background are presented here as an introduction to the use of the AES.

Detecting apathy depends on identifying specific changes in 3 areas: observable (overt) activity, thought content, and emotional responsivity.

Decrements in overt behavior may entail subtle inefficiencies in the way people get their work done at home or at work. Or they may entail severe impairments in initiating and sustaining goal-directed behavior such that patients require prompting to perform personal and instrumental activities of daily living.

The cognition of patients with apathy reveals a decrease in goal-related thought content. For example, patients will report, "I have no plans," "I'm just not interested in much any more" or "I have little desire to do anything today."

Diminished emotional responsivity refers to shallow, abbreviated, or unchanging emotion in response to goal-related events. For example, confronted with personal losses, health problems, or financial misfortune, patients with apathy will be described as emotionally indifferent, placid, inappropriately euphoric, affectively shallow or flat. Favorable events similarly elicit attenuated emotional responses.

There are many explanations for symptoms such as these. Diminished activity, diminished goals, and attenuated emotional responses occur in many psychiatric, neurological and medical disorders (3,8). What distinguishes apathy is that all three aspects of goal-directed behavior -- overt activity per se; cognitions associated with goals, such as plans, curiosity, or interests; and emotional responses to goal-related events -- are affected simultaneously.

This analysis provides an *operational definition of apathy: simultaneous diminution in the overt behavioral, cognitive, and emotional concomitants of goal-directed behavior.*

The operational definition implies that the essential meaning of apathy is lack of motivation: The critical aspect of this operational definition is that patients with apathy show

[1] Reliability and validity of a Children's Motivation Scale, based on the AES, has been reported (1).

changes in the behavioral, cognitive, and emotional aspects of **goal-directed behavior**. It is apathy's relationship to goal-directed behavior that implies its essential meaning is lack of motivation. As described by Atkinson (11), motivation is concerned with understanding the "direction, intensity, and persistence" of goal-directed behavior. Or, as summarized by Jones (12), *motivation is concerned with how behavior "gets started, is energized, is sustained, is directed, is stopped and what kind of subjective reaction is present in the organism when all this is going on."* If applied to measuring the severity of apathy these definitions mean that **patients show apathy to the extent that they show diminished activity due to lack of motivation** (relative to the norms for their age and culture) (8). This distinguishes apathy from other causes of diminished activity, such as mood disturbance (depression or anxiety), intellectual capacity (dementia), or attention (delirium).

It is important to realize that, thus identified, patients with apathy are showing diminution in a fundamental aspect of behavior. Western intellectual traditions (13) recognize three realms of behavior: the intellectual, the emotional, and the conative (13)[2]. Psychiatric nosology offers many examples of disorders of intellect and emotion. Apathy and related disorders of diminished motivation (8-10) are examples of a third domain of psychopathology defined by impairment in motivation.

Motivation is essential for human adaptation. Therefore, patients with apathy suffer from an impairment which causes disability in virtually all essential areas of human functioning. Diminished motivation increases the risk of treatment failure because patients will not initiate or persist in following prescribed treatments (6,8). Medication compliance will suffer. Appointments will be missed. Engagement in intensive treatment programs -- for example socialization, physical rehabilitation, vocational training, pulmonary therapy, renal dialysis -- will be attenuated.

In summary, apathy means lack of motivation. Motivation or its inverse, apathy, is operationalized in the AES by evaluating the overt behavioral, cognitive, and emotional aspects of goal-directed behavior. Thus, the AES includes items to evaluate: Diminished goal-directed overt behavior, for example, diminished productivity, lack of effort, and initiative; cognitive evidence of apathy, for example, lack of interests, lack of curiosity, and decrease in the importance attributed to age appropriate goals or values, e.g. health, finances, or the welfare of others; and emotional evidence of apathy, for example, shallow affect, emotional indifference, and impersistence of emotional responses.

ADMINISTRATION OF THE APATHY EVALUATION SCALE

[2]. Conation refers to willed behavior. This is roughly equated with the domain of motivation. The essential difference is that motivation refers to both conscious and unconscious determinants of behavior.

General Considerations:

Three versions of the AES: The foregoing definitions are incorporated into the AES. The AES is an 18 item scale. It requires 10-20 minutes to administer depending on the subject's abilities and the version used. There are 3 versions of the scale: **self-** (**AES-S**), **informant** (**AES-I**; significant other, e.g. personal or professional caregiver), and **clinician** (**AES-C**) rated versions. This affords flexibility in rating apathy since the clinical population and clinical circumstances often dictate a preference for one form of administration over another[3]. The clinician version has somewhat better validity than the informant version. The overall validity of the AES-S is less than the AES-C and AES-I. Therefore, when possible the clinician version is preferred. The AES assessment of apathy is based on subjects' current functioning. For outpatients or patients rated within 3-4 days of hospitalization the period rated is defined as the previous 4 weeks. Changes necessary for hospitalized and other institutionalized individuals are discussed later.

Types of items: Each version consists of the same 18 items. Consistent with the operational definition of apathy, there are 3 types of items: each item is primarily an index of overt goal-directed behavior, goal-related cognitions, or goal-related emotional responses. This categorization of items is indicated in the right hand column of the clinician version of the AES-C: B= behavioral item; C= cognitive item; E= emotional item[4]. Items are worded with positive or negative syntax (+ or -); most are positive. The rating of Self-evaluation (SE) and quantifiable (Q) items, as denoted in the right hand column of the AES-C, is described below.

[3] Evidence of reliability of validity of each version has been presented and supported by subsequent studies (see 8; 14-17).

[4] The items for initiative (#17) and motivation (#18) are coded as other (O) since they are not readily classified as B, C, or E items. Their inclusion is based on the psychometric data used for scale development.

Two types of administration procedures: The self and informant rated versions are administered as *paper and pencil tests*. Cognitively impaired patients can provide meaningful responses[5], particularly if the rater reads the items and records the subject's responses. Experience to date (2) suggests that primary caregivers are sensitive, reliable sources of information about apathy.

The AES-C is administered as a *semi-structured interview*. Items are rated based on current functioning as evident from the subject's "thoughts, feelings, and actions" during the past 4 weeks.[6] It is crucial to understand that the AES-C ratings are based on the clinician's assessment of the patient's self-reports. In other words, except for the self-evaluation (SE) items discussed below, the *ratings given for the AES-C are based on the clinician's best judgment (or "objective" assessment) of the subject's motivational state.* To carry out this assessment, *verbal and non-verbal data must be evaluated.* Specific Instructions (below) describes how to integrate verbal and non-verbal observations. Two principles underlie the use of non-verbal information: first, as indicated in the above definitions of apathy and motivation, *emotional responsivity provides information about motivational state*; second *how the individual deals with questions (verbally and non-verbally) is assumed to provide information about how other activities are dealt with* (for example, with initiative, exuberance, or lethargy). Thus, the AES-C interview is viewed, in effect, as a "motivational laboratory": what the subject says and how it's said provides a valid sample of subject's overall motivation in other situations.

Learning to use the AES:

Basic clinical skills suffice to apply the above definitions to administering the AES. The detailed instructions that follow likely will seem complex on first exposure. With minimal experience, however, they are readily appreciated and applied. Before attempting to assimilate the detailed instructions it is recommended that a new user read the sections titled Specific instructions and the introduction section of Guidelines for Coding Severity. Then administer the scale to 1 or 2 individuals showing minimal and moderately severe levels of apathy. If unfamiliar with the syndrome of apathy (4,8), it is better to begin with neurological patients who present lack of motivation without depression; patients with Alzheimer's disease of mild to moderate severity often fulfill this requirement. After this brief experience with the AES, the utility of the additional material is readily assimilated.

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[5] Meaningful ratings can be obtained in subjects with Mini-mental state scores as low as 10, particularly if they are rated using the AES-C or AES-I.

[6] This information can be supplemented by other clinical information when the rater judges the subject's responses of doubtful validity. In practice this is rarely necessary. For clinical purposes the use of external information presumably enhances the validity of AES-C ratings. However, the impact of this procedure on AES scores has not been evaluated.

With modest experience, it will be evident that the AES is based on what is in many ways a common sense clinical approach to interpreting motivation. In the author's experience, bachelor's level raters can be introduced to the concept of apathy and taught to use the AES with adequate reliability with only 4-6 hours experience. Research levels of inter-rater agreement can be reached by experienced clinicians by rating as few as 5-10 subjects.

Specific Instructions:

The AES should be administrated in a quiet room. A few minutes should be provided to introduce the scale and its purpose and to develop adequate rapport with the patient to insure satisfactory candor.

A consistent format should be used in introducing the scale and administering the items. The following statement is recommended as an introduction to the procedure. It orients the subject to the domains of interest and provides the rater with an initial data base that will be used in rating individual items, in particular, Are you interested in things? (#1): "I am going to ask you a series of questions about your thoughts, feelings, and activities. Base your answers on the last 4 weeks. To begin, tell me about your current interests. Tell me about anything that is of interest to you. For example, hobbies or work; activities you are involved in or that you would like to do; interests within the home or outside; with other people or alone; interests that you may be unable to pursue, but which are of interest to you--for example, swimming even though it's winter or reading even though your vision may not be good enough."

The responses to the first question are carefully observed and recorded. The interviewer should make note of: (1) Number of interests reported; (2) degree of detail reported for each interest; (3) affective aspects of expression (verbal and nonverbal).

The interviewer then states: "Now I'd like you to tell me about your average day. Start from the time you wake up and go to the time you go to sleep."

The interviewer again notes the number of activities, degree of detail, intensity and duration of involvement in activities, and the affect associated with presentation of this information.

To assure consistency in presentation, prompting is indicated only if the subject seems not to understand what information is being sought or has forgotten the question.

Each item of the AES is now presented using the wording of the item itself. Begin with items #1 and #2 even though the information just gathered permits a preliminary evaluation. Additional information may be requested to clarify ambiguous responses but patients should not be pressed for detail if their initial responses are clear. Simple bridges between items may be used to preserve a conversational quality to the interview. Since AES-C ratings are based on the rater's integration of all verbal and non-verbal information obtained from interviewing the

patient, each item of the AES-C the rating of each item is also influenced by information accumulated through responses to all previous questions. For example, individuals with high standards and high motivation are likely to "expect too much from themselves." This will be increasingly evident over the course of the interview. They may underrate their motivation. Thus, if the subject responds to the final question (Do you have motivation?) with a "Somewhat motivated," the rater would record "A Lot," which says, in effect, "She says 'somewhat' just because her standards are so high. Relative to others, her rating is really 'a lot.'"

Guidelines for coding severity:

Introduction: The 3 versions of the AES use a similar 4 point, Likert-type scale, "Not at all," "Slightly," "Somewhat," and "A Lot." Criteria for these options are not specified for the AES-S and AES-I. For the AES-C, these four response options are defined as follows:

1. Not at all characteristic (none, no examples given)
2. Slightly characteristic (trivial, questionable, minimal).
   Example: "I guess so." "Yea, sort of." "May be a little."
3. Somewhat characteristic (moderate, definite).
   Example: "Yes." "Definitely." "I enjoy playing bridge and dancing." "A fair amount." (stated without facial or vocal change to suggest intensity)
4. A Lot characteristic (a great deal, strongly). "A Lot" requires verbal or nonverbal evidence of intensity.
   Example: "Oh yes, absolutely, I love it." "You bet!" Or, non-verbal evidence of intensity such as vigorous head nodding; raising amplitude or frequency of speech; sitting up straight and gesturing with hands, etc.

How much is A Lot? In the AES-C "A lot" refers to a level of activity, interest, or emotional intensity seen in normal individuals. It does not refer to levels of intensity that are "supernormal," e.g. hypomanic or manic. In the AES, manic behavior would be coded as "A Lot" and thus could not be distinguished from a well functioning normal individual.

Quantifiable (Q) items: The criteria for applying these codes are quantified for several items (#1, #2, #4, #5, #12). These quantifiable items (labeled Q in right hand column of AES-C) are rated by counting the number of instances cited by the subject for a particular item (e.g., number of interests, number of friends):

1. Not all characteristic: 0 items
2. Slightly characteristic: 1-2 items
3. Somewhat characteristic: 2-3 items
4. A Lot: 3 or more

Example of rating quantifiable (Q) items:

Rater: Are you interested in things? (#1)
Subj.: Yes, for sure...no question about it.

Comment: "For sure" and "no question" suggest higher levels of intensity, and therefore a rating of 4. A Lot. However, for a quantifiable (Q) item, further information is necessary. Therefore, rater asks:

Rater: Can you give any examples?
Subj.: Well, sure. I like to keep busy. I'm interested in the house most of the time ... I have to clean up the house every day... may be read some magazines...I guess that's about it.

Comment: Subject identifies only two interests: house care and reading magazines. Therefore, despite initial response, score is "3. Somewhat characteristic.")

Guidelines for evaluating responses that fall on the boundary between two response options: It is common for subjects to provide responses that are on the boundary between two scoring options. For example, in the above example, if the subject also had specified a third interest, such as "We try to go bowling once or twice a week," then there would be a total of 3 responses; these 3 responses could be coded as either Somewhat or A Lot, since 2-3 items merits a Somewhat score and 3 or more is scored A Lot. The following guidelines are used for such boundary cases:

1. Consider the presence of verbal and nonverbal evidence of affect. In the present example, the initial expressions, "Yea, for sure," and "You bet," suggest higher levels of motivation. This would shift the response to this item to a 4. A Lot. Blunted affect or lack of enthusiasm would suggest a more apathetic scoring, and therefore a coding of 3. Somewhat.

2. Consider the degree of differentiation of responses. For example, in rating Item 1 "Interested in things": Score Slightly if a subject simply specifies "reading" (i.e. 1 interests), but Somewhat if 2-3 specific books or television programs can be specified. Similarly, if a subject is interested "only" in reading, but provides multiple examples of reading materials, rate Slightly, Somewhat, or A Lot based on the number of examples given. When subjects offer broad categories such as reading or television, it is appropriate to prompt them once for each item with the question, "Can you give me any examples?"

3. In ambiguous instances, rate toward the more apathetic score.

4. When still in doubt, one may ask the patient whether, for example, "Somewhat" or "A Lot" is the more appropriate descriptor.

Self-evaluation (SE) items: The self-evaluation (SE) items (#3, #8, #13, #16) are *coded exclusively on the subject's rating of severity. The clinician rater's appraisal is not considered for SE items.* Thus, if a subject says "A Lot" when asked "Is getting together with friends important to you?" (#12) then the response is coded 4. A Lot -- even if the rater's "objective" assessment is 2. Slightly because the subject was able to name only 1 friend in the previous question. The purpose of relying on the subject's self-evaluation is that it indicates that the subject still treats having friends or Getting things done during the day (#16), etc. as being very importanct. In effect, then, SE items are indices of the subjective importance an activity or goal has for the subject. Practically speaking, the SE items are often sensitive to the preservation of motivation in individuals who otherwise seem quite apathetic. Thus, someone who gets little or nothing done each day may still show intact goals or values by asserting that Getting together with friends is "very, (i.e. A lot) important to me."

Using non-verbal information to simplify the rating of items 7 and 14: Other than quantifiable and self-evaluation items, the rating given for items is based on the descriptors given above, e.g. 2. Slightly is equivalent to trivial, minimal, or questionable. In practice, these descriptors are sufficient to provide excellent reliability for the AES-C. For two items additional clarification is helpful for distinguishing between Somewhat and A Lot. These items are 7. S/he approaches life with intensity, and 14. When something good happens, s/he gets excited. For these items, it is recommended that the score is "3. Somewhat characteristic" if the patient affirms that these statements are true without verbal or non-verbal evidence of positive affect and "4. A Lot Characteristic" if such evidence is present. Rating these items is also aided by remembering that the subject's overall level of responding during the rating procedure provides much information regarding how they respond "when something good happens" or whether they "approach life with intensity."

Item 15, which concerns an "Accurate understanding of his/her problems" calls on the rater to evaluate the adequacy of patients' insight into their personal or, if present, clinical problems. This item may be introduced by saying, "Now let me ask you this. We've been talking about your interests and activities. But we all have problems too. Could you give me an idea about the things that you view as your problems." Ratings are then based on the appropriateness and accuracy of the response given.

Scoring the AES:

For clinical purposes, apathy is conceptualized as a pathological construct. Therefore, AES items are scored so that high AES scores indicate more apathy, i.e. less motivation. This requires recoding items that are stated with positive (+) or "healthy" syntax. Therefore, all but 3 AES items (#6, #10, #11) have to be recoded. The recoding rules are the same for the AES-S, AES-I, and the AES-C. Recoding means changing item codes so that 1=4, 2=3, 3=2, 4=1.

Cut-off scores: Scores for the AES range from 18 to 72. In the original validation study (2), the mean (standard deviation) score for 30 healthy elderly controls were: AES-C: 26 (+/-6); AES-I: 26 (+/-7.5); AES-S: 28 (+/- 6).

Using a criterion of mean + 2 S.D. this suggests cutoff scores of 39-41, depending on which version of the AES is used. Clinical correlation suggests that these cutoffs are probably slightly low. This is undoubtedly due at least in part to the effect of "volunteerism": individuals who volunteer for a study on apathy probably have higher than average motivation compared to the general population. It should also be noted that the original validation study was performed in a geriatric population. Age and culture are important sources of variance for rating apathy. Also of importance is that the number of healthy controls (n=30) was insufficient for a standardization procedure. For these reasons, the author recommends that investigators using the AES develop their own norms.

Clinicians using the AES-C in a sample over age 60 years will find that a score of 42 or more generally indicates minimal or mild apathy. Somewhat lower scores are probably significant in younger populations. However, formal recommendations cannot be given at this time.

Using the AES in hospitals or other institutional environments:

The AES was originally developed for individuals living outside of residential environments which structure much of individuals' daily behavior, e.g. through treatment programs, group meetings, etc. This approach was taken for strategic purposes. The original study was a construct validation study. Priority was given to eliminating the confounding effect on motivation of evaluating subjects when much of their goal-directed behavior was dictated by the external environment. To adapt the AES for this and other effects of institutionalization a few minor adjustments are needed.

1) Motivational impact of change in environment: Being admitted to a hospital, nursing home, rehabilitation facility, or other institution is expected to alter motivation. This does not indicate a weakness of the AES or the concept of apathy. Rather, it reflects the fact that motivation is determined by an interaction between biological, psychological, and socioenvironmental variables. This should be considered in deciding how to administer the AES for people in institutions. The author recommends the following:

a) Items that refer to activities which are directly structured by the environment: As a measure of motivation, the AES is concerned with thoughts feelings, and actions which represent the subject's initiative, effort, interests, etc. Therefore, subjects should not be given credit for having initiated an activity which was dictated by the schedule or program of the environment. Therefore, "getting things done during the day," "putting

effort into the things that interest you", having initiative, etc., are evaluated relative to activities initiated or carried out by the individual in addition to those strictly called for by the patient's schedule or treatment plan. An example is helpful. For the item (#2), "He or she gets things done during the day," a subject does not receive credit for going to the regularly scheduled 10 a.m. group therapy session. But reading a book, playing one's own videogame, or writing a letter in unscheduled time all would. Note that not all AES items are so susceptible to such environmental effects. For example, the response to "getting things done during the day is important to me" is not directly influenced by such environmental effects.

2) Ambiguity in defining period of current functioning in subjects recently admitted to hospitals or other institutions: The general instructions state that current functioning refers to the 4 weeks prior to the time of evaluation.

a) Individuals who have been hospitalized for only a few days should answer AES questions with reference to the 4 weeks prior to their admission. After only a few days, it is easy and usually natural to report one's general level of functioning for the preceding 4 weeks.

b) Once individuals have been hospitalized for a week or more, they should consider "current functioning" as their thoughts, feelings, and actions within the institution. When admission occurred less than 4 weeks previously it is generally best to restrict the period of interest to the most recent 1-3 weeks. In other words, once adjusted to a hospital environment, the subject ignores the period prior to hospitalization.

c) Periods as short as 1 week generally permit useful reference periods for evaluating motivational status with the AES. Thus, if there has been an acute event, such as a stroke, or if there has been a marked improvement in functioning, for example, due to successful treatment of apathy or depression, a shorter period -- one representing relative stability -- is appropriate.

In summary the guidelines for the AES-C are:

1) Prime the subject with the two questions regarding current interests and daily activities.

2) Administer each item using the wording of each item.

3) Except for self-evaluation (SE) items, the rater integrates verbal and non-verbal information to

rate each item. Responses to items are based on the subject's response to the individual item and other information already acquired during the course of the interview. Self-evaluation items are rated exclusively on the basis of the subject's judgment.

4) Guidelines are provided to distinguish between ratings of Not at all, Slightly, Somewhat, and A Lot characteristic. For quantifiable (Q) items the number of examples and the degree of differentiation for each example is considered in rating each item.

5) Boundary responses are rated by considering verbal and non-verbal evidence of affect, degree of differentiation of responses, subject's judgment regarding the more appropriate rating category, and by rating toward the more apathetic coding.

6) Additional suggestions are included to help in rating Items 7, 14, and 15.

7) Minor adjustments are helpful in rating individuals recently hospitalized or residing in institutions.

Additional questions, comments, or suggestions are welcome. Refer them to Robert S. Marin, M.D., Western Psychiatric Institute and Clinic, 3811 O'Hara St., Pittsburgh, PA 15213. Tel. 412 586 9305. E-mail: marinr@upmc.edu.

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