AICT

Advanced Illness Care Teams

for Nursing Home Residents with Advanced Dementia

IMPLEMENTATION MANUAL

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Introduction

Nursing home residents with advanced dementia pose a particular challenge to families and health care staff caring for them. The loss of memory and cognition in these residents contribute to fluctuations in their day-to-day functioning. These changes need to be monitored and addressed to ensure that the appropriate level of care is provided. Since dementia is an incurable and fatal condition, hospice care would seem to be the treatment of choice for people suffering from this illness. Hospice care, however, is not generally used for individuals who have a primary diagnosis of Dementia or Alzheimer's because of the indeterminate longevity associated with these disorders. As a result, nursing homes are the site of terminal care for an increasing number of older adults with dementia.

In response to this trend, there has been ongoing interest in improving end-of-life care for people with dementia. In New York State, the Department of Health has identified six priority areas in their Dementia Grant Program including end-life-care, pain management, and culture change. Advanced Illness Care Teams (AICT) provide a means for health care facilities to implement these priorities and to improve the quality of care available to residents with advanced dementia. The Institute of Gerontology, working in collaboration with the Carmelite Sisters, proposed the development of an AICT at two New York City nursing homes (Ozanam Hall & St. Patrick's Home) operated by the Carmelite Sisters. The Avila Institute, which functions as the research and training arm within the Carmelite system of care, was instrumental in the development of AICTs at Ozanam Hall and St. Patrick's Home.

This project began in 2002 and was eventually funded by the New York State Department of Health's Dementia Grants Program. The focus of this grant project was to develop and evaluate the effectiveness of Advanced Illness Care Teams (AICT) for nursing home residents with advanced dementia. With respect to end-of-life care, the model was designed to help nursing homes improve planning and service delivery to residents with advanced dementia before a crisis occurs. This team approach was also designed to make staff more aware of resident and family member/surrogate needs.

AICTs were implemented on two units at Ozanam Hall and three units at St. Patrick's Home, yielding a sample size of 120. A total of 30 residents on each of the two units at Ozanam and 20 residents on each of the three units at St. Patrick's were seen by the team over a period of 12 months. Residents were brought into the study during five discrete intervention periods over this period of time. Each new intervention period enrolled 24 residents. Initially, a total of 24 residents were randomly assigned to treatment or control (usual care) groups. The control groups received the usual care provided to all residents.

The treatment groups received the eight-week AICT intervention. The AICT intervention included a review and revision of residents' care plans by the interdisciplinary team. This team met a minimum of five times over the eight-week intervention period. The families or surrogates for each resident were invited to participate in these team meetings early in the intervention period to provide their thoughts, concerns, and perspective on the care plan.

After eight weeks, a new intervention period began. Those who were receiving usual care were placed in the treatment group, and 24 new residents were randomly assigned across both groups as previously described. This rotational process continued until each of the identified residents

on the unit received AICT treatment. Table 1 (below) illustrates how the assignment to treatment condition unfolded during the five intervention periods. It should be noted that months eleven and twelve were not a new intervention period but rather part of the last intervention period in which residents assigned to usual care crossed over to treatment.

Table 1

Number of Unit Residents by Experimental Condition for each Intervention Period

AICT Intervention Periods (n=120)	Residents in the Usual Care Group	Residents in the AICT Intervention Group	
		Initial	Crossover
Months One and Two	12	12	-
Months Three and Four	12	12	12
Months Five and Six	12	12	12
Months Seven and Eight	12	12	12
Months Nine and Ten	12	12	12
Months Eleven and Twelve	-	-	12

The hypothesis for this study was that residents who were seen by the AICT would experience significant decreases in pain, discomfort, depression, and agitation when compared to residents receiving usual care. In order to test this hypothesis, nursing, social services, and spiritual care staff completed the following observational instruments with residents both before and after their participation in each arm of the study: the FLACC Scale, the Pain Assessment in Advanced Dementia Scale, the Cohen Mansfield Agitation Inventory, the Cornell Scale for Depression in Dementia, and a spiritual assessment.

The statistical analysis for this study was undertaken by the Institute of Gerontology at the University at Albany. Additionally, staff from the Institute of Gerontology surveyed participating family members/surrogates before and after the resident's participation in the study to assess their satisfaction with nursing home care and the AICT intervention model. These staff also observed selected intervention sessions in order to obtain team process data, and they served as a resource for the AICTs.

Separate steering committees comprised of Ozanam Hall staff and St. Patrick's Home staff provided project oversight, education, and in-services that helped support the AICTs in care planning. Members of the steering committee were assigned to monitor particular functions of the teams. Each member was identified and listed as a resource for the AICTs to utilize.

Note: At no time in the study was a resident who required specialized or emergency care denied care due to their participation in the treatment or control group.

Forming the Team (AICT)

The Steering Committee – In preparing for the implementation of an Advanced Illness Care Team (AICT), it is essential to have the commitment, involvement, and support of facility management. This is essential because the AICT will require a significant change in practice for most facilities. Facility staff, as well as management, needs to be aware of how these changes will impact daily routines and schedules. For example, an AICT may require more frequent team meetings and more staff participating in these meetings. Team meetings will encourage brainstorming, equitable 'give and take' among team members, and aggressive solicitation of family input in the care planning process. To implement this approach, key management staff needs to be supportive of, as well as involved in, the planning and oversight of the AICT. This group of key management staff is the Steering Committee.

In most facilities, the Steering Committee will include the Nursing Home Administrator and the directors of Nursing, Social Services, and Spiritual Care. Other unit directors or coordinators involved in resident care should also be considered for participation on this committee. The Steering Committee will be initiating this new program and they will be instrumental in facilitating and supporting the change process as staff implements this new model of care.

The AICT – The AICT model of care will require significant changes in the way staff develop care plans. Initially, the Steering Committee will be involved in the regular care planning meetings to ensure fidelity with the AICT model of care. Steering committee members will help the team build an operational consensus around what the AICT looks like and how it functions within the unique context of each facility. Membership on the AICT will include activities coordinators or directors, doctors, nurses, nursing assistants, psychologists, social workers, and spiritual advisors.

The AICT will use a holistic approach in the assessment of each participating resident, and this approach will subsequently shape the individualized care plans developed for each resident. Central to this holistic approach will be the consideration of five (5) potential sources of pain. These sources of pain are listed below along with the instruments used to measure them. To obtain these instruments, please see the appendix at the end of this manual.

- Physical pain – FLACC Behavioral Pain Scale & Pain Assessment in Advanced Dementia (PANAD).
- Mental pain – Cornell Scale for Depression in Dementia (CSDD).
- Spiritual pain – Spiritual assessment of choice (staff preference).
- Emotional pain – Cohen-Mansfield Agitation Inventory (CMAI).
- Familial pain – Family Satisfaction with Cancer Care Scale (FAMCARE).

Nursing staff will complete the instruments for physical pain, and social services staff will administer the emotional, mental, and familial pain scales. Spiritual care staff will perform the spiritual assessment. Members of the Steering Committee, who have some expertise or specialization in one of the five pain areas, will serve as advisors or consultants for the AICT members responsible for assessing the potential areas of pain listed above.

Screening, Selection, and Enrollment of Residents

Approximately four weeks prior to the start of each intervention period, the director of nursing identified a list of residents to be considered for enrollment in AICT. For each of these residents, nursing and social services staff completed the following screening instruments: the Mini-Mental State Examination, the Global Deterioration Scale, and the Activities of Daily Living Scale. The steering committee coordinator reviewed these results and completed the Screening Decision Form, which was used to help guide the enrollment decision.

In communicating with the steering committee coordinator, the unit social worker identified a family member/surrogate for each selected resident. The family member/surrogate was invited to attend a family informational meeting where they were able to learn more about the AICT project. This meeting was held prior to AICT enrollment and, whenever possible, the resident was included. If the family member/surrogate was unable to attend this group meeting, the social worker arranged an individual family meeting.

Approximately three weeks prior to the start of the intervention, the family meeting was scheduled and an informed consent was obtained from the resident and family or surrogate. It was at this point during the AICT study that the resident was randomly assigned to the intervention or control group. Staff from the steering committee, social services, and the Institute of Gerontology facilitated this process. If consent was obtained for the family satisfaction study, the family member/surrogate was then given the family satisfaction pre-test.

In the week prior to the intervention start date, nursing, social services, and spiritual care completed the AICT pre-test observational instruments with residents in both arms of the study. During the eight week intervention period, the AICT had at least five meetings to develop individualized care plans for the residents in the treatment arm of the study. Residents in the control condition continued to receive their usual care. The family member/surrogate for each resident in the treatment condition was invited to the third AICT meeting to provide input into the individualized care plan.

At the end of the eight week intervention period, post-test observational instruments were completed for each of the residents in the treatment arm of the study. Pre-test observational instruments were once again completed for each resident in usual care as well as for the new group of residents being enrolled for the second intervention period. During the next eight week intervention period, the new group of residents assigned to the treatment condition was added to the first group of residents crossing over from usual care to treatment.

At the end of this second intervention period, post-test observational instruments were completed on all of the residents finishing treatment and on the first group of treatment condition residents who finished treatment during the first intervention period (treatment condition residents have a post-test and follow-up separated by eight weeks). This process continued over five intervention periods during the course of the AICT study. Table 2, which is shown on the next two pages, illustrates the timetable of activities for a single intervention period.

Table 2

AICT Intervention Timetable from Pre-Intervention through One Intervention Period

Tasks/Intervention Activities	Pre-Intervention Weeks				Weeks During Intervention*							
	4	3	2	1	1	2	3	4	5	6	7	8
Director of nursing identifies a list of potential study participants	x_1								x_2			
Nursing and social services staff complete screening instruments	x_1								x_2			
Steering committee coordinator verifies that residents meet the study's inclusion criteria	x_1								x_2			
Social worker identifies family members/surrogates and invites them to attend informational meeting	x_1								x_2			
The group family meeting is held wherein informed consent and randomization take place		x_1								x_2		
Nursing, social services, and spiritual care complete pre-test observational instruments				x_1								x_2
Family satisfaction pre-test survey completed by family member/surrogate				x_1								x_2
AICT meeting one- Introduction, problem identification, & intervention formulation					x							
AICT meeting two- Information & continued intervention development/monitoring						x						
Social worker reminds family members/surrogates about AICT meeting three and invites residents and/or specialists to attend						x						
AICT meeting three- Care planning with residents and/or family members/surrogates							x					

x_1 = *Prerequisite timelines relating to the initial two-month intervention period* x_2 = *Prerequisite timelines relating to subsequent intervention periods*
x = *Activities/timelines common to all intervention periods*

** With the exception of the first intervention period, prerequisite tasks for intervention periods begin midway through the preceding intervention period*

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Table 2 (continued)

AICT Intervention Timetable from Pre-Intervention through One Intervention Period

Tasks/Intervention Activities	Pre-Intervention Weeks				Weeks During Intervention							
	4	3	2	1	1	2	3	4	5	6	7	8
AICT meeting four- Care planning progress and changes									x			
Social worker invites residents and/or family members/surrogates to attend the last AICT meeting									x			
Social worker conducts family/member surrogate session(s)										x	x	
AICT meeting five- Evaluation of progress and future directions with residents and/or family members/ surrogates												x
Nursing, social services, and spiritual care complete post-test observational instruments												x
Family satisfaction post-test survey completed by family member/surrogate												x

x_1 = *Prerequisite timelines relating to the initial two-month intervention period* x_2 = *Prerequisite timelines relating to subsequent intervention periods*
x = *Activities/timelines common to all intervention periods*

Care Plan Meeting One

Residents assigned to the treatment condition will be introduced to the AICT. The physician, charge nurse, social worker, and spiritual care worker jointly conduct this introduction.

- The physician (or charge nurse as designee) will present a brief medical history as well as information about diagnosed medical conditions, potentially undiagnosed conditions, current lab results/vital statistics, and prescribed medications.

- The charge nurse will present scores from the three screening instruments as well as the pre-test FLACC and PANAD scales.

- The social worker will present scores from the Cohen-Mansfield Agitation Inventory and Cornell Scale for Depression as well as a brief social history.

- The spiritual care worker will present the results of the spiritual assessment (if able to be completed with the resident) as well as any information known about the spirituality and/or religious beliefs of the resident/family.

Following this introduction, the team will identify potential problem areas requiring additional information or observation over the coming week. The charge nurse will lead this discussion and document all information requests in the data collection notebook's intervention section.

- The physician will conduct a thorough examination of the resident and will assume responsibility for any needed medical assessments/tests.

- The charge nurse will direct staff nurses/assistants to record observations daily. Observations will be made using an *antecedents*, *behaviors*, and *consequences* framework noting any changes in the resident's physical/ emotional pain level.

- The social worker will collect needed information from the resident and/or family member/surrogate.

- The spiritual care worker will collect needed information from the resident and/or family member/surrogate regarding their spiritual practices and related needs.

The team will also use the following multi-step format, organized by the five pain areas, to identify potential interventions for immediate implementation. The charge nurse will lead this discussion and document all intervention ideas in the data collection notebook's intervention section.

Physical
- Review the need for over the counter and/or prescribed pain medications
- Review the need for treatment of current and/or undiagnosed medical conditions
- Review the need for physical and/or occupational therapy interventions
- Review the need for nutritional interventions
- Review the need for exercise

Psychological/Behavioral

- Review the need for behavior problems to be observed in an ongoing manner using the *ABC* framework and/or modified with operant conditioning
- Review the need for additional, behavior specific intervention strategies
- Review the need for psychotropic or other medications

Emotional/Interactional

- Review the need for depression treatment using the Cornell Scale for Depression
- Review the need for social interaction (one-on-one contact or in small groups)
- Review the need for engagement in specific nursing home activities
- Review the need for multi-sensory stimulation (such as the use of light, music, aromatherapy, etc.)
- Review the need for reminiscence/life review (using memory cues, personal objects, stories, etc.)

Spiritual

- Review the need for the resident to participate in prayer groups and activities
- Review the need for specific resident and/or family member/surrogate ministrations
- Review the need to discuss specific spiritual questions/issues with the resident and/or family member/surrogate at the third AICT meeting wherein the care plan will be finalized

Familial

- Review the need for family/surrogate education regarding the dementia disease course and the philosophy of advanced illness care
- Review the need to explore advance care planning interventions (based on the presence or absence of proxy and/or instructional directives, doctor's orders, etc.)
- Review the need for grief and loss counseling
- Review the need to discuss related questions/issues with the family member/surrogate at the third AICT meeting

<u>Care Plan Meeting Two</u>

One week following the initial resident meeting, the team will convene to initiate care planning.

- The physician (or charge nurse as designee) will report any changes in the resident's condition, as well as the results of any requested medical assessments/tests.

- The charge nurse will summarize nursing staff reports of *antecedents*, *behaviors*, and *consequences*. Particular attention should be given to the resident's pain levels along with any emergent situations or patterns affecting the resident's condition.

- The social worker will report any information obtained from the resident and/or family member/surrogate as well as scores from any other pertinent assessment instruments.

- The spiritual care worker will share information regarding the spiritual practices/needs of the resident and/or family member/surrogate.

The team will again use the five pains framework to guide the care planning process. The charge nurse will lead this discussion and document all interventions/changes in the intervention section of the data collection notebook.

Physical

- Review over the counter and/or prescribed pain medications
- Review treatment of current and/or undiagnosed medical conditions
- Review physical and/or occupational therapy interventions
- Review nutritional interventions
- Review exercise interventions

Psychological/Behavioral

- Review the need for behavior problems to be observed in an ongoing manner using the *ABC* framework and/or modified with operant conditioning
- Review behavior specific intervention strategies
- Review psychotropic or other medications

Emotional/Interactional

- Review depression treatment
- Review social interaction interventions
- Review engagement in specific nursing home activities
- Review multi-sensory stimulation interventions
- Review reminiscence/life review interventions

Spiritual

- Review participation in prayer groups and activities
- Review specific resident and/or family member/surrogate ministrations
- Review the need to discuss specific spiritual questions/issues with the resident and/or family member/surrogate at the third AICT meeting

Familial

- Review family/surrogate educational activities
- Review advance care planning interventions
- Review grief and loss counseling interventions
- Review questions/issues to be discussed with the family at the third AICT meeting

Following this meeting, the social worker will call the family member/surrogate to remind them about the third AICT meeting. Other staff involved in the resident's care plan should also be invited to this meeting along with the resident if this is appropriate.

Care Plan Meeting Three

One week following the second AICT meeting, the team will meet with the resident and/or family member/surrogate to finalize care planning. If the family member/surrogate is not in attendance, the AICT will proceed with the care plan and the social worker will invite the family to attend a make-up meeting. The social worker will also facilitate the care planning process and document all interventions in the care plan.

- The social worker will introduce the team to the family and briefly explain the care planning process including the five pains framework.

- The physician (or charge nurse as designee) will briefly describe the physical areas of concern identified by the team, the proposed interventions, and any changes in the resident's medical condition or pain level since the last meeting.

- The charge nurse will briefly describe the psychological/behavioral areas of concern identified by the team, the proposed interventions, and any changes in behavior since the last meeting.

- The social worker will briefly describe the emotional/interactional areas of concern identified by the team, the proposed interventions, and any changes in the resident's emotional state since the last meeting.

- The spiritual care worker will briefly describe the spiritual areas of concern identified by the team, the proposed interventions, any questions generated by the team, and updates since the last meeting.

Immediately following these reports, the social worker will ask the resident and/or family to share their thoughts, feelings, and ideas regarding the proposed interventions, as well as any additional areas of concern for inclusion in the care plan. The family will then be asked;

- What aspects of the resident's care are you most pleased with? What areas do you feel need improvement?
- Would you like to receive additional education/materials regarding dementia, advanced illness care, and/or what to expect with your loved one?
- Would you like to receive additional education/materials regarding communication strategies and/or activities to use with your loved one?
- Would you like to receive help in dealing with the grief and loss issues that often accompany this disease?
- Would you like to receive information regarding the decisions and related options you may need to make as the resident's health care proxy?
- Is there any other information or support that the team could provide to improve your experience with the resident and his/her dementia/advanced illness care?

The social worker will lead the team in finalizing resident care interventions and/or developing family member/surrogate objectives for immediate documentation in the care plan.

With regard to resident care interventions, the charge nurse should continue to direct staff to document *antecedents*, *behaviors*, and *consequences* as well as pain concerns in the resident log on a shift-by-shift, daily basis.

Family member/surrogate objectives may be addressed either through one-on-one social work/ spiritual care interventions or via group activities with other families/surrogates (see the section titled *Family Member/Surrogate Sessions* for additional information).

Meeting Four

Two weeks following the third meeting (week five of the intervention period), the team will convene to review progress. For each of the five pain areas, the team will discuss four key points as specified below.

Physical

- The physician (or charge nurse as designee) will briefly describe: the extent to which planned medical interventions have been implemented; any related changes in the resident's health, presentation, or behavior based on personal examination; any new information/issues requiring attention; and any suggested modifications to the care plan.

Psychological/Behavioral

- The charge nurse will briefly describe: the extent to which planned pain and/or behavioral interventions have been implemented; related changes using the *ABC* framework; any new information/issues requiring attention; and any suggested modifications to the care plan for team consideration.

Emotional/Interactional

- The social worker will briefly describe: the extent to which planned emotional and/or interactional interventions have been implemented; related changes based on personal observation, resident interviews, and pertinent events contained in the resident log/chart; any new information/issues requiring attention; and any suggested modifications to the care plan for team consideration.

Spiritual

- The spiritual care worker will briefly describe: the extent to which planned spiritual interventions have been implemented; related changes based on personal observation, resident interviews, and pertinent events contained in the resident log/chart; any new information/issues requiring attention; and any suggested modifications to the care plan for team consideration.

Familial

- The social worker and spiritual care worker will briefly describe: the extent to which planned family member/surrogate interventions have been implemented; related feedback based on personal participation; any new information/issues requiring attention; and any suggested modifications to family member/surrogate objectives.

The social worker will then lead the team in formally modifying the resident care plan in accordance with changes/additions to the interventions at hand. Following this meeting, families will be invited to attend the final AICT meeting, which is scheduled for the last week of the intervention period (week eight). The resident is also invited if the team deems his/her attendance to be appropriate.

Care Plan Meeting Five

Three weeks following meeting four (week eight of the intervention period), the team will meet with the resident and/or family member/surrogate to review progress made during the course of the study. If the family is unable to attend this meeting, the AICT will proceed in their absence.

- The social worker will re-introduce the resident and/or family member/surrogate to the team and briefly explain the summary purpose of the meeting.
- The physician (or charge nurse as designee) will briefly describe the physical progress achieved via the care plan interventions.
- The charge nurse will briefly describe the psychological/behavioral progress achieved via the care plan interventions, and any remaining areas of concern for future planning outside the scope of the study.
- The social worker will briefly describe the emotional/interactional progress achieved via the care plan interventions, and any remaining areas of concern for future planning outside the scope of the study.
- The spiritual care worker will briefly describe the spiritual progress achieved via the care plan interventions, and any remaining areas of concern for future planning outside the scope of the study.

Immediately following these summaries, the social worker will ask the resident and/or family to share their thoughts and feelings regarding the impact of the care plan interventions. This should include their thoughts about the planning process and family sessions.

Family Member/Surrogate Sessions

At the third AICT meeting, the family member/surrogate is asked if they would like to receive information or assistance regarding the issues listed below.

1. What to expect with the dementia disease course/advanced illness care
2. Strategies/activities to engage the resident
3. Feelings of grief and loss
4. Decision making at the end of life
5. Practical/other issues

For those wishing to receive assistance, the social worker (or spiritual care worker) will schedule at least one individual session, during which the following items may be addressed:

Family Education

- Discuss commonly held misconceptions as well as realistic expectations for the dementia disease course and dying trajectory
- Discuss the overall philosophy of advanced illness care including pain management
- Provide the family member/surrogate with available resources such as books, websites, and advocacy/support groups

Communication Strategies/Activities

- Participate in creating a personal memory album to enhance the resident's positive life recollections and sense of self
- Review and select stage appropriate communication strategies and/or activities for use with the resident

Grief/Loss Issues

- Discuss common feelings of fear and/or guilt associated with advanced dementia, such as conflicts between individual needs and those of the resident and emotionally letting go before the resident has physically died
- At discretion of the social worker, discuss the current state of pre-arrangements for death and, if needed, assist the family member/surrogate in making such arrangements
- Link the family with others who have been through, or are going through this process
- Provide a referral for grief counseling if needed/desired

End of Life Decision Making

- Review instructional and proxy directives with the family/member surrogate
- Discuss values/goals regarding end of life decision making and beliefs potentially conflicting with those of the resident, other family members, physician, etc.
- Engage in proactive education/discussion of end of life preferences for the resident with attention given to hydration, nutrition, resuscitation, ventilation, medication use, restraint use, and aggressive diagnostic procedures

These sessions may take place during weeks six and/or seven of the intervention, wherein the AICT does not meet. If needed, alternate arrangements should be made to accommodate a family member/surrogate's schedule. If a family member/surrogate does not wish to receive any information or assistance, the family intervention portion of the study may be omitted.

Appendix

FLACC Scale Behavioral Pain Scale

Merkel, S.I., Voepel-Lewis, T., Shayevitz, J.R., & Malviya, S. (1997). The FLACC: A behavioral scale for scoring postoperative pain in young children. Pediatric Nursing, 23 (3), 293 – 297.

Pain Assessment in Advanced Dementia (PANAD)

Warden, V. (2003). Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. Journal of the American Medical Directors Association, 4 (1), 9 - 15.

Cornell Scale for Depression in Dementia (CSDD)

Alexopoulos, G.S., Abrams, R.C., Young, R.C., & Shamoinan, C.A. (1988). Cornell Scale for Depression in Dementia. Biological Psychiatry, 23, 271 – 275.

Cohen-Mansfield Agitation Inventory (CMAI)

Cohen-Mansfield, J., Marx, M.S., & Rosenthal, A.S. (1989). A description of agitation in a nursing home. Journals of Gerontology: Medical Sciences, 44, M77 – 84.

FAMCARE Scale

Kristjanson, L.J. (1993). Validity and reliability testing of the FAMCARE Scale: Measuring family satisfaction with advanced cancer care. Social Science and Medicine, 36 (5), 693 – 701.

Global Deterioration Scale

Reisberg, B., Ferris, S.H., de Leon, M.J., & Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. American Journal of Psychiatry, 139, 1136 – 1139.

Mini-Mental State Examination

Folstein, M.F., Folstein, S.E., McHugh, P.R. (1975). Mini Mental State: a practical method for grading the cognitive state of patients for the clinician. Journal of Psychiatric Research, 12, 189 – 198.