Assessment and Treatment of Decline and Dementia

Amy K. Rodriquez,

Deborah Grossett, Ph.D., &

Kay R. Lewis, MD

AAIDD Texas Chapter Annual Convention

Corpus Christi, Texas

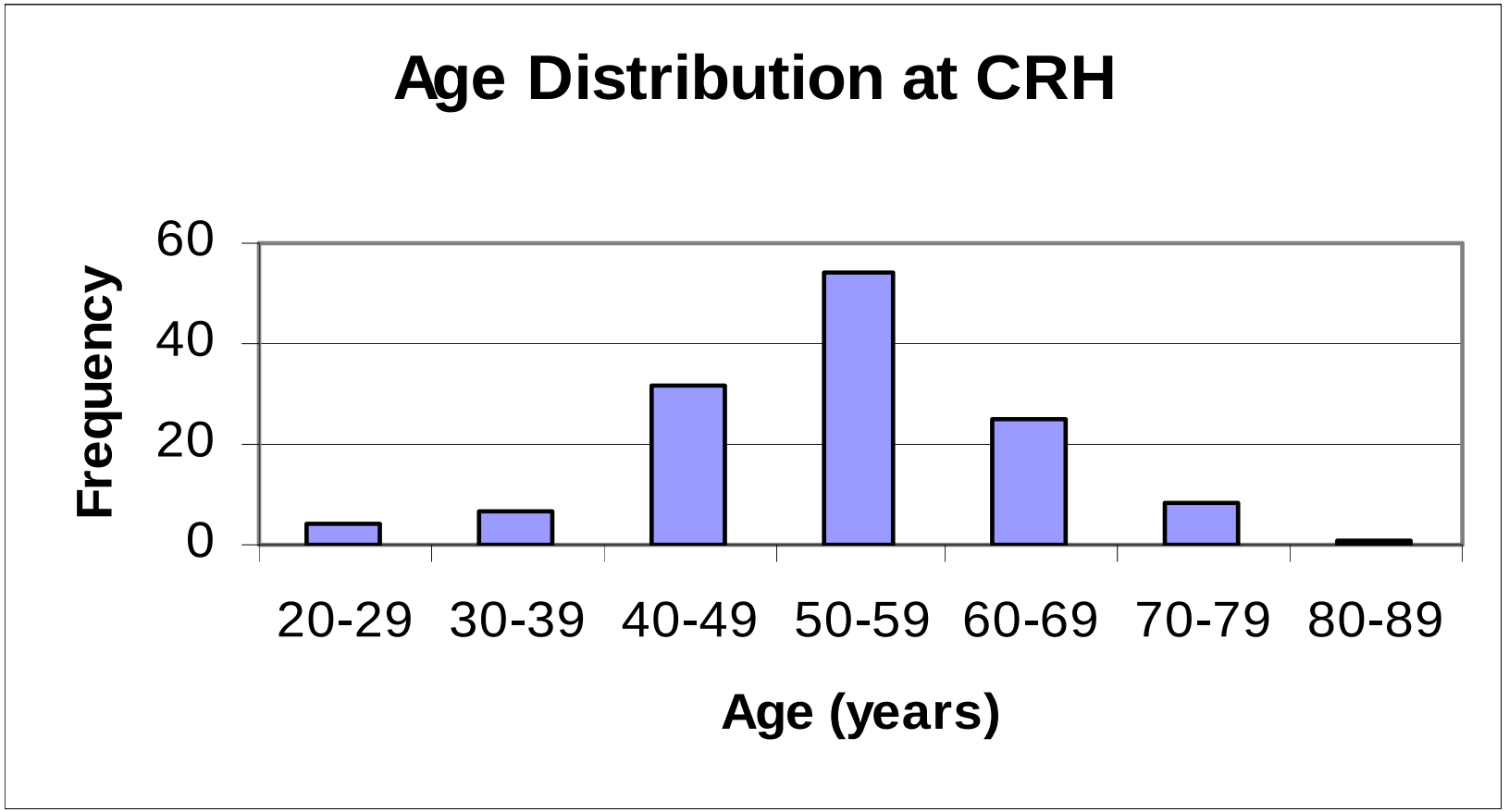
July 16, 2009

Risk of Dementia Increases with Age

- Risk increases between 50-55 years for persons with Down syndrome
- For others with intellectual and developmental disabilities without Down syndrome, the risk increases between 65-70 years of age.
- Important to establish a baseline of functioning prior to age of onset

Aging Residential Population

- 68% over 50 years, Ave. age =54



Assessment of Decline and Dementia

- Recommend longitudinal assessments of intelligence, adaptive functioning, behavior problems, and dementia.
- Cognitive – Include test with minimal "floor effects" and lower cut off scores
- Adaptive – When deficits are noted, repeat assessments more frequently
- Behavior – Include functional behavior assessments and on-going monitoring
- Dementia – Baseline for Down Syndrome before 40 and 50 for others. Repeat every few years and more if decline noted

Cognitive Assessments

- Standard intellectual tests such as the Wechsler Adult Intelligence Scale (WAIS) can't be used to assess individuals with severe and profound mental retardation as the lowest IQ score is 45.
- In addition to standard tests, consider adding tests which can assess lower levels of mental retardation, such as the Leiter International Performance Scale (LIPS), Slosson Intelligence Test (SIT), and the Peabody Picture Vocabulary Test (PPVT).

Adaptive Assessments

- Vineland Adaptive Behavior Scale – main domains include communication, daily living, and socialization skills. Deficits were noted in communication first, then daily living skills, and finally socialization.
- Inventory for Client and Agency Planning (ICAP) – includes adaptive assessment of motor, social and communication, personal and community living skills plus problem behaviors.

Behavior Problems

- Behavior problems appear to emerge as a means to escape/avoid demand or aversive situations (e.g., work, social interaction, noise), obtain lost tangibles, or gain attention and assistance from others
- Increases in wandering, hoarding, falling, aggression, crying, screaming, cursing, arriving late to work, sleeping during the day, getting up at night, misplacing personal belongings, spending time alone
- Decreases in participating in programs, leisure and group activities, following work schedule, interacting with others

Dementia Screening Instruments

- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID). Reference: **Deb, S., Hare, M., Prior, L., & Bhaumik, S. (2007)** Dementia Screening Questionnaire for Individuals with Intellectual Disabilities. *British Journal of Psychiatry.* **190.** 440-444.
- Dementia Scale for Down Syndrome (DSDS). Reference: **Gedye, A. (1995)** *Dementia Scale for Down Syndrome. Manual.* Vancouver, BC: Gedye Research & Consulting.

Dementia Screening - DSQIID

- Assess speech, daily living skills, and behavior issues, e.g.,
- Part 2: “Does not initiate conversation”, “Needs help eating”, “Wanders at night”, “Hides or hoards objects”, “Puts familiar things in wrong place”, “Cannot find way in familiar surroundings”, “Cannot remember names of familiar persons”, Score 0 for always been the case or does not apply and score 1 for always but worse and new symptom.
- Part 3: “Lost some skills (e.g., brushing teeth)”, “Walks slower”, “Slower speech”, Score “yes” or “no”

Dementia Scale - DSDS

- Early Stage Features – “Loses or misplaces objects he/she values”
- Middle Stage Features – “Does not know difference between breakfast and supper, has lost usual responses to breakfast, supper”
- Late Stage Features – “No longer recognizes closest friends/relatives or is forgetting their names

Assessment of Memory and Other Cognitive Decline

- **Mini-Mental State Exam (MMSE)** is used with older adults, but may yield scores too low for persons with severe and profound mental retardation (e.g., 2/30).
- Test for Severe Impairment (TSI) - neuropsychological measure which is a downward extension of the MMSE. Total TSI Score (24 max). Reference: **Mulryan, Tyrrell, Cosgrove, Reilly, McCallion, & McCarron (2009).** The test for severe impairment. In V. P. Prasher (ed.), Neuropsychological Assessments of Dementia in Down Syndrome and Intellectual Disabilities (pp.129-142). London: Springer Science.

Test for Severe Impairment

- **Language – Comprehension** “Point to your ear” **Score (1, 0)**1- points to ear
- **Language – Production** “What is this called?” Point to your nose. “What is this called” Show Consumer the key
- **General Knowledge** "How many ears do I have?“
- **Conceptualization** (*two large paperclips, one pen)* "Which one of these is different from the other two?" Spread objects on the table.

Test for Severe Impairment - Motor

- **Motor Performance Part A** - “Show me how you would use this comb.” Hand Consumer the comb. Score: Correctly demonstrates combing, score 1. “Write your name” Hand Consumer pen (without top) and place paper on table in front of Consumer. Score: Writes name correctly (first or last name legibly)
- **Motor Performance Part B** "Thank you for spending time with me." Extend hand to shake hands. Correctly shakes hands, score 1.

Test for Severe Impairment – Immediate Memory

- **Memory – Immediate.** One large paperclip. "Watch carefully" Place clip in your hand so Consumer can see. Hold hands out to Consumer, with hands open "Which hand is the clip in?“
- With hands closed, "Which hand is the clip in?“
- Score 1: Correctly points to hand with clip

Test for Severe Impairment – Delayed Memory

- **Memory – Delayed present** *Thread, key, and paperclip* "Which one of these haven't we done something with while you were here with me?" Place objects and spread out on the table.
- **Score: Correctly points to the thread**

Behavior Decline Assessed with VABS

- McKenzie, Harte, Patrick, Matheson, & Murray (2002) (Reference: *Journal of Intellectual Disabilities,* 6(2), 175-184.) used the VABS to link behavioral decline with possible dementia and found 23 out of 44 clients had sustained decline in a minimum of one adaptive skill over the period of time they were assessed (between 12 and 24 months). Areas most affected by decline were communication and domestic skills.

Increasing Conversational Skills

- Bourgeois (1990) (Reference: Enhancing conversation skills in patients with Alzheimer's disease using a prosthetic memory aid. *Journal of Applied Behavior Analysis,* 23, 29-42.) enhanced the conversational skills of adults with AD who were trained to use various sets of memory aids or stimuli (3 inch by 4 inch, laminated cards) as prompts for relevant topics and appropriate statements during conversational sessions with a partner. Results showed that participants made more on-topic statements with the use of the memory aid stimuli.

Present Project

- Like the McKenzie et al. (2002) study, the present project conducted a follow-up, assessed decline in adults with DS, and used the assessment findings to create treatment plans to assist the client with any skills showing marked decline.
- Similar to Bourgeois (1990), prompts were used to enhance communication skills. Behavioral technologies were employed to effectively teach adaptive skill deficits among aging adults with DS.

Vineland Adaptive Behavior Scale (VABS)

Participant:	1st VABS	2nd VABS	Follow-up
Ken	44	22	16 years
Carol	40	23	14 years
Margaret	45	34	18 years

- Ken's largest deficits were in written communication and daily living skills. Carol's deficits were in areas of written communication and socialization. Margaret's deficits were identified in the areas of written communication and domestic knowledge of daily living skills.

Identify Skill Deficits

- Cannot recall current address.
- Does not respond to simple conversational cues.
- Cannot write first, middle or last name.

Create treatment programs.

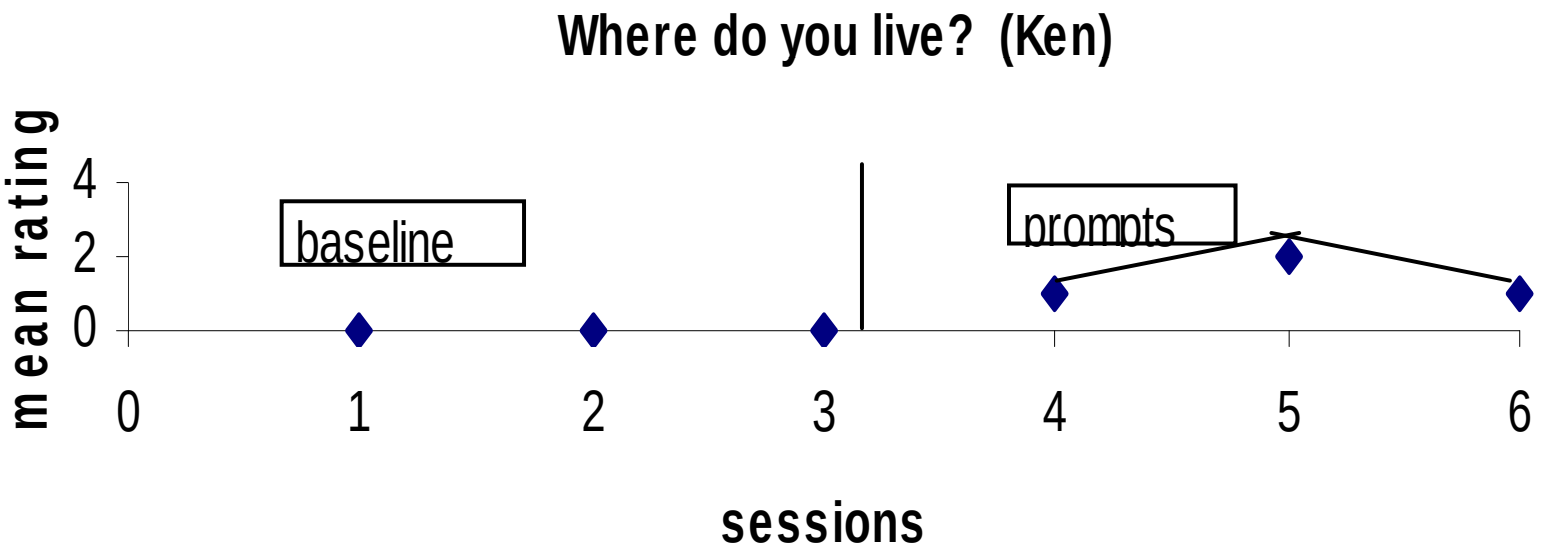
- Program 1 target- To recite/recall the current address.
- Program 2 targets- To provide independent verbal responses.
- Program 3 targets- To write the first, middle and last name.

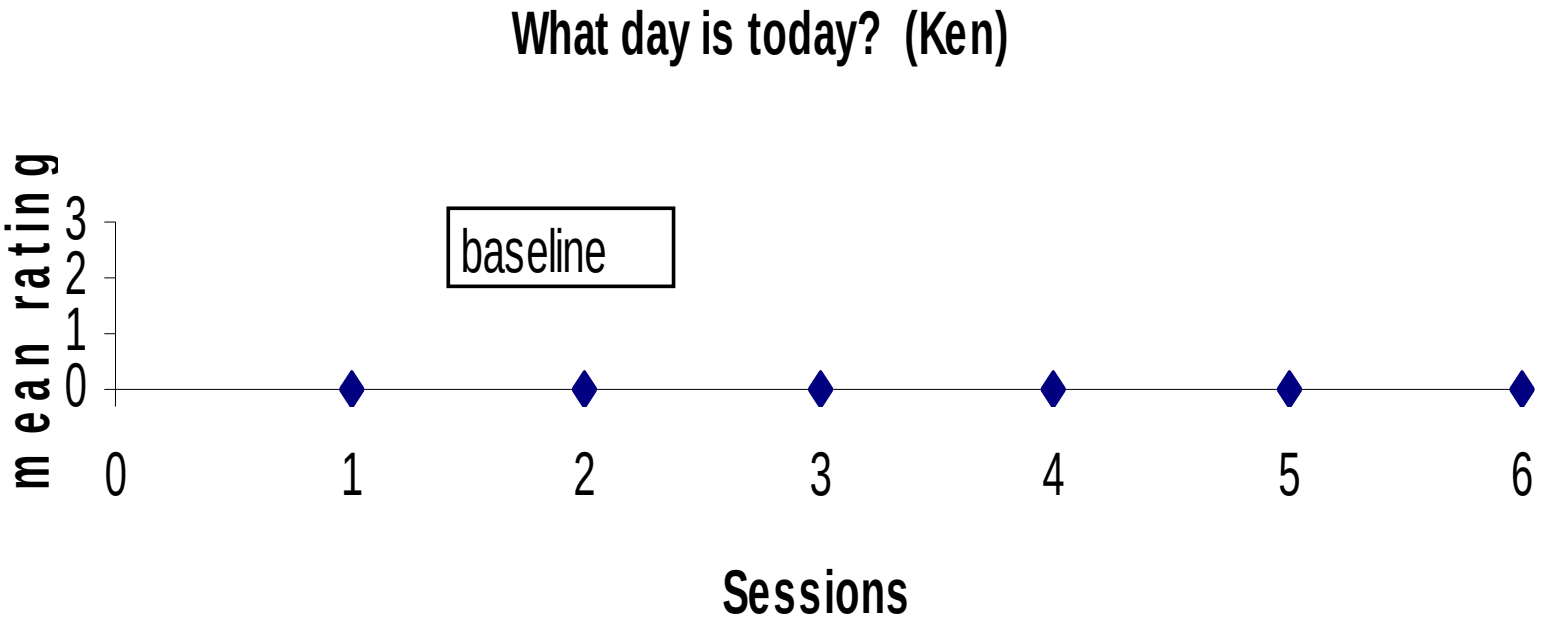
Visual aids and stimuli

- Program 1- tracing exercise with perforated letters and numbers.
- Program 2- flashcards with icons/ emoticons.
- Program 3- tracing exercise with perforated letters.

Program 1

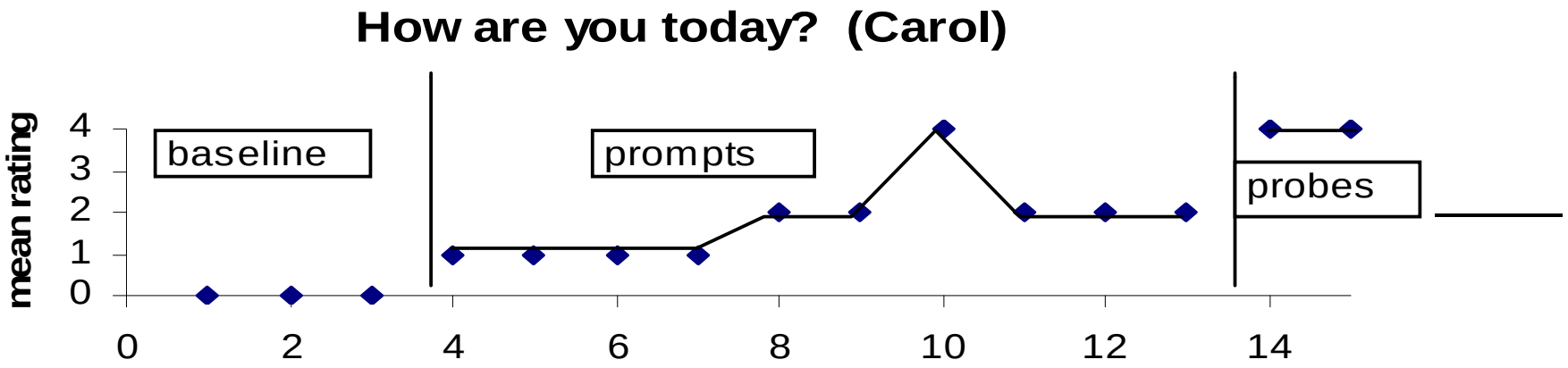
- Once skill deficits were identified, acquisition programs to improve skills were developed.
- Ken received training on reciting his current address and identifying the current day of the week. He was reported to wander out of his residence at night. His treatment program was designed to help him remember and recite his current address.

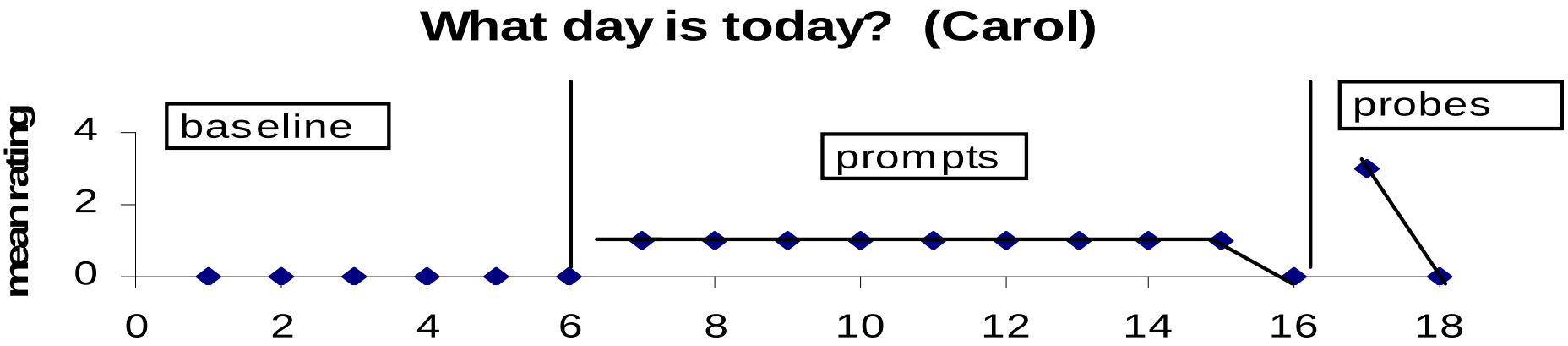

Where do you live? (Ken)
mean rating
4
2
0
baseline
prompts
0
1
2
3
4
5
6
sessions

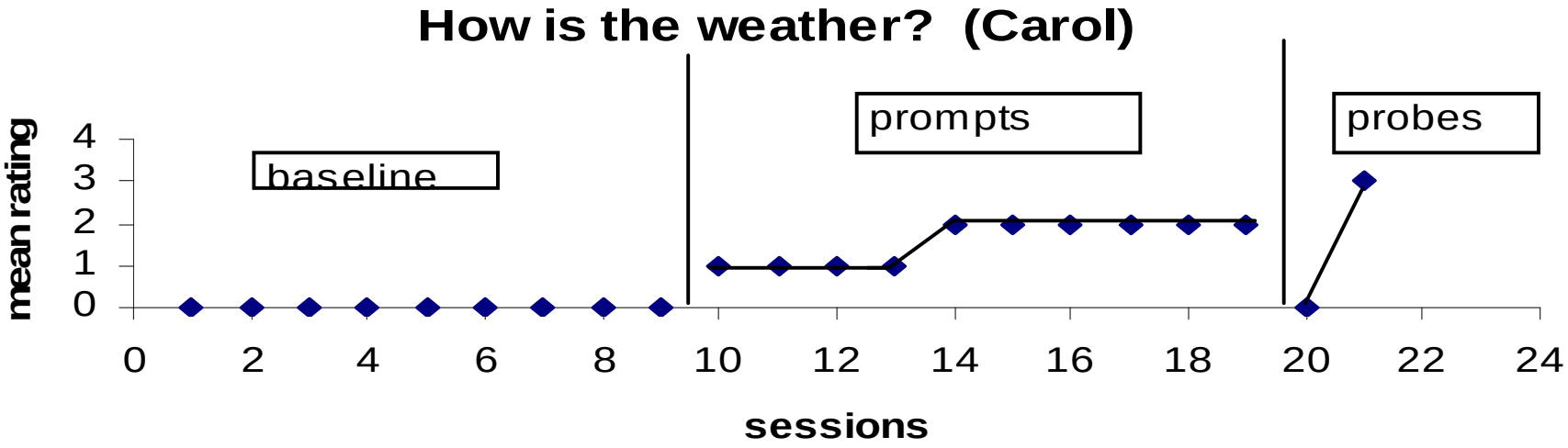

What day is today? (Ken)
mean rating
3
2
1
0
baseline
0
1
2
3
4
5
6
Sessions

Program 2

- Carol received training on verbally responding to questions regarding her current mood, current weather conditions, and identifying the current day of the week. She rarely responded to questions posed to her in daily interactions. She was observed to remain mute in scheduled psychotropic medical reviews with her doctor. She had a history of talking to others not present. Her treatment program was developed to promote appropriate vocal responding in daily interactions with others.

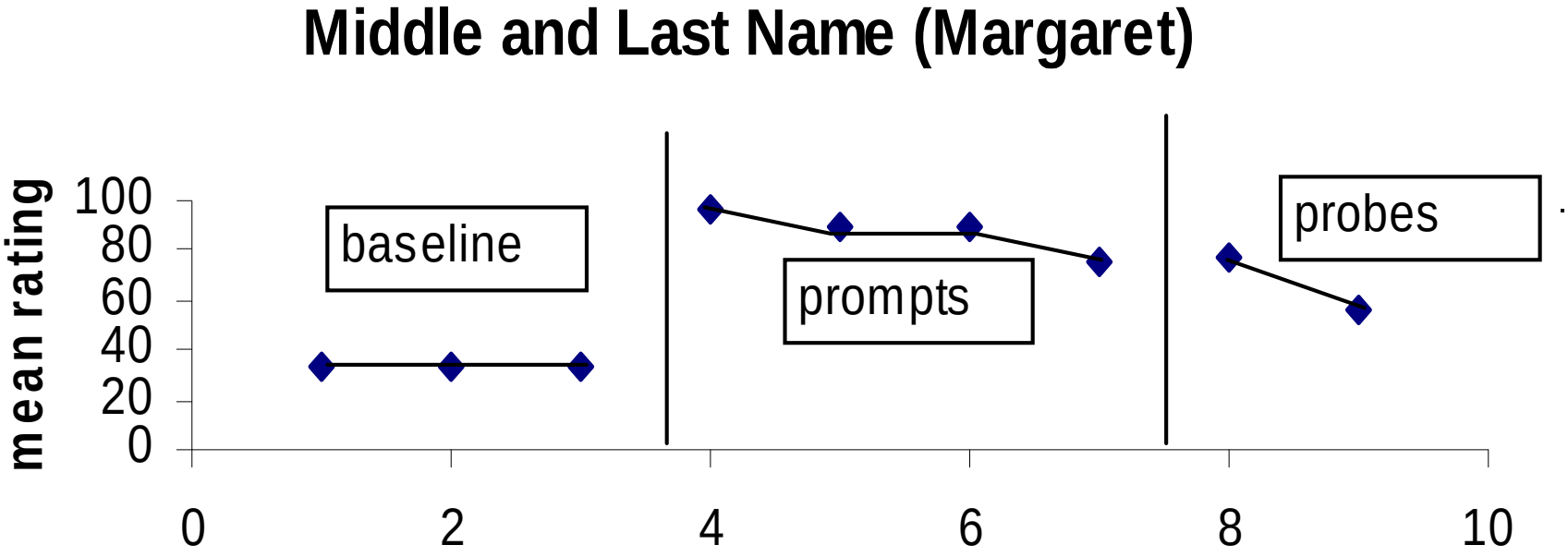

How are you today? (Carol)
mean rating
4
3
2
1
0
baseline
prompts
probes
0
2
4
6
8
10
12
14

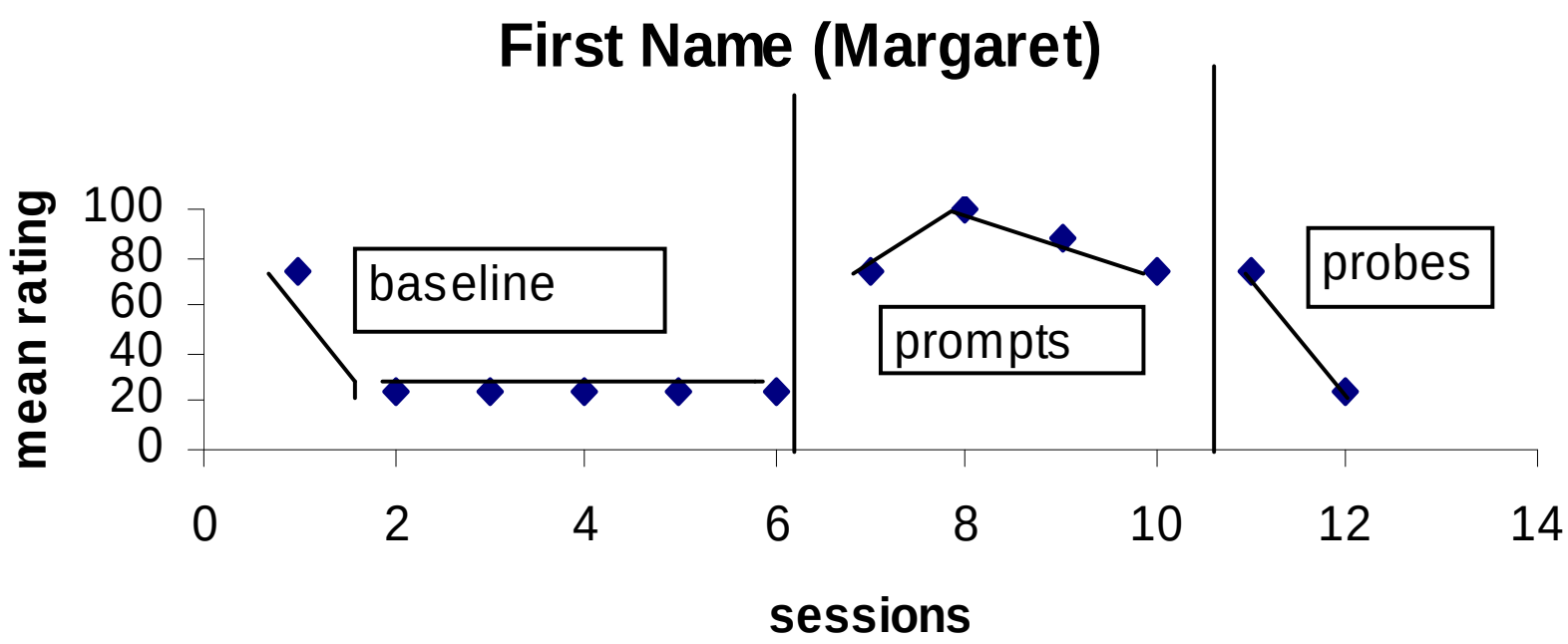

What day is today? (Carol)
mean rating
4
2
0
baseline
prompts
probes
0
2
4
6
8
10
12
14
16
18


How is the weather? (Carol)
mean rating
4
3
2
1
0
baseline
prompts
probes
0
2
4
6
8
10
12
14
16
18
20
22
24
sessions

Program 3

- Margaret received training on writing her first, middle and last name. She was observed to have great difficulty signing her name on forms regarding her residence status and daily programming. A skill acquisition program was designed to improve and maintain the ability to sign her name on documents regarding her welfare.


Middle and Last Name (Margaret)
mean rating
100
80
60
40
20
0
baseline
prompts
probes
0
2
4
6
8
10


First Name (Margaret)
mean rating
100
80
60
40
20
0
baseline
prompts
probes
0
2
4
6
8
10
12
14
sessions

Dementia - Definition

Dementia is a gradually acquired impairment in intellectual functioning in at least two spheres – 1) memory and 2) any other area of cognition, such as language, visual=spatial ability, personality, judgment, object recognition, ability to dress and do other semiautomatic tasks, abstraction, calculation, information synthesis, or problem solving.

Causes of Dementia

Alzheimer's Disease (50% of Dementias in general population; almost all in persons with Down Syndrome)
Multi-infarct Dementia (25%)
Other Causes: (25%)

- Parkinson's Disease
- Huntington's Disease
- Wilson's Disease
- Normal Pressure Hydrocephalus
- Dementia Syndrome of Depression
- Nutritional deficiencies (B-12, folate, protein deficiency)
- Trauma
- Neoplasms
- Infections (e.g., HIV, Syphilis)
- Toxic-metabolic
- Vascular dementias
- Lewy Body Disease
- Pick's Disease
- Other degenerative and/or demyelinating diseases
- Drugs (opiates, narcotics, anticholinergics)

Dementia Evaluation

FIRST IDENTIFY TREATABLE CAUSES

- History, Physical and Mental Status Exam
- LAB: CBC, Electrolytes, CMP metabolic profile, Thyroid profile and TSH, B12 and folate levels, STS, Immune deficiency tests (if history indicates), Urinalysis,
- EKG, Chest Xray,
- CT Head (to R/O mass, recent bleed, normal pressure hydrocephalus)
- MRI - <u>also</u> more sensitive for ischemia, infarction, subcortical or brainstem pathology than CT

Differential Diagnosis of Dementia

- When changes in functioning are observed, it is important to rule out possible medical problems (e.g., Hypothyroidism, Sleep Apnea, Pain, Hypertension, Late onset Seizures, Diabetes, Stroke, B-12 or Folic acid deficiency)
- Delirium – acute; usually treatable cause;
- Psychiatric issues (e.g., Depression, Psychosis)
- Changes in sensory functioning (e.g., reduced hearing, vision, mobility)

Early signs of Major Depression in Older Adults

- Loss of interest in usual activities
- Decreased social interaction
- More time spent in bed during daytime
- Difficulty falling asleep, staying asleep at night
- Decreased grooming, state of dress

•Depression vs Dementia

- Depression:
  - Pt. Complains of memory loss;
  - Loss milder than complaint;
  - Orientation good;
  - Preserved reasoning;
- Dementia:
  - Pt. appears unaware of memory loss
  - Loss severe, but dismissed or excused
  - Orientation, reasoning impaired

Depression in Aging: "Pearls" to remember

- Milder forms of Depression (subsyndromal depression, dysthymic disorder, masked depression) harder to recognize
- Change, loss, or a move may precipitate a depression
- When depressed mood dominates a person's daily life, treatment is indicated, even if there is a cause!

PHARMACOTHERAPY OF DEMENTIA

- Antidementia medication may be prescribed to retain cognitive functioning, slow down decline, and help with emotional control.
- It is important to detect symptoms early and introduce treatment to prevent loss of skills.

Cholinesterase inhibitors:

- Donepezil (ARICEPT) – 5mg/d – 10mg/d
- Rivastigmine (EXELON) – 1.5mg bid to 6mg bid (daily patch available)
- Galantamine (RAZADYNE, RAZADYNE ER)-4mg bid up to 12mg bid

NMDA [N-methyl-D-aspartate] receptor antagonist:

- Memantine (NAMENDA) (for mod-severe dementia) – 5mg up to 10 mg bid

Two Behavioral Symptoms Associated with Dementia Likely to Lead to a Move to a More Restrictive Setting

INSOMNIA and AGGRESSION

Management of INSOMNIA in Dementia - A

1) FIRST, increase structure and activity during the day.
2) Implement a late afternoon exercise program.
3) Add structure, consistency to bedtime and rising routine.
4) If person awakens at night, react calmly, assist them to bathroom, offer water or milk, and guidance back to bed
5) Give activating meds more in AM; Give sedating meds more at HS
6) IMPLEMENT SLEEP HYGIENE PRACTICES
7) Avoid over-the-counter sleep aids, e.g., Benedryl and Tylenol PM – anticholinergic properties may cause confusion in demented patients.
8) Sedative-hypnotics should be used sparingly in pts with dementia, as they can further impair memory, cause paradoxical excitement, or interfere with balance, leading to falls.
9) Trazodone 25mg hs.(200 max), or melatonin 3-6mg hs.

Sleep Disorders - Sleep Hygiene Rules - 1

1) Sleep as much as needed but no more; curtail time in bed
2) Regular time to get up
3) Steady daily exercise
4) Eliminate noise
5) Slightly cool (not cold) room
6) Light bedtime snack if hungry

Sleep Disorders - Sleep Hygiene Rules - 2

7) Avoid chronic use of sleep meds
8) Avoid caffeine, tobacco, excess alcohol
9) If angry and frustrated at being unable to sleep, turn on the light and do something else

Management of AGGRESSION in Dementia - A

1) Medications for Aggression involve significant risks and are usually only partially effective.
2) USE BEHAVIORAL APPROACHES FIRST!
3) Analyze function of behavior and design plan as previously presented.
4) Be sure the responses of the caregivers do not INCREASE the aggressive behaviors rather than resolve the agitation.
5) At first warning signs of aggression, stop what is happening, and initiate a more soothing and relaxing activity.
6) Address pts underlying concerns, if possible. (e.g., if pt accusing others of stealing, help him find what is lost.)
7) Use ***The 36 Hour Day***, by Nancy Mace and Peter Rabins, to train caregivers, as well as other materials from the Alzheimer's Association.

Management of AGGRESSION in Dementia - B

8) In considering medication for an aggressive patient with dementia, FIRST, consider any underlying or associated medical conditions (i.e., pain, depression, causes of delerium, psychosis, insomnia) when selecting medication.
9) SSRI: Zoloft [sertraline], Celexa [citalopram], Lexapro [escitalopram]

10) Antipsychotics: Risperidone 0.25mg bid; Olanzapine 2.5mg/d; Quetiapine 12.5 mg bid; Aripiprazole 10mg/d. (minimize dose and try to avoid in vascular dementia)

11) Insomnia Rx: Sleep Hygiene; Trazodone 25 – 50mg at bedtime.

THERE is NO SIMPLE ANSWER YET!

THE END

Positive Reinforcement

- Thank you for your participation!

- The End!