

Slide Notes

Common Reasons for Ψ C-L

1. SF
 - small, provincial town $\bar{c}$ strong well organized + accomplished
 - current epidemiology, trends, City budget ^{gay community}
 - consortium of ~~town~~ Community, City DPH + Univ. Resources
 -
 2. SFCH
 - $\rightarrow$ utilization figs: County - hosp of last resort
 - Univ. run; prof. staff = U. positions / Residency Pgm
 - early reputation for innovation, research + humane treatment
 3. Psychosocial Issues in AIDS
 - no reason to be labor: SF was no different really than others
 4. Ward 86 / Dev of 5A
 - Jan '83. Psy C+L Svc. Established
 - liaison in true sense of word, not just the "rescue squad" but attended uds, worked closely $\bar{c}$ RN staff — Education + helped develop the ward:
 - Sense of Excitement: something wonderful seemed to be developing out of something horrible — the dedicated AIDS Unit wh was a Ψ C+L consultants' dream. Close ties $\bar{c}$ RN staff, ongoing involvement $\bar{c}$ gp of committed vol. prof's who to a person were aware
1. Issue of Leper Colony vs. Special Care

that what we ¹⁰ had to offer pts was emotional support + sensitive care.

Environment developed then to sharp focus on pt care issues + bec. AIDS has, from beginning been an intensely political, it also occurred in a fishbowl.

- close ties to community resources — which have grown + dev. over the yrs: housing, emot, ^{practical} support, home care

4. AIDS SVC Agencies

- emphasis on home care, hsg, ~~social~~ social svc support + Mental health SVCS.

5. AIDS Health Project

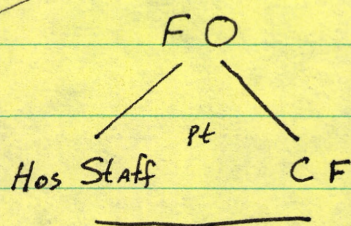
- Continuity of Care {
- Mental Hlth SVCS PNA's — MAR 1984 — 1 FTE
 - 1/2 time ψ — now 2 1/4
 - ASAP — 2 1/2
 - Home based ~~svcs~~ Consultation Svc — emphasis on Neuropsychological Assessments / ^{behavioral/} management issues / staff

6. Common Reasons for Psychiatric Consultation

- Really not so different from usual C+L for $\bar{x}$ against the social/political backdrop of course we've already talked re + $\therefore$ the confluence of pblms + the intensity is often different.
- Specifically — the potential for Family of Origin

Impact on both
staff + Pts

- 3 -



triangulation can become particularly difficult. These issues have led only somewhat over the yrs as AIDS has become more well understood + to some extent, more accepted.

a. Most common - early: tho certainly arbitrary

b. More recently: 6, 7 + 9, 10 becoming much more common - Changing Population.

- 5A 20 beds, now ~ 1/2 are IVU's

- 7B dedicated wgt unit - 2/4/D; 65 adults
60% were psychotic + either marked/mild
dementia.

1. Factors Influencing Psych Consultation in HIV-Spectrum Pts

a. NP Cxs - newest & social stressor - Am I
losing my mind? - Pts + HGW's

b. changing epi - not only IVU's, but > #s WOMEN, children

c. Mult. Dxs - more + more: Sub A; personality disordered,
+ Suicidal pt to mild, but
Complex chronic diarrhea; who is
demanding + manipulative re:
NP Cxs + Dementia
Abd. pain + cramping.

- d. Wider Use of Abx Testing : 1) ^{Management in HIV} 2) ^{Drug implications for Rx}
- e. Greater awareness that the forecast looks ↑ grim for those who r sero+ :

f. Lack of Clarity re: Med/Legal Issues:

- DUTY TO WARN — sexual ^{acting out}, "reckless" ^{"reckless"}
- Suicidal terminally ill — cognitively impaired pt - working

8. Future Challenges

- a. > #s + kinds : more 10 MH pts -
- b. Medical advances AZT, Acronized Pent, ^{an array of} new drugs
- c. "Living Now" - Sword of Damocles DTC / Ant Abuse / Dexten 50g
- d. Decisions re: Exp. Drugs
- e. "Taking Care of Ourselves"
 - SF Med Society Survey - 2/3 didn't want to : .
 - NYC Residents : 25% OK.
 - Burnout

9. Impt Rsch Q's in Psych

- a. HIV AP + Behavior
- b. Effects + med. Rts. - AZT ^{proliferation Denervation} ^{hypoxemia} ^{genotoxic}
- c. Anti-depressants

Wed 8³⁰ 2nd + 4th

Febr 10,

John Nickens

Joy

Bertie Mo

Tina Yee

Coucho -

Bertie Mo.

John Nickens
Thurs.

PURPOSE:

1. Identify unmet mental health needs for persons infected with HIV, PWAs, PWARCs, and their care providers, including family members and significant others.
2. Identify appropriate types of care and services to meet unmet need.
3. Identify fiscal and regulatory steps necessary to implement the appropriate care system utilizing federal, state, county and private resources.
4. Draft State legislation to provide appropriate care and services.
5. Create an opportunity for information sharing and coalition building among the participants.

AIDS MENTAL HEALTH LEGISLATION

An act relating to mental health, making an appropriation thereof.

SECTION 1. The Legislature finds and declares that there exists a critical need for: intake assessment and counseling for persons with AIDS, AIDS Related Complex (ARC), those who are HIV antibody positive, and their families, friends and significant others; treatment of suicidal ideation and other seriously debilitating mental disorders related to ongoing mental health services; treatment of neurological impairment, including dementia, associated with HIV infection; and training for mental health volunteers, peer counselors, and mental health professionals.

SECTION 2. The Department of Mental Health shall initiate a statewide mental health program for persons with AIDS, ARC, those who are antibody positive, and their families, friends and significant others. The Department shall seek the cooperation of County Mental Health Departments and community-based organizations in this effort.

SECTION 3. The Department of Mental Health shall initiate a statewide broad-based AIDS mental health training program for mental health volunteers, peer counselors, and mental health professionals. The Department shall seek the cooperation of County Mental Health Departments, community-based organizations, and appropriate state licensing boards in this effort.

SECTION 4. The sum of _____ (\$ _____) is hereby appropriated from the State General Fund to the Department of Mental Health for the purposes of this act.

JSM, AIDS PROJECT LOS ANGELES, 1/88

John Mortimer APLA

Intro:

• Thank you — Chicago — medical school experience

• I feel privileged to address you today because I feel I'm speaking to a group of professionals who are already AIDS knowledgeable + aware of many of the nuances that AIDS brings to medical practice. In that regard, I am grateful as I'm sure you are for the work of your own AIDS Consultation team.

Staff/Liaison issues related to AIDS + Psychological issues of those w/ HIV + how they've dealt.

1. Review Svc Development

2. Review Prg C+L issues

3. Talk re: ~~future~~ Developing Factors Affecting C+L

4. Research

I will do this in the context of the AHP + an emphasis on the development of our hospital based svcs.

Objectives for today — asked to talk from an historical perspective: with an emphasis on how things have changed as the AIDS epidemic has unfolded and specifically how those changes have affected ~~staff relations~~ pts w/ HIV related problems and also the staff who care for them.

Share w/ you some of our experiences + place in the context of the AIDS epidemic in SF.

• To accomplish this, begin by reviewing the development of service delivery at SFGH; ~~and~~ highlighting the issues prominent

then and moving along to where
we find ourselves today. I will
then close with some comments about
where we may be headed and the
challenges that will accompany them.

SPECIAL REPORT

PREFERENCES OF HOMOSEXUAL MEN WITH AIDS FOR LIFE-SUSTAINING TREATMENT

THE acquired immunodeficiency syndrome (AIDS) raises questions about appropriate care for patients with this incurable and progressive disease. Although individual episodes of infection and malignant disease can be treated, the underlying immune deficit cannot now be reversed. Decisions about whether to undertake life-sustaining treatment, such as mechanical ventilation and cardiopulmonary resuscitation, must frequently be made. Because these decisions require value judgments and informed consent as well as technical expertise, they should be made jointly by physicians and patients.¹⁻³

The care of patients with AIDS also illustrates the usefulness of advance directives about life-sustaining treatment. Many patients with AIDS become mentally incompetent and unable to participate in decisions about their care. It has been recommended that patients provide advance directives to guide their care if they become incompetent.⁴ These directives may take the form of discussions with physicians, friends, or family members; a living will; or a durable power of attorney for health care, which allows the competent patient to designate a proxy to make decisions about medical care if he or she should become incompetent to make such decisions.

For incompetent patients, the traditional approach is shared decision making by the physician and the family, following the patient's previously expressed wishes.³ Many patients with AIDS, however, want their partners or friends, not family members, to make the necessary decisions with their physicians. Yet the patient's partner or friend has no legal standing to make decisions unless designated as a proxy through a durable power of attorney for health care.

Little is known about the preferences of patients with AIDS for life-sustaining treatment and their use of advance directives. We surveyed 118 homosexual male outpatients with AIDS in order to answer these questions: (1) Had they thought about life-sustaining treatment? (2) What were their preferences about life-sustaining treatment? (3) How did they react to thinking about life-sustaining treatment? (4) What were their preferences for discussing such treatment with physicians? and (5) Were patients providing advance directives to guide care?

METHODS

The study was conducted between January and May 1985 at the outpatient AIDS clinics at San Francisco General Hospital and the University of California, San Francisco. The San Francisco General Hospital clinic cares for approximately 50 percent of homosexual men with AIDS in San Francisco and is a major referral center.

Patients eligible for the study were homosexual men who met the criteria of the Centers for Disease Control for the diagnosis of AIDS^{5,6} and who came to the clinics on selected days. Eligible patients were identified through a review of their medical records and by the clinic staff. Patients were excluded if they declined to

take part or if they were visiting the clinic for the first time. New patients were asked to participate during a subsequent visit.

After giving informed consent, patients completed a 15-minute self-administered, closed-response questionnaire. The questionnaire asked patients whom they wanted to designate to make decisions about their health care if they became too sick to make decisions themselves and what specific care they would want. The questionnaire is available from the authors upon request. Specific topics included (1) how much patients had thought about life-sustaining treatment; (2) preferences for treatment of *Pneumocystis carinii* pneumonia, the most common opportunistic infection in AIDS and a frequent cause of death (patients were asked about hospitalization, intensive care and mechanical ventilation, and cardiopulmonary resuscitation for both a first and a subsequent episode of *P. carinii* pneumonia); (3) preferences for the treatment of severe *P. carinii* pneumonia and severe memory loss, with "no chance" that their condition would improve; (4) emotional responses to thinking or talking about life-sustaining treatment; (5) preferences for discussions with physicians about life-sustaining treatment and perceptions of physician's interest in such discussions; (6) preferences for substitute decision makers if they were unable to make decisions themselves; (7) whether patients had talked to their physicians, partners, friends, or family members about life-sustaining treatment, completed living wills, or executed durable powers of attorney for health care; (8) estimates of the survival to hospital discharge of patients with *P. carinii* pneumonia who require intubation and mechanical ventilation, both for a first and for a subsequent episode; and (9) the consistency of patient's preferences over time.

The questionnaire also asked about demographic variables, such as education and employment; medical variables, such as previous hospitalizations and functional status; psychological variables, such as depression and social support; and social variables, such as involvement in a primary relationship and the parents' knowledge of and attitudes toward the patient's sexual preference. Information about each patient's age, diagnoses, date of diagnosis of AIDS, and previous hospitalizations was collected from medical records. Participation was voluntary and did not affect patient care. To minimize bias, we worded the questions so that all answers, such as a desire for more or less care, seemed equally acceptable.

The study and the questionnaire were approved by the Committee on Human Research at the University of California, San Francisco. A code was used to maintain the confidentiality of the data. Physicians were unaware of their patients' responses. Student's *t*-tests and chi-square analyses were used to assess the statistical significance of differences between groups of patients.

In testing for factors associated with dependent variables, we used the following independent variables: demographic variables (time since diagnosis, education, and employment); medical variables (prior hospitalizations, prior hospitalization in the intensive care unit, diagnosis of *P. carinii* pneumonia, and ability to walk one block or climb one flight of stairs); psychological variables (depression, number of close friends and relatives, and number of friends who had been hospitalized or had died from AIDS); and social variables (involvement in a primary relationship and the parents' knowledge of and attitudes toward the patient's sexual preference).

RESULTS

Patients' Characteristics

Questionnaires were completed by 118 male patients, 112 from San Francisco General Hospital and 6 from the University of California, San Francisco. Three patients declined to participate. The majority of the patients were young, well educated, and severely ill (Table 1). Most of their friends and parents knew they were homosexual.

Consideration of Life-Sustaining Treatment

Seventy-eight percent of the patients had thought a lot or a moderate amount about what care they would

Advance Directives

Two thirds of the patients had provided advance directives to guide care if they became mentally incompetent (Table 3). Patients who had been hospitalized in the past year were more likely to have discussed life-sustaining treatment with their families than those who had not (49 percent vs. 19 percent; chi-square = 7.25, $P < 0.01$) and were more likely to have completed a living will (38 percent vs. 15 percent; chi-square = 4.59, $P < 0.05$).

Of all the patients, 28 percent had executed a durable power of attorney for health care. This group included 42 percent of patients who wanted their partners or friends to act as decision makers, 41 percent of patients who had thought a lot or a moderate amount about substitute decision makers, 40 percent of patients who did not want intensive care for pneumocystis, 37 percent of patients who had pneumocystis, and 34 percent of patients who had been hospitalized during the previous year. Patients who had executed a durable power of attorney were in the minority in all subgroups.

Estimates of Prognosis for *P. carinii* Pneumonia

Patients overestimated the survival of patients with pneumocystis who required intubation (Fig. 1). They gave a mean estimate ($\pm$ SD) of 53 ± 23 percent for the proportion of patients surviving to discharge after a first episode of *P. carinii* pneumonia requiring intubation, and one of 30 ± 23 percent for the proportion surviving a second episode. The reported survival rate is 14 percent.⁷ Patients' estimates of survival were not significantly associated with their preferences for life-sustaining treatment or with the diagnosis of *P. carinii* pneumonia.

DISCUSSION

Increasingly, physicians and patients must decide what treatment is appropriate for chronic, progressive, and incurable diseases such as AIDS. Patients with AIDS may have advantages in reaching decisions about life-sustaining treatment, because they are often young, previously healthy, and well educated and because they often take an active role in decisions about their medical care. They are an important group for studying the preferences of patients for life-sustaining treatment and the feasibility of advance directives.

Table 3. Advance Directives for Life-Sustaining Treatment among the 118 Patients.

TYPE OF DIRECTIVE	PERCENT*
Discussion with family	42
Discussion with partner	69†
Living will	31
Durable power of attorney for health care	27
Discussion with physician	24
No advance directive	33

*Some patients provided more than one form of advance directive.

†Percentage of patients in a primary relationship (n = 42).

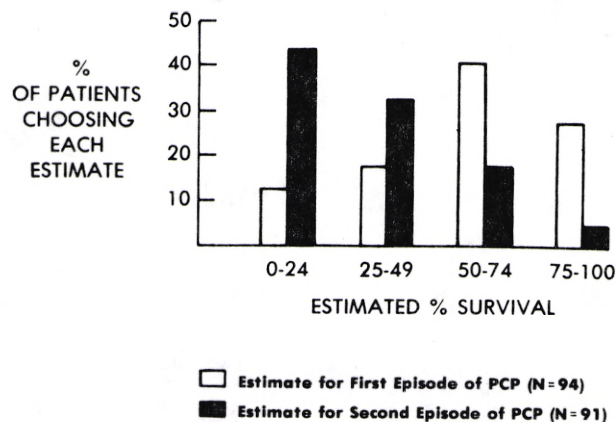


Figure 1. Patients' Estimates of Prognosis in Cases of *P. carinii* Pneumonia (PCP) Requiring Intubation.

AIDS is a new disease, and knowledge of its pathophysiology is rapidly increasing. When our understanding of a disease is incomplete and alternative treatments seem equally acceptable, the preferences of the patient may be even more important than in the case of diseases for which prognosis and therapy are well established.⁸ In *P. carinii* pneumonia, as noted earlier, survival to hospital discharge after intubation is 14 percent.⁷ Some patients may consider the possibility of additional weeks or months of life to be worth intensive treatment; other patients may desire only supportive care. Furthermore, some patients with AIDS may want experimental therapy, in the hope that a therapeutic breakthrough will reverse their disease.

Our results refute several common objections to discussing life-sustaining treatment with patients. These objections include the following: (1) patients have not thought about life-sustaining treatment and advance directives; (2) patients do not want such discussions; (3) patients have negative emotional reactions to such discussions; and (4) patients' preferences for care can be predicted without discussions. We found that most patients had thought about care for *P. carinii* pneumonia and advance directives and wanted to discuss them with physicians. Similarly, most patients over the age of 65 or with chronic diseases that might require life-sustaining treatment want to discuss such treatment with physicians.⁹

Discussions between patients and care givers do not always ensure that patients' preferences about life-sustaining treatment are elicited or respected.¹⁰⁻¹² In one study, 4 of 136 decisions not to resuscitate were made against the wishes of the patient or the family.¹¹ In another study, patients or family members were involved in 83 percent of decisions not to resuscitate but in only 25 percent of decisions to resuscitate.¹² Similarly, living wills are problematic. They are ambiguous, inflexible, and legally binding only in limited situations.

The durable power of attorney for health care has advantages over other advance directives because it is flexible and gives legal sanction to shared decisions by

physicians and proxies.⁴ Patients with AIDS would particularly benefit from it if they had strong preferences about life-sustaining treatment or wanted their lovers or friends, rather than family members, to make decisions for them. Without the durable power of attorney, partners and friends have no legal standing in sharing decisions with physicians. In our study, however, less than half the patients who wanted their partners or friends to be substitute decision makers had executed durable powers of attorney for health care.

We also found that many patients overestimated the effectiveness of life-sustaining treatments. This finding should not discourage physicians from discussing life-sustaining treatment with patients. Rather, it emphasizes the need for repeated discussions with patients, beginning in the outpatient setting. Physicians can elicit patients' questions, provide counseling and education, and make sure patients' directives are consistent and realistic. Listening to patients, discussing their concerns, and stressing supportive care may be helpful to patients with chronic incurable disease. Physicians may also bring the durable power of attorney for health care to the attention of their patients.

It is unclear why so many patients who wanted to discuss life-sustaining treatment with physicians had not done so. It seems plausible to suggest that some patients were less likely than others to act on their desire to have such discussions — for example, those who perceived their physicians as insensitive, awkward, or too busy, those who did not have pneumocystis, those who had never been hospitalized, or those who had had AIDS for only a short period. Our data, however, do not support these hypotheses, although the number of patients in some analyses was small. The nature of the barriers to discussion is not clear, but several factors may have an effect. Outpatients may deny the gravity of their illness, for instance, or may fear abandonment if care is limited. Another possible barrier is diffusion of responsibility among many care givers.¹³ Since patients may find it difficult to change their traditionally passive role,¹⁴ care givers may wish to initiate discussions about these sensitive issues.

Our study has several limitations. First, our conclusions may not be generalizable. San Francisco General Hospital is a major referral center for patients with AIDS. San Francisco has an active homosexual community and special resources for AIDS patients, including volunteer counseling and legal support. Such resources may encourage patients to think about life-sustaining treatment and to provide advance directives for care. Moreover, our conclusions may not apply to patients with AIDS who are not homosexual. Second, our study is based primarily on patients' own reports, which may not always be accurate. For example, patients may have forgotten previous discussions of life-sustaining treatment with their physicians. In further studies, researchers may wish to interview care givers or to observe interactions between doctors

and patients. Third, the preferences of patients may change over time — for example, when their disease progresses and they are hospitalized. Our cross-sectional study could not determine how frequently such change occurs. A prospective cohort study could provide information on changes in patients' preferences over time. Fourth, the power of our study to detect associations was limited by the sample size. Fifth, because of multiple comparisons, some associations may appear statistically significant when in fact they are based only on chance.

In conclusion, our study suggests that most patients with this fatal progressive illness have thought about life-sustaining treatment, have preferences about their care, and want to discuss life-sustaining treatment with their physicians. However, many patients have not provided advance directives, including some who might benefit from the durable power of attorney for health care. Many patients also have misconceptions about the effectiveness of life-sustaining treatment, even though they are well educated and live in a city where their illness is widely publicized. We suggest that physicians who care for patients with AIDS and other serious chronic illnesses should take an active role in educating patients about life-sustaining treatment and inviting them to provide advance directives.

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Table 1. Characteristics of 118 Homosexual Male Patients with AIDS.

Mean age, yr (range)	35 (22-55)
Months since diagnosis (range)	10 (2-39)
Underlying illness (%)	
<i>P. carinii</i>	56
Kaposi's sarcoma	53
Hospitalization (%)	
Within past 12 months	73
In intensive care unit	12
Functional status (%)	
Unemployed or disabled	73
Trouble walking 1 block or climbing 1 flight of stairs	32
Education (%)	
High-school graduate	97
College graduate	55
Parental attitude (%)*	
Definitely knew patient was homosexual	90
Highly or mostly accepting	73
Friends knew patient was homosexual (%)	93
In primary relationship (%)	36
Depressed (%)	35

*Percentage among patients whose parents were living (n = 98).

want if they had *P. carinii* pneumonia. Sixty-six percent had thought a lot or a moderate amount about whom they wanted to designate to make medical decisions for them if they were unable to do so themselves. Nine percent of patients had changed their minds about life-sustaining treatment, and 22 percent had changed their minds about substitute decision makers.

Preferences for Treatment of Pneumocystis

Ninety-five percent of the patients wanted hospitalization and antibiotic treatment for *P. carinii* pneumonia, 55 percent wanted admission to the intensive care unit and mechanical ventilation, and 46 percent wanted cardiopulmonary resuscitation. There were no significant differences in the preferences of patients for care of first or subsequent episodes of *P. carinii* pneumonia. No demographic, medical, psychological, or social variables predicted patients' preferences for intensive care and mechanical ventilation. If they acquired both severe memory loss and severe *P. carinii* pneumonia, 19 percent of patients wanted intensive care and intubation, and 17 percent wanted cardiopulmonary resuscitation.

One patient poignantly stated his anguish and ambivalence about life-sustaining treatment:

I switch back and forth in my view. On the one hand, I do not want to die in the hospital and am terrified of dying on a respirator. On the other hand, if there were a chance for recovery, I would equate the decision not to go on with suicide. . . . I don't have any hope anymore that something is going to be found to cure me before I die. . . . I sometimes wish I would get run over by a bus before I have to face these problems.

Emotional Reactions to Discussing Life-Sustaining Treatment

Patients had ambivalent but generally positive reactions to discussing life-sustaining treatment (Table 2).

One patient commented, "I hope physicians everywhere will remember they are dealing with real people and not with plastic dolls they can manipulate at whim. I am frightened, but not of death. Rather, I am frightened of being helpless."

Preferences for Discussing Life-Sustaining Treatment with Physicians

Although 73 percent of patients wanted to discuss life-sustaining treatment with their physicians, only one third had done so. No demographic, medical, psychological, or social variables predicted which patients wanted such discussions. In particular, patients with negative emotional reactions to discussing life-sustaining treatment wanted such discussions as often as other patients.

Patients with *P. carinii* pneumonia had discussed life-sustaining treatment more often than patients who did not have the disease (33 percent vs. 13 percent, chi-square = 6.11, $P < 0.01$). No other independent variable identified the patients who had had discussed life-sustaining treatment with their physicians.

Of the patients who wanted such discussions, 58 percent said the patient should initiate them and 36 percent said the physician should do so. Sixty-nine percent of these patients wanted to discuss life-sustaining treatment as outpatients, after getting to know their physicians; 54 percent wanted such discussions in the hospital when they were seriously ill; 37 percent, on hospital admission; and 24 percent, when AIDS was diagnosed.

Table 2. Emotional Reactions of the 118 Patients to Discussing Life-Sustaining Treatment.

REACTION	PERCENT*
In control of things	56
Cared for	47
Anxious	44
Sad	40
Relieved	33
"It's all over"	19
Giving up	12

*Most patients gave multiple responses.

Preferences for Substitute Decision Makers

Forty-seven percent of patients wanted their partners or friends to act as substitute decision makers if they became incompetent, 32 percent wanted family members, and 14 percent wanted their physicians. Patients whose parents were only somewhat or not at all accepting of their homosexuality wanted their partners or friends to be the decision makers more often than patients whose parents were more accepting (73 percent vs. 39 percent; chi-square = 9.39, $P < 0.01$). One patient commented, "I used to feel my parents were always the ones to make decisions if I got really sick. Now I feel my best friend is more qualified because he sees me all the time and knows my wishes better than my parents."

Possible further addendum physical exam.

Cranial nerves continued,

16. Nystagmus

17. Smooth pursuit eye movements. _____

18. Tremor.

0 Absent.

1 Fine tremor present at rest.

2 Coarse tremor present at rest.

3 Fine tremor worse with movement.

4 Coarse tremor worse with movement.

5 Other.

8 Could not asses.

9 Not tested.

comments _____

19. Gait.

0 Normal.

1 Appears unsteady.

2 Worse when turning.

3 Spastic.

4 Waddling.

5 High stepping.

6 Limping.

7 Other.

8 Could not asses.

9 Not tested.

comments _____

20. Abnormal Movements.

0 No abnormal movements.

1 Choriiform movements.

2 Athetoid movements.

3 Ballisms.

4 Other.

8 Could not asses.

9 Not tested.

21. Strength.

0 Normal.

2 Questionable weakness.

3 Slight weakness.

4 Moderate weakness.

5 Severe weakness.

6 Very severe weakness.

7 Complete paralysis.

8 Could not asses.

9 Not tested.

Right

Left

Arms

Legs

0 Normal

1 Legs weaker than arms.

2 Arms weaker than legs.

3 Generally weak.

4 Weakness greater proximally.

5 Weakness greater distally

6 Weakness greater right side.

7 Weakness greater left side.

8 Could not asses.

9 Not tested.

22. Coördination.

0 Normal

1 Mildly impaired

2 Moderately impaired

3 Severly impaired

4 Other (N.B. Slowed)

8 Could not assess

9 Not tested

23. Finger nose test _____

24. Nose finger nose test _____

25. Heal shin test _____

26. Pronation/supination of forearm -- _____

comments _____

Work in Progress

Characteristics (Early Stage)

HIV Dementia

Alzheimers

Speed of Cognition:

slowed

normal

Memory:

Immediate

normal to mild

impaired

30' Delayed

improves with cues

cueing does not help

Language:

Verbal Fluency

slow

normal

Expressive Speech

anomia-absent

anomia-paraphasia present

Visual-Spatial Skills:

Impaired esp. mental rotation, scanning, (?fig.-ground)

OK v-s copy maybe poor

Abstract Reasoning:

poor

poor

Motor:

Speed

slow

normal

Tremor

present

absence

Coordination

poor

normal

reflexes

hyperflexia

OK

Personality Changes:

organic affective psychosis

If psychotic-simple delusions

Prepared By: Alicia Boccellari, Ph.D.

J. Cummings, M.D.

~~Ben~~

Principles of Medical Ethics

~~Conscient~~

1. ¹ Individual has dominion over himself
2. Physician is not "automated tool" of the patient

Exceptions

1. Great pain: die to rid
2. Psychotic (use $\bar{c}$ consent of alternate decision maker).
3. Emergency

Jurba SH and Zawacki BE: Autonomy of burned pts when survival is unprecedented NEJM 297: 308-11, 1977.

Px that will reverse illness + restore health is necessary.
Treatments that are not medically indicated are not necessary.

Imperative vs. Elective

Can illness be reversed or how far it can be reversed is most ~~basic~~ + difficult Q.

"Every human being of adult years and sound mind
has a right to determine what shall be done
with his own body... (Schloendorff v.
Society of NY Hospitals, 1914)

Carbozo Dictum

Intro:

~~the act of taking one's ^{own} life,
Suicide, as a matter of choice — for the
sake of discussion today we have been~~

mental processes that precede the
Suicide is the act of taking one's own life. ^{What are the}
ending of one's life, cannot be accomplished
without a decision-making process occurring.

For ^{my} ~~our~~ purposes today, as a part of this
panel, I would like to concentrate on the
decision-making aspect + consider two
main issues: One is the aspect of
competency and the other is a related,
and very impt issue in the treatment of AIDS
pts — the infection of the brain by the HIV
and the relatively high prevalence of CNS
problems that AIDS pts can develop.

Competency is 1st + foremost a legal determination, not
a + a psychological.

"Competency is presumed as long as the pt. modulates his or her behavior, talks in a comprehensible way, remembers what he or she is told, dresses + acts so as to appear to be in a meaningful communication + the clinician, has not been declared legally incompetent."

Standards of Competency

- 1) the pt evidences a choice about Rx (one who manifests behaviorally or verbally, a clear preference for or v Rx)
- 2) pt's choice ^{is deemed} ~~seems~~ reasonable (test involves the evaluation of the pt's capacity to reach the right, reasonable or responsible decision).
- 3) pt's choice is based on rational reasons (is decision the consequence of delusional thinking?)
- 4) pt manifests ability to understand (understands risks/benefits of + the alternatives to Rx, including the consequences of NO Rx)
- 5) pt manifests actual understanding of the info relevant to consent or refusal.

Siegel -
unimpaired
mental processes
understandable

Ultimate choice of standard + particularly threshold of competency is a matter of social policy + law not psychiatry or mental health.

Procedures are important to ensure a thorough clinical eval:

- 1) consider the dynamics of consent/refusal
- 2) has the pt been told? Assess understanding of procedures, risks/benefits, alternatives to treatment
- 3) assess the pt's stability of choice and ability to understand over time
- 4) pt may not give reliable info - obtain obj. info
- 5) Competency within social/interactive network - may not trust you, but will trust another

Legal presumption for adults is competency.

Valid Informed Consent:

- 1) Must be voluntary
- 2) must be knowing or informed
- 3) must be competently given

Ψs compelled ethically + practically if not legally bound to assess Competence, the ability to make decisions re. his care.

Process of determining competency in theory does not seem complex, in practice is very complicated.

What are the proper criteria and what is the proper procedure. While ultimately the determination of competency is a legal task, the practice of determining competency involves an array of medical, social and even moral dimensions.

Determinations of competency serve to validate or set aside individual rights. An incompetent person may be treated as an object: someone who may have things done to them rather than with them.

When the pt consented to or refused medical Rx, a condition of mental illness, mental retardation or severe mental disability was present + prevented the person from understanding what was proposed.

Ψ are asked to give opinions about a pt's de facto competency as a prelude to, or instead of, a formal legal review, even if the Ψ's opinion lacks a legal investigation.

What is the central issue in the case?

What are the usual procedures?

From your perspective as a member of the house staff: what is the most difficult aspect of cases like these?

- Committed to take best possible care likes to do in clinic
- from your pt of view, whole best possible care

2 kinds of DNR

Exploring I Looking for pt's preference

New dx - setting the stage;

- Respiratory failure in 1st time PCP - suggest is indicated if pt wants it. 15% chance they'll ~~of~~ come off.
- SA - has 50% survival rate

Informing

II 3rd time PCP; failing Septa, can't take Pent.

PO_2 is 60 + $\downarrow$

- this should be DNR
- some hospitals say you don't have to tell pt.
- What's yr. understanding - we're all pulling for you - blood O_2 will fall.

This is what we'll do - give you O_2 , give you medicine

- intubating you would just prolong rd you're feeling uneasy. We have no medicine. If your ht + lungs should stop, we won't try to make them start again -

Psychiatry - Ethics.

1. Where the person is

Come in + sit down -

1) Dr. Social talk

2) Tell me what your ~~of~~ understanding is
of the overall situation

- it may or may not take up the
big question

MD's have a lot
of anxiety when
pt is

great

doing poorly

- attitude



Good to be
anxious.

- I'm glad you feel this - but an
optimistic attitude is right; but
some things - "No"

- Prioritize for -

- In mind person

Be clear of yr objective when you're
going in.

⊗ DNR on medical gds - it
refr

- 3 -

emphasize what we will do

- Conflicts go into jt II & have a type I conversation - suggests to jts there's medication available.
- if not medically indicated; inst that jt doesn't think it available.
- Def Intubation
 - tube in their throat - ventilator that gives O₂ for breathing
 - it's uncomfortable, but not worst as the world. Frustration & isolation from not being able to communicate.
 - Rx'd like a lung is bad -
 - worse afterward

LIFE SUPPORT AND NO CODE
ISSUES FOR PERSONS WITH AIDS

James W. Dilley, M.D.

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University of California School of Medicine
San Francisco General Hospital "

--
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San Francisco General Hospital

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San Francisco General Hospital

The Acquired Immune Deficiency Syndrome (AIDS) is an illness which poses unique problems not only for the individual with the disease, but also for those who care for him. The staff of 5B, the Special Care Unit for persons with AIDS at SFGH has been confronting these issues since its opening in July of 1983.

This brief report will address only one of the unique problems confronting patients and the health care provider: the issue of advanced life support and cardiac resuscitation. When and how should decisions about these measures be made?

We will present two clinical vignettes to illustrate some of the difficulties we have encountered in this area. These will be followed by a statement of our beliefs about these issues. Finally, we will present guidelines to facilitate dealing with these issues in hopes of minimizing similar problems in caring for persons with AIDS.

Case #1

A 32 year old white male with a four month history of Kaposi's Sarcoma was admitted to 5B with neurologic abnormalities. Though able to speak at admission, his condition deteriorated rapidly leaving him arousable, but unable to communicate. He was attended around the clock by his roommate and friend of nine years.

The patients' social history included abandonment by his parents at age three. The youngest of four, he was raised by the maternal grandmother who refused to care for him when she learned of his diagnosis. His siblings refused to visit though they lived nearby. His parents wrote that his illness was God's punishment for being gay.

As no legal provision had been made for making decisions on the patients' behalf, he remained a full code. His friend insisted that the patient did not wish advanced life supports and contacted the patients' clinic physician who was also aware of the patients' wishes. A no code

order was written.

The patient had also communicated his wish to be cremated and he and his friend had planned his funeral. Upon the patients' death, the friend learned that the hospital could release the body only to the next of kin or a legally designated substitute. The patients' father was contacted who dictated that the body be flown back to the Midwest for burial despite the patients' stated wishes.

Case #2

This was the first SFGH admission for this 48 year old white male who presented with wasting and dehydration. Past history revealed a diagnosis of AIDS a year and a half previously with a successfully treated course of pneumocystis.

After a week of treatment, the patient appeared to stabilize and plans for discharge were formulated. The patient was to return home with attendant care. On the weekend before he was to leave, his condition suddenly deteriorated during the night. His nurse was aware that the patient had repeatedly stated that he did not wish resuscitation in the event of arrest. However, a "No Code" order was not in the chart. The nurse paged the cross-coverage team to evaluate the patient, becoming increasingly anxious and angry as he felt trapped between his legal obligation to initiate treatment should the patient arrest, and his desire to see the patient's wishes respected.

The housestaff on call felt the patient was nearing the end of his life and though they had verbal instructions from both the patient's lover and brother not to intervene, they were not empowered by hospital policy to write a "No Code" order in the chart. The attending physician was not in the house. It was not until the following morning that an attending from the outpatient clinic was able to come in to write the order thus relieving the staff from their legal obligation and insuring the patients' wishes were respected.

These examples illustrate some of the difficulties encountered when the issues of life support measures are not raised early in the treatment of persons with AIDS. The high mortality rate, the common development of

neurologic complications, and the frequently brief interval from first diagnosis to death, combine to dictate that early consideration of these matters is an integral part of good care for these patients. The staff of 5B, the Special Care Unit at SFGH, has adopted the following beliefs* regarding the issues of advanced life supports and cardiac resuscitation.

We believe that:

- 1) a patient has the right to participate fully in all decisions pertaining to his medical treatment;
- 2) this right includes the right to accept or refuse life-sustaining treatment;
- 3) the physician is an essential participant in this discussion;
- 4) the discussion of these issues is intrinsic to addressing a life-threatening diagnosis and that patients are thus empowered to make informed decisions in accordance with their wishes;
- 5) this discussion should occur at a time when the patient is relatively healthy and most able to make a competent decision;
- 6) patients, with few exceptions, are better off knowing the truth about their condition;
- 7) the natural course of AIDS is unpredictable and the clinical status of patients with AIDS can change abruptly.

PROPOSED GUIDELINES FOR DISCUSSION
OF ADVANCED LIFE SUPPORT AND NO CODE
ISSUES FOR PERSONS WITH AIDS

1. Life support and no code issues should be raised with all patients admitted to SFGH with an AIDS diagnosis. This discussion should be an early part of the overall admission procedure, e.g. within the first seventy-two hours.
2. As part of an ongoing educational process, resuscitation and advanced life support should be explained. The patient should be informed of his right to determine what measures will be instituted. "
3. The patient should be assured that choice of a no-code status will not obviate treatment of treatable conditions. It should be emphasized that pain management, comfort measures and emotional supports will be provided in all situations to all patients.
4. The patient should be informed of what he must do to assure his decisions are carried out. He can accomplish this through a discussion with his physician resulting in a no code order being written. Other legal measures include preparation of a living will or designation of a durable power of attorney. Legal services are available.
5. Special attention should be given to the fact that the law does not recognize gay relationships. The patient should be informed that if he becomes unable to make decisions for himself, his lover cannot act on his behalf unless he has been legally designated durable power of attorney.

6. In the event that the patient is medically unable to address the issue of life support, the discussion should occur with the patient's designated durable power of attorney or next of kin.

7. The primary or assigned nurse will help coordinate communication between the housestaff, the counseling staff and the patient regarding these issues. Pertinent details will be recorded in the nursing progress notes.

8. The responsibility for discussion of code status and no-code orders lies with the housestaff and the designated attending physician. In some instances, the AIDS clinic physician will have developed a long-standing relationship with the patient and may have valuable input regarding these issues. Housestaff should consult with the patients' clinic physician regarding these issues.

9. In accordance with hospital policy, the attending physician or his designate will order code status changes and document them in the patients' chart.

The authors wish to acknowledge the staff of Ward 5B, members of the psychosocial care team, and Drs. C. Wofsy, D. Abrams, P. Volberding, and M. Sande for their review and support of these guidelines.

*These beliefs have been adapted in part from the work of Wanzer et. al., The Physicians' Responsibility Toward the Hopelessly Ill Patient. New England Journal of Medicine 1984;15:955-959.

RECEIVED

JAN 12 1988



ALERT

News from the UFMCC on AIDS Legislation, Education, Research and Treatment.

NEW DIAGNOSTIC TEST: HIV p24 ANTIGEN TEST

JANUARY 1988

By Gary McClelland, M.D.

In the September, 1987 issue of Annals of Internal Medicine a new HIV antigen was reported which may aid in the screening, diagnosis, and treatment of HIV infection. This test, the HIV p24 antigen detection test, is now commercially available and will detect the presence of HIV infection (actual virus rather than antibody as in previously available tests) in serum, plasma, spinal fluid, and body tissues at even low concentrations. Its name comes from the fact that the core protein of HIV has a molecular weight of 24 kilodaltons. This protein is the product of a highly conserved core gene and, as such, is less likely to be affected by HIV stain variability.

As mentioned above, there are a number of potentially important uses for this test although at a current cost of \$125.00 per test it may not be widely utilized. While this cost is less than that of present methods of actual virus detection (culture); it is hoped that with more widespread usage this cost will decrease. The antibody tests currently in use only reveal the presence or absence of antibodies to HIV - indirect evidence of the presence of virus in those who are seropositive. The antigen test measures actual presence of the virus and also its concentration - direct evidence of HIV infection - and can be detected in HIV infected individuals within two to three weeks following infection which is months before the antibody may be detected. As with existing antibody tests, informed consent of the patient is required before performing the test. It is also recommended that the test be done confidentially since it has the same medicolegal implications as an official part of the medical record as does the antibody test. The ability to detect HIV infection much earlier than existing tests makes this an invaluable tool in screening blood donors and in detecting infection earlier especially in newborn infants where the presence of maternal antibodies transferred in utero currently masks the infant's serologic status.

Since the test is quantitative (measures not only the presence or absence, but the concentration of the virus) an even more important use may be to assess the effects of antiviral therapy. It has been shown in patients taking AZT (Retrovir) that there was a steady decline in p24 antigen while in control (untreated) patients the level remained unchanged or increased. This may give an early indication if a drug is working or not, or even if the dose should be

increased or decreased. Given the serious side effects of many antiviral medications, this "fine tuning" of drug dosage is a very important use of this new test.

Another use may be to help in the decision of whether or not to start antiviral therapy in individuals who are antibody positive but asymptomatic, especially if the T4 count is reduced. Those with the presence of antigen - particularly at elevated levels - would be candidates for therapy, while those with negative tests would not require treatment. Approximately 1.5 million people in the U.S. are estimated to be infected with HIV. If these individuals are not to become a part of the ever increasing and staggering numbers diagnosed with AIDS or ARC, therapeutic intervention needs to occur before the T4 cells are depleted to such a level that clinical evidence of opportunistic infection occurs. To facilitate this intervention would seem to be one of the most significant future uses for this important new diagnostic test.

PWA BRACELETS AVAILABLE

PWA bracelets inscribed with the names of those who have died from AIDS are now available from the Mother Cares Foundation. The \$10 donation will go to three AIDS organizations: Forty percent to Mother Cares, forty percent to the distributing agency or church, and twenty percent to Mothers of AIDS persons. Organizer Mark Manning states, "When there has been a cure, we hope to collect all the bracelets and melt the metal down and create a memorial from the material." For more information on obtaining or sponsoring bracelets, contact Mark Manning, Mother Cares Foundation, c/o Pride Media Relations, 8833 Sunset Blvd., Suite 304, West Hollywood, CA 90069; or call, (213) 933-3662.

RAPID INCREASE IN PEDIATRIC AIDS

The number of young children with AIDS is expected to more than triple within the next three to four years according to a new congressional report released December 14, 1987. Of the estimated 279,000 people expected to be diagnosed with AIDS by 1991, 3,000 will be under the age of 13. Currently pediatric AIDS cases account for 2% of all AIDS cases. The report says such an increase of the disease among children threatens to overburden the nation's health and foster care programs, because the communities they live in are not equipped to handle the financial, emotional and physical toll of AIDS.

AIDS, A MANUAL FOR PASTORAL CARE

by Ronald H. Sunderland & Earl E. Shelp

(Reviewed by Rev. Steve Pieters)

This concise manual on pastoral care in the AIDS crisis offers a helpful outline of many of the issues confronting anyone who is ministering to people affected by AIDS. From medical facts to ethical issues, Sunderland and Shelp present well-documented arguments for ministries of compassion and presence. The book is particularly strong in discussing the dynamics of grief.

They do, however, retreat from taking stands on issues which many in the Church Universal would consider to be controversial. While raising concerns regarding suicide, assisted suicide, abortion, and mercy killing as they relate to AIDS, they generally do not suggest more than that clergy should become familiar with the moral discussions related to these areas. The authors could have presented more of their own thought processes about each of these issues, even without coming down on one side or the other. They are very careful not to give offense.

Regarding homosexuality, they quote John Boswell's challenge to think through what is natural and unnatural. There is an assumption that many of their readers perceive homosexuals, IV drug abusers, and prostitutes to be in one moral category. Their attitude is focused on page 40 in discussing the pastoral response to these various lifestyles: "The AIDS patient must be recognized as an individual whose integrity must be respected, and who has a claim on the pastor for acceptance as a person. Such acceptance does not imply either acceptance or rejection of the patient's lifestyle." They do suggest that there may be some pastors who should refrain from AIDS ministry, if their moral belief system is going to get in the way of the suggested neutral acceptance. They also warn against trying to proselytize the patient, or engage in "missionary activity". They urge the acceptance of a Gay PWA's lover as a family member. But this is as far as they are willing to go, and they end by suggesting that the reader think these issues through very carefully before entering a pastoral relationship with Gay AIDS-affected persons. Throughout the book, it is assumed that the reader is a heterosexual clergyperson of a mainstream denomination.

The medical facts are presented in a concise and clear manner. However, as with any book portraying the medical situation, this manual will become quickly outdated, with each advance in research. Already, many have questioned the Central Africa-Haiti-U.S. transmission route described in this book.

For a book on pastoral care in the AIDS crisis, this book talks little of hope and faith in facing the disease, and there is nothing about healing, either spiritual or physical. The life, death and Resurrection of Jesus Christ are a powerful theological base for ministry with persons affected by AIDS, and yet there is little in this book on

how the Christian faith can help a person face a life-threatening illness. While the authors strongly state that individual Christians, as well as the Church, have "no option" but to be present with compassion to those suffering from AIDS, one is left with the feeling that hope, healing, and quality of life are not something to be offered to persons affected by AIDS by the caring Christian.

This book is strong as an outline of issues presented by AIDS, but it leaves the reader hungry for more in-depth analysis, more hope, more faith, and stronger stands.

CHURCH PROGRAM FOR AIDS MINISTRY

(H.A.N.D.S. Program developed by MCC Dallas, TX)

Helpers

II Corinthians 1:24 - "Not that we lord it over your faith, but are workers with you for joy; for in your faith you are standing firm".

Accepting

Romans 15:7 - "Wherefore, accept one another, just as Christ also accepted us to the glory of God."

Needs

Hebrews 4:16 - "Let us therefore draw near with confidence to the throne of grace, that we may receive mercy and may find grace to help in time of need."

and Delivering

Hebrews 2:15 - "and might deliver those who through fear of death were subject to slavery all their lives."

Services

Hebrews 12:28 - "Therefore, since we receive a Dominion which cannot be shaken, let us show gratitude by which we may offer to God an acceptable service with reverence and awe."

H.A.N.D.S. is a lay ministry service program of the church extending a helping hand to those in need. As believers, we are called to extend our hands to those in need of services. This program is designed to allow an opportunity for the congregation to extend their hands to those in need on an individual and time available basis.

MCC Dallas invites all churches in UFMCC to join H.A.N.D.S. by adopting a H.A.N.D.S. program. Toward this end, the Dallas H.A.N.D.S. Coordinators have developed the "H.A.N.D.S. Start up Packet" which includes: Camera ready H.A.N.D.S. brochures for distribution to congregation, Inservice Program outlines, "Care Group" Program Outline, and an introductory issue of the newsletter, AIDS: Health Information for the Caregiver. The packet is available for \$5.00 to cover printing, postage and handling costs. Write to:

H.A.N.D.S. Program
MCC Dallas
2701 Reagan
Dallas, TX 75219

ST. LUKE'S MCC HOUSE FOR PEOPLE WITH AIDS

St. Luke's MCC in Jacksonville, Florida has established a residence for people with AIDS. The five bedroom house, with one and a half baths, can house up to four PWA's in addition to the house manager, Ms. Donnie Kreutz. Located in an older, low-income section of the city, the house is being signed over to the church by a person with AIDS who decided to move closer to the National Institute of Health where he is being treated. University Hospital helps to support the House with a monthly financial grant.

To be eligible to move into the House, a person must be a medically indigent University Hospital AIDS-affected patient. Since its formation in the spring of 1987, there have been many inquiries from around the state, and program coordinator Steve Crosby has had to turn down a number of requests for housing.

Tenants must sign a contract agreeing "to refrain from the use of alcoholic beverages and nonprescription drugs; to abstain from sexual activities within or without the premises which could promote the spread of AIDS; to assist in housekeeping and the clean and sanitary maintenance of the assigned room plus the common areas; and to be a positive influence in helping to build and maintain a wholesome atmosphere necessary to promote the well-being of those other household residents who are AIDS-affected". Once a person's SSI benefits begin, he or she is required to pay a token rent. Medicaid has provided a hospital bed for the most severely ill patient.

The Visiting Nurse Association visits at least three times a week, and is on 24-hour call. Food is provided through resident's food stamps, as well as through donations from MCC members and local Gay and Lesbian businesses, whose responses have been "excellent," according to coordinator Crosby.

Problems arose with state and local regulatory agencies, due to anonymous complaints received by the Florida Times Union and a local TV news department. These complaints claimed that the house was unregulated and unaccountable to health authorities, while also charging mismanagement of funds. In response, Crosby met with City Council Member Sandra Darling, who assured him she had no problem with the house, and that she knew that it had been thoroughly inspected and approved. The next day an article appeared in the Times Union, stating that Darling was concerned over the lack of regulations governing such homes, and was proposing legislation to strictly regulate them, to prevent houses like St. Luke's from becoming "dumping grounds". The legislation would require notification of the entire neighborhood, and allow any concerned citizens to appear at a public hearing to approve such homes. Currently, the neighbors are unaware of the function of the house, which the staff believes is necessary to safeguard the residents from harrassment.

Rev. Michael Piazza, former pastor of St. Luke's MCC and current pastor of MCC Dallas, was quoted in the Times Union, stating, "It is a cruel bill. It is a reaction to our house. She is looking out for property values. Where does she want these people to go?"

When police and the Department of Health and Rehabilitative Services arrived to check out the complaints, the entire Board of Directors of St. Luke's MCC were present for questions. The chief inspector questioned everyone and "went away happy".

While Darling's bill is still before the city council's Urban Affairs Committee, Crosby points out that this house is not a hospice; no therapy or medicine is administered by the staff, and when patients become too ill, they are hospitalized. "This house is a pioneering stab at keeping down costs for persons affected by AIDS. We have been successful at keeping at least a few patients out of the hospital when they are ambulatory and well enough to live in the residence, but unable to live on their own," Crosby told ALERT. University Hospital recognizes that the \$500 a month grant providing housing for three or four patients saves the hospital a great deal, since they would be assuming the \$500 to \$750 a day cost for each patient having to stay in the hospital.

There is a real family feeling to the house. Steve Crosby has assumed the role of "disciplinarian," while Donnie Kreutz is affectionately called "Mom" by the residents. She is also a paralegal and criminologist, and has helped residents prepare wills and powers of attorney.

The people with AIDS living in the House help each other, simply by being together, helping each other through medical and governmental hoops, playing and shopping together, and encouraging each other to live with AIDS.

AZT PRICES DROP

The price of AZT, the only federally approved drug to treat AIDS, has suddenly become less expensive. Burroughs Wellcome Company has announced that AZT prices will be reduced by 20% effective December 15, 1987. The cut comes as a result of savings in production costs. Depending on patient dosage, the current retail cost of AZT can range from \$800 to \$1000 a month. However, it is still unclear whether or not drug retailers will pass along the savings. Burroughs Wellcome says it only establishes the wholesale price; beyond that the company has no control in the matter. If drug retailers were to lower their prices as well, the average patient cost for AZT would drop to about \$600 a month, or from \$188 to \$150 for 100 capsules.

Don't We Care?

Members of Congress don't hear from us, and wonder if we don't really care.

Our community's organizations and lobbyists are hard at work, advocating a vigorous, effective and non-hysterical response to the AIDS crisis. But, despite opinion polls showing support, legislators seldom receive mail from constituents supporting our positions.

What's worse, our Far Right opponents are exploiting the health crisis for political gain—

mobilizing hostile constituent pressure. While our advocates work the halls of Congress, our opponents work the streets and avenues of Congressional districts across the country. And, as a result, legislators too often are afraid to stand with us on controversial and emotional issues.

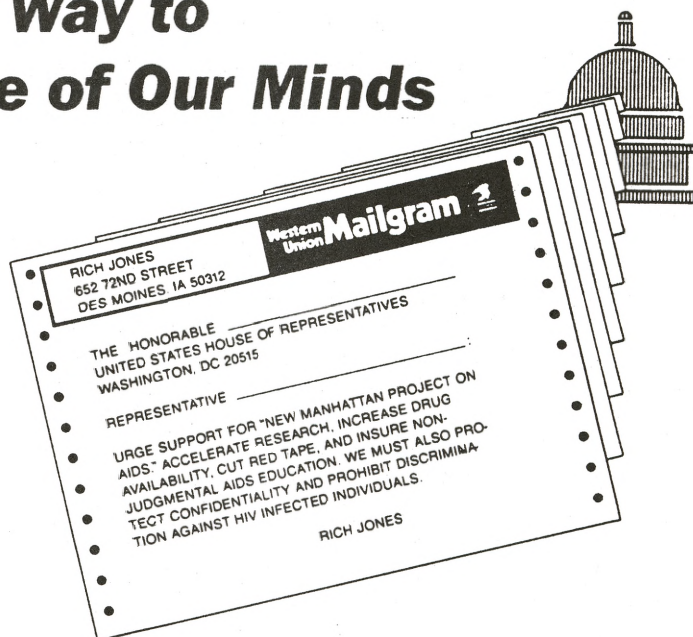
With critical AIDS funding decisions, the defeat of countless AIDS hysteria measures and basic fairness questions hanging in the balance, we just have to turn this situation around!

Finally, Here's an Easy Way to Give 'em a Piece of Our Minds

The Fairness Fund's Public Opinion Mailgram campaign now gives us an easy way to make our voices heard on Capitol Hill on the issues we care about. A POM is a 50-word mailgram that costs just \$4.50 each (the same 50-word message would cost almost 3 times as much outside this system). They are charged to your telephone bill. You don't even have to know who your legislator is—that'll be taken care of for you.

Too often, there just doesn't seem like there's time to write a letter. And sometimes you're just not sure what to say or when to write. Now, by signing one of our Public Opinion Mailgram authorization forms, or by calling the 800 number we have established, you can ensure that your voice will be heard in a timely, articulate fashion.

And, because the Fairness Fund works in close cooperation and with the support of the Human Rights Campaign Fund and other national gay/lesbian groups, your mailgram will reflect



our community's current lobbying strategy and priorities.

Won't you take just a minute, right now, to make a difference. Let's prove that we really *do* care.

The National Mailgram Campaign

Public Opinion Mailgram Authorization for Fairness and Privacy

Please print

Last Name, First Name

Telephone Number

Address

City

State

Zip

I support fairness and privacy for lesbians and gay men and adequate AIDS funding and therefore authorize the Fairness Fund to use my name to send _____ (2-12 or unlimited) Public Opinion Mailgrams (50 words) during the next year at a cost of just \$4.50 each. (The mailgrams will be charged to the phone number authorized, CANCEL AT ANY TIME.) The mailgrams will be sent to elected officials (at all levels) at critical times on the general categories of: increased AIDS funding, defeat of AIDS hysteria measures, and support for justice for gay men and lesbians.

Signature

The Fairness Fund, P.O. Box 1723, Washington, D.C. 20013

Call

1-800-257-4900,
Oper. 9184 to send
AIDS Mailgrams or
Oper. 9188 to send
Fairness Mailgrams.

THE
FAIRNESS FUND

(202) 347-0826

(Save for future reference.)

ATEU Protocols (As of 11/20/87)

ATEU Protocol #/Description	Lead Investigator	Known or Anticipated Collaborators
001 AZT in KS	Dr. Valentine, NYU	NYU, Rochester, USC, UCLA, Hopkins, UCSF, Stanford, UCSD, Harvard, MSKCC, Duke, Minnesota, Tulane, Mt. Sinai
002 AZT post first episode of PCP	Dr. Fischl, Miami	All ATEUs except NYU
003 Phase I – AZT in pediatric AIDS/ARC	Dr. Scott,* Miami	Miami, Duke
004 Phase I – AZT + DHPG in AIDS/CMV-associated disease	Dr. Dolin/ Dr. Reichman, Rochester Dr. Richman, UCSD Dr. Hochster, NYU	Rochester, UCSD, NYU
005 AZT in AIDS dementia and CNS HIV infection	Dr. Price, MSKCC	MSKCC, Hopkins, UCLA, Harvard, Stanford, NYU, Miami, Rochester, UCSD, Texas, Tulane, U. Wash., Mt. Sinai, Einstein
006 Doxorubicin in KS	Dr. Fischl, Miami	Miami, UCSF, MSKCC, Texas, NYU, UCLA, Harvard, USC, Mt. Sinai
007 PROJECTED		
008 Phase I – chemotherapy + AZT with or without radiotherapy in AIDS lymphoma	Dr. Levine, USC	USC, NYU, UCSF, UCLA, Mt. Sinai
009 Phase I – chemotherapy + radiotherapy + AZT in CNS lymphoma	Dr. Levine, USC	USC, NYU, UCSF, UCLA, Mt. Sinai
010 AZT + acyclovir in symptomatic ARC or PGL	Dr. Corey, U. Wash.	U. Wash., UCSD
011 DDC pharmacokinetics in AIDS/ARC	Dr. Lietman, Hopkins	Hopkins
012 Dose-ranging trial of DDC in advanced ARC and AIDS	Dr. Merigan, Stanford	Stanford, Miami, Harvard, UCSD
013 Phase I – AZT + interferon in KS	Dr. Fischl, Miami	Miami
014 Phase I – AZT + interferon in KS	Dr. Krown, MSKCC	MSKCC

*The lead investigator may be someone other than the physician/scientist named on the list of ATEUs.

015 Foscarnet in CMV retinitis	Dr. Jacobson, UCSF	UCSF
016 Safety/efficacy of AZT in early ARC	Dr. Fischl, Miami	All ATEUs except MSKCC
017 Phase I – AZT in HIV-infected hemophiliacs	Dr. Dolin, Rochester	Rochester
018 Trimetrexate for first PCP episode	Dr. Sattler, USC	USC, NIAID AIDS Program†
019 Safety/efficacy of AZT in HIV-infected asymptomatics	Dr. Volberding, UCSF	All ATEUs
020 AZT toxicity in AIDS/ARC	Dr. Masur/ Dr. Allegra, NIAID AIDS Program†	NIAID, all ATEUs except UCLA and Miami
022 AL721 in PGL/ARC	Dr. Mildvan, Mt. Sinai	Mt. Sinai, MSKCC, UCSF, USC, Texas, Minnesota, Tulane
027 Phase I – AZT + probenecid + quinine in ARC/AIDS	Dr. Kornhauser, Hopkins	Hopkins
029 (PENDING) Trimetrexate + leucovorin vs. TMP-SMX in PCP	Dr. Sattler, USC	USC (possibly others)

† Contact: Barbara Baird, RN, (301) 496-9565.

Abbreviations

AZT – azidothymidine, also called zidovudine
or Retrovir

CMV – cytomegalovirus

CNS – central nervous system

DDC – 2'3'-dideoxycytidine

DHPG – ganciclovir

IFN – interferon

KS – Kaposi's sarcoma

PCP – *Pneumocystis carinii* pneumonia

PGL – persistent generalized lymphadenopathy

TMP-SMX – trimethoprim-sulfamethoxazole

METHODIST CONFERENCE ON AIDS

By Rev. Jim Mitulski

In November, I attended the National Consultation on AIDS Ministries sponsored by the United Methodist Church. The conference took place outside San Francisco. Representatives from nearly every United Methodist Conference (similar to districts in UFMCC) attended as well as interested clergy and lay leaders; there were about 400 attendees in all.

The conference sessions began with moving testimonies by United Methodist persons with AIDS, describing their experiences; for many of the conference participants, it was their first opportunity to hear from gay men, their lovers, and in one instance, the mother of a PWA. The first ripples of consciousness dawned in that opening session as the Methodists began to realize that AIDS was not simply "them", but "us" as well. I also felt some discomfort in the group as the PWA's continually stressed that lovers and friends are "family" for lesbians and gay men, in the deepest sense of the word.

The undercurrent of tension surfaced that evening during the keynote speech by Professor Karen Lebacqz of Pacific School of Religion. (Professor Lebacqz is known as an advocate to MCC San Francisco students attending Pacific School of Religion). As a non-Methodist, Professor Lebacqz commended the Methodists for taking the constructive step of organizing the conference. She also criticized the UMC for its teaching a sexual ethic of "celibacy in singleness, fidelity in marriage," because this definition precluded Lesbian and Gay relationships. Lebacqz questioned the church's seriousness about AIDS ministry while maintaining a homophobic theological stance, suggesting a positive first step would be performing Holy Unions as a means of honoring Lesbian and Gay relationships. Lebacqz was a satisfying and challenging speaker. Many Methodists were encouraged by her candor; some were uncomfortable with it. During the ensuing question period, the real underlying issue of the conference surfaced: the fear of Methodist clergy that they would be disciplined for condoning the public affirmation of Lesbian and Gay relationships. I was proud of UFMCC and our willingness to perform Holy Unions publicly. As a Gay man, I would like to continue in dialogue with Lebacqz and her insistence on monogamy as an ethic for homosexual and heterosexual alike.

The remainder of the weekend consisted of plenary addresses and workshops for the participants. On Saturday, I led a workshop for about 50 Methodist ministers on a ministry of presence for PWA's. As a non-Methodist pastor of a Lesbian and Gay congregation, I was able to say things from a unique perspective for them. I described MCC San Francisco as a church with AIDS; much like a person with AIDS, with all the difficulties and all the spiritual gifts that that condition entails. I taught the group the "Song to Remember Harvey Milk" by Holly Near, and the verse "We are Gay and Straight Together" took on a special meaning for that group. That night, Rev. Jim Sandmire addressed the

convention briefly as part of an interfaith panel; Sandmire, after his remarks about losing his son Dean to AIDS, was greeted with a standing ovation, the only speaker to be so honored.

The Methodists are to be commended for taking this initial step, albeit six years into the crisis. Regional representatives from across the country will make sure the vital information reaches people in remote places. In my workshop I stressed that AIDS is not a situation limited to San Francisco, Los Angeles, and New York; many knew that already because parents of Lesbian and Gay children in the major cities are found in their congregations everywhere.

Some criticisms are in order. Why come all the way to San Francisco, one of the world's greatest resource centers for AIDS care, and spend the entire time in a hotel 15 miles away? The conference could have been enriched by field visits to San Francisco General Hospital, the San Francisco AIDS Foundation, the Gay and Lesbian neighborhoods, MCC and other sites. The single biggest issue faced by the UMC in AIDS ministry is the extent to which it is compromised by its teaching that "homosexuality is incompatible with the Christian lifestyle," a tenant the conference made clear is unlikely to change. The closet is a potent force in United Methodism; probably half of the conference participants were Lesbian or Gay; only a handful could openly admit this. I'm aware of how my openly gay identity has enhanced my ability to do ministry; this resource is a terrific loss to them. The closet also affects heterosexual people; some of the most poignant stories were told of parents who suffer in silence in their Methodist churches, afraid to share their pain at the loss of a Gay son for fear of censure by the church and community.

Change happens slowly; it was a tremendous breakthrough for the UMC to host this conference, to share controversial resources, and to begin to take progressive stances on civil rights for persons with AIDS. I pray that the same spirit that convened the consultation will continue to work within the UMC. This is a good time for MCC's to contact UMC district representatives to inform them of how we can be a resource for them. Perhaps some cooperation between the UMC and the Lesbian and Gay community can be a tangible sign of God's healing power as a result of this Consultation.

AmFAR RAISES \$2.5 MILLION

The American Foundation for AIDS Research (AmFAR) has raised \$2.5 Million from sales of works by 600 artists at 75 New York Galleries since June, 1987. The final night at Christie's raised \$400,000 in one night. The fund raising drive may be extended to Los Angeles and other urban Art Centers to increase fund raising for AIDS Research. Elizabeth Taylor was among the stars leading the auction at Christie's.

NIAID EXPERIMENTAL PROTOCOLS

The National Institute of Allergies and Infectious Diseases (NIAID) is currently investigating the following protocols at the National Institute of Health in Bethesda, Maryland.

<u>DESCRIPTION</u>	<u>STATUS</u>
1. AZT in early KS	closed
2. AZT + alpha interferon in early KS	open
3. Phase I - CGP 19835 A (muramyl triptide, MTP-PE) in later KS	open
4. DHPG in CMV colitis	open
5. Alpha interferon in HIV-infected asymptomatics	open
6. AZT + bone marrow transplantation + peripheral lymphocyte transfer in asymptomatic/ARC/KS patients with non-infected identical twin.	open
7. Alpha Interferon in KS	closed
8. Phase I - gp160 recombinant protein vaccine trial, HIV seronegative males	open

Patients must be referred by physicians for these experimental protocols. Further information can be obtained by calling Vicky Davey, RN, Dianne Lee, RN, or Margaret Magill RN at (301) 496-7196.

CLINICAL STUDIES EXPANDING

In order to extend experimental drug trials beyond the 19 AIDS Treatment Evaluation Units, NIAID has established 17 AIDS Clinical Study Groups (CSGs). Approximately \$100 million has been budgeted for 1987 through 1992.

NIAID CLINICAL STUDY GROUPS (CSGs)

Alan G. Barbour, MD, University of Texas Health Science Center, San Antonio
Neil R. Blacklow, MD, University of Mass. Medical School, Worcester
Edward M. Connor, MD, New Jersey Medical School, Univ. of Medicine & Dentistry of New Jersey, Newark
M. Elaine Eyster, MD, Milton S. Hershey Medical Center, Hershey, PA
Robert J. Fass, MD, Ohio State Univ. Medical Center, Columbus
Peter T. Frame, MD, Univ. of Cincinnati College of Medicine Cincinnati, Ohio
David J. Gocke, MD, Robert Wood Johnson Medical School, Univ of Medicine & Dentistry, New Jersey, New Brunswick
Michael H. Grieco, MD, St. Lukes/Roosevelt Institute for Health Sciences, New York
Michael M. Lederman, MD, Case Western Reserve School of Medicine, Cleveland, OH
Kenneth McIntosh, MD, Childrens Hospital, Boston, MA
John P. Phair, MD, Northwestern Univ Medical School, Chicago IL
Roy T. Steigbigel, MD, State Univ of New York at Stony Brook School of Medicine, Stony Brook

CATHOLIC BISHOPS ISSUE CONDOM STATEMENT

Orange County Bishop, Norman F. McFarland, has joined the force of other Catholic bishops opposed to the wording of the latest statement by the U.S. Conference of Catholic Bishops on the use of condoms and AIDS education. McFarland calls the statement "imprecise & ambivalent." The part of the report under fire reads, in part, "educational efforts, if grounded in the broader moral vision...could include accurate information about prophylactic devices or other practices proposed by some medical experts as potential means of preventing AIDS." Bishops from all over the country have since publically responded to the report in outrage, forcing the president of the Nat'l Conference of Bishops to issue a clarifying statement explaining why the matter of condoms was included in the report.

The so-called clarifying statement acknowledges, "many public health officials have recommended use of condoms to reduce the risk of transmitting or acquiring the AIDS virus," and that fact will be part of the churches' comprehensive factual presentation on the disease.

McFarland said the final wording on the original statement seems to imply "our condonation, our acceptance" of the use of condoms. In fact, McFarland says the church questions the effectiveness of condoms and considers their use morally wrong.

REFORM JEWS PASS AIDS RESOLUTION

At the 59th General Assembly of the Union of American Hebrew Congregations, a resolution called "Confronting the AIDS Crisis" was approved almost unanimously.

The resolution called for opposition to mandatory AIDS testing, opposition to discrimination against PWA's in employment, health care, and housing, effective AIDS education in congregations and religious schools, programming in local congregations to actively support PWA's, a call for more alternative care facilities for PWA's, increased access to treatment for IV drug users, and improved AIDS training for health care workers.

Also approved by a large majority was a resolution calling for "Support for Inclusion of Lesbian and Gay Jews." This resolution promoted the active participation of Lesbians and Gay men in worship and congregational leadership, increased education to facilitate greater understanding, and equal employment opportunities for Lesbians and Gay men. The resolution also called for inclusive language in the liturgy.

The question of ordaining openly Gay and Lesbian rabbinic students remains open: the Committee on Homosexuality in the Rabbinat will present their final report to the Central Conference of American Rabbis in 1989.

The Harvard Medical School Mental Health Letter

Volume 4, Number 7

January 1988

The Nature and Causes of Depression — Part I

For most people depression is yesterday's bad mood, gone today; for some, it is a debilitating, even deadly chronic illness. The mood becomes a mental health problem when it is both deep and persistent enough to interfere with work, friendships, family life, or even physical health. Then it is a symptom, and in combination with other symptoms constitutes a disorder. In its mild forms, depression is merely a mood; in more severe forms, although it is called a mood disorder, it usually involves much more.

An episode of severe (major) depression may last for several weeks to several years. One common set of symptoms is insupportable misery accompanied by despair and guilt. Patients feel totally worthless and inadequate; they see no hope for the future and think constantly about death and suicide. (Half of all suicides in the United States are suffering from major depression, and the lifetime risk of suicide for persons with this disorder is 15 percent). They may think that they have lost all their money, or are being punished for grave sins, or dying of incurable diseases. Some depressed persons do not admit sadness or guilt; instead they withdraw from human contacts, lose all interest in life, and become incapable of feeling pleasure. Time passes slowly for them and the world seems dreary and meaningless. Normal emotional responses, even ordinary despondency or grief, become impossible. They are fretful and irritable. They cannot concentrate or make even minor decisions. They turn the same few ideas over and over in their minds. The depression may be retarded, with slow movements, toneless speech, and an expressionless face—in extreme cases, muteness and immobility resembling catatonic stupor. Depression may also be anxious and agitated, with pacing, moaning and handwriting.

Physical symptoms are common: chronic fatigue, loss of appetite and insomnia (or, occasionally, over-

sleeping and a ravenous appetite), backaches, headaches, upset stomachs, and constipation. Depressed people seeing doctors account for a large share of the nation's medical costs. The symptoms vary with age. In children, inability to concentrate, listlessness and physical symptoms are most common. (See *HMS Mental Health Letter*, July 1984). In old people, depression often takes a form resembling dementia, with disorientation and loss of memory (See *HMS Mental Health Letter*, September 1984).

One method used to diagnose depression is an interview with a fixed format, such as the Schizophrenia and Affective Disorders Scale (SADS). Another method is projective testing; the Thematic Apperception Test, for example, requires the patient to interpret an ambiguous picture. Ratings based on checklists of symptoms are also used; the most popular checklist scales for depression are the Beck, which relies on the patient's own responses, and the Hamilton, which is based on the observations of a mental health professional.

It is not easy to say how common depression is, because different studies use different definitions and different ways of collecting information. The

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Determining Suicide Risk



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Depression . . .

number of depressive symptoms found in community surveys does not always indicate the rate of depression serious enough to come to medical or psychiatric attention. Nevertheless, depression is clearly one of the most widespread psychiatric disorders. By some estimates, 2 to 3 percent of men and 4 to 9 percent of women in the United States are suffering from major depression at any given time. The lifetime risk is as high as 10 percent for men and 25 percent for women.

A person's first episode of major depression usually occurs in the 20s; the rate of depression peaks at ages 55 to 70 in men, and 35 to 45 in women. About 20 percent of depressions last two years or more; the average is eight months. In 40 percent of cases the first episode is the only one, but in half, the depression returns within two years. When it recurs, the average number of episodes in a lifetime is seven. In some people the episodes begin abruptly and recovery is total; others have a slower onset and a less complete recovery. Drug treatment or electroconvulsive therapy reduces an episode to an average of four months.

Major depression is only one of several depressive disorders; they are classified by the nature of the symptoms, their severity, and the patterns in which they recur. For purposes of diagnosis and treatment the most important distinction is between simple (unipolar) major depression and bipolar disorder, in which major depression alternates with uncontrollable elation, or mania (See *HMS Mental Health Letter*, January and February 1985).

Simple depression also takes a milder, less incapacitating but more chronic form sometimes called dysthymia (from Greek roots meaning a defective or diseased mood). Dysthymia lasts for years and is sometimes hard to distinguish from a personality trait. Up to 25 percent of patients who develop major depression are already suffering from chronic milder depression. In fact, many people with longstanding dysthymia come to medical or psychiatric attention only when they develop symptoms of major depression, and even after they are treated for that, the dysthymia often persists. Cyclothymia (Greek, 'cyclic mood') is the common name for alternating elation and depression which is milder than the symptoms of bipolar disorder. It too is long-lasting and for that reason sometimes appears to be a personality problem.

At one time it was popular to distinguish between endogenous (Greek, 'arising from within') and reactive depressions. Some depressions were said to be generated by internal biological processes, while

others were reactions to personal loss and other disappointing events. The distinction is now passing out of use, because there is no evidence that an episode of depression has different symptoms just because it follows an event like a death in the family or the loss of a job. Now the word 'endogenous' is used without reference to causes, simply to describe a certain set of symptoms: serious weight loss, early awakening, feeling worse in the morning, extreme listlessness to the point of immobility, severe guilt, and inability to feel even a little better for a moment.

'Vegetative' and 'melancholic' are other names for these symptoms. It is unclear whether they constitute a distinct type of depression. Patients with these symptoms are sometimes said to respond particularly well to drugs and electroconvulsive therapy, and better to some drugs than to others. On the other hand, a person often suffers some episodes of depression that have endogenous or melancholic symptoms and some that do not. And there is little evidence that these specific symptoms (as opposed to mood disorders in general) run in some families more than others.

About 15 percent of patients with major depression have psychotic symptoms—usually delusions, but sometimes hallucinations or even a loss of the capacity for coherent thought. It is not clear that psychotic or delusional depression is a distinct type; for example, there is no evidence that it runs in families, and it is not related to age, social status, or external stress. (According to some authorities, however, it responds especially well to certain treatments.) The characteristic delusions are despairing: *I have an incurable illness and I am dying; I am in hell because of my sins; the world has been annihilated and I am alone*. These are known as mood-congruent delusions.

Some patients have another kind of delusion, more typical of schizophrenia: *Creatures from other planets are sending messages through me; thoughts are being inserted into my head from outside; someone is monitoring my thoughts and broadcasting them to the world*. When such delusions are the dominant symptom or arise before the depression, the condition may be called schizoaffective disorder (See *HMS Mental Health Letter*, August 1987). Authorities are unsure whether it is a distinct disorder, and if not, whether it is a form of schizophrenia, a form of mood disorder, or sometimes one and sometimes the other.

Causes of Depression

Heredity is the first source of depression to consider. In families of patients with major depression or bipolar illness, the rate of depression is at least two or three times the average. Twenty-five percent of patients with major depression and up to 50 percent of patients with bipolar disorder have a relative with some form of mood disorder, mild or severe. These families also have a high rate of

various depressive symptoms, as well as other disorders such as anorexia nervosa and agoraphobia with panic attacks. Family transmission is clearest in the case of bipolar disorder. The rate of bipolar disorder in the families of bipolar patients may be as high as 10 percent, which is 10 to 20 times higher than average. A child of two parents with bipolar illness has a 75 percent risk of developing a mood disorder. A patient's family history of mood disorders is often the easiest way to distinguish mania from acute schizophrenia, which has many of the same symptoms.

Family transmission, of course, does not mean genetic transmission. Studies that compare adopted with biological children, and monozygotic (identical) with dizygotic (fraternal) twins are widely recognized means of making this distinction. The hereditary influence is clear in bipolar disorder, but less certain in unipolar major depression. If one of a pair of identical twins has bipolar disorder, there is an 80 percent chance that the other twin will also have bipolar disorder, and nearly 100 percent chance that the other twin will have some mood disorder. The fraternal twin of a person with bipolar disorder is no more likely to have a mood disorder than any other brother or sister of that person. In a study of adopted children who developed bipolar disorder, 31 percent of their biological parents but only 12 percent of their adoptive parents had a mood disorder. Some, but not all, twin and adoption studies have found evidence for the genetic transmission of major depression.

Families genetically vulnerable to bipolar disorder are also vulnerable to unipolar depression, but not vice versa. Although relatives of a person with bipolar disorder have a high rate of unipolar depression, the relatives of a person with unipolar depression have only an average risk of bipolar disorder. This suggests that bipolar illness, the most severe and least common form of mood disorder, requires the strongest genetic predisposition.

Recent gene mapping studies using recombinant DNA suggest that certain families are vulnerable to bipolar disorder because of a single mutation. Among the Amish of Pennsylvania, bipolar disorder occurs in only a few of the family lines or pedigrees. Researchers have now found that in one Amish pedigree, the disorder is associated with certain variations in DNA sequences known as genetic markers, which lie in or near two genes on chromosome 11. One of these genes encodes the production of insulin, and the other is called the *HA-ras* oncogene. In themselves, the markers have nothing to do with psychiatric disorders; they usually have no obvious effect at all. They are inherited along with bipolar illness presumably because they are close to a yet-unidentified site on the same chromosome where a mutation causes a predisposition to bipolar illness. Similar studies in Israeli families suggest that there is also a gene for bipolar disorder lying on the X chromosome between a marker associated with color blindness and one associated with a

deficiency of glucose-6-phosphate dehydrogenase, an enzyme that catalyzes a step in the body's metabolism of sugar.

It is already known that in some families bipolar disorder is not linked either to the markers on chromosome 11 or to those on the X chromosome. Since the disorder affects nearly one percent of the population, other genetic sources for it will probably be found. Meanwhile researchers have been looking at the critical region of chromosome 11 for the precise spot where bipolar disorder originates in the Amish pedigree. One possibility is the gene that codes for the synthesis of tyrosine hydroxylase, an enzyme vital to the production of certain neurotransmitters.

Genetic mapping is useful in many ways. It may allow researchers to identify persons who are at risk for a serious mood disorder and find ways to prevent it. Patients with different underlying genetic abnormalities may have subtly different symptoms or respond to different treatments. Furthermore, not everyone with a hereditary marker actually develops a mood disorder. By comparing those who do with those who do not, either in the same or in different families, researchers can learn more about other causes of depression.

Neurotransmitters

Depression begins with a disturbance in brain and body systems that govern mood and activity levels. Most people regain equilibrium quickly when subjected to everyday stress. For them depression (or elation) is a passing mood. If the stress is too great or a person's adjustment mechanism is unresponsive, the abnormal mood may deepen and persist. The vulnerability sometimes has a genetic basis; more immediately, it may involve a combination of neurochemical imbalances, childhood losses, adult disappointments, and social conditions, in proportions that vary in different cases. Each of these constantly influences the others in ways that make it hard to identify the origin of the disorder; symptoms that look similar may have entirely different sources. For the same reason, many different kinds of treatment are helpful. They break into the circle of interlocking causes and effects at different points: drugs and electroconvulsive therapy at the neurochemical level; psychotherapies at the level of thinking and relations with other people.

At the neurochemical and physiological level, the most important source of evidence is the study of neurotransmitters, the substances that carry impulses between nerve cells. One group of pathways in the nervous system that is closely associated with depression makes use of the neurotransmitter norepinephrine (NE). In NE pathways, the transmitter is released from the end or terminal of one neuron (nerve cell), and passes across a small space (the synaptic cleft) to a receptor site on an adjacent neuron, where it stimulates an electrical impulse. Then

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Depression . . .

some of the NE is reabsorbed into the original neuron and the rest is broken down into smaller molecules (metabolized). The transmitting nerve terminal has its own receptor sites sensitive to NE, and they tell it when to shut down production. In many severely depressed patients, the supply and distribution system is not working properly, and receptors on both sides of the synaptic cleft have become oversensitive or insensitive, responding either not at all or too intensely to changes in the availability of NE. When this poorly functioning regulatory system is put under stress, symptoms of depression may result. Thus, for example, the urine of many depressed patients has an unusually high or low level of 3-methoxy-4-hydroxyphenylglycol (MHPG), a breakdown product of NE.

Antidepressant Drugs

The earliest and still most widely prescribed antidepressant drugs, the tricyclics (imipramine, desipramine, and others) act mainly in NE pathways. Over a period of several days to several weeks, they alter the sensitivity of receptor sites on certain NE neurons, allowing the system to adjust and run more smoothly. The process is called down-regulation; its details are still poorly understood. Other antidepressant drugs also act in NE nerve pathways. The MAO inhibitors suppress the activity of monoamine oxidase (MAO), an enzyme that catalyzes the breakdown of NE in the body. Lithium, used to treat both mania and depression in bipolar disorder, may also affect certain NE neurons.

Another neurotransmitter associated with depression is serotonin, or 5-hydroxytryptamine (5-HT).

Neurons that use 5-HT operate in much the same way as those that use NE. In some depressed patients, especially those who are violently suicidal, the spinal fluid has unusually low levels of 5-hydroxyindoleacetic acid (5-HIAA), a breakdown product of 5-HT. Several studies have found a deficient number of receptor sites for 5-HT in the brains of people who commit suicide. And some newer antidepressant drugs act in pathways that use 5-HT rather than those that use NE.

Because the brain is so complex, the original source of any disturbance is hard to identify; pathways using different neurotransmitters are intricately interconnected and exert constant mutual influence. Some antidepressants affect neither NE nor 5-HT; their mechanism of action is unknown.

To be continued...

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INSIGHTS

Foods, Brain and Behavior: New Links

by Bonnie Spring, Ph.D.

Folk wisdom has accustomed us to the idea that foods can influence behavior. Some of the more widely applied prescriptions are sugar for energy and fish as 'brain food.' These associations happen to be spurious, but other dietary strategies, pioneered by mental health professionals, have shown some value. Many of them arose from efforts to treat mental disturbances that are caused or exacerbated by dietary deficiencies. Certain vitamin supplements are already well established as treatments: folate or vitamin B12 for certain kinds of dementia, thiamine for Korsakoff's syndrome, and niacin for pellagra psychosis. Eliminating food constituents

that exacerbate certain symptoms (such as caffeine in anxiety disorders) is also helpful.

Researchers are now discovering new links between food and behavior that shed light on the neurological basis of eating habits and suggest novel ways to influence mental states. Whether consumed in pure forms or in food, ordinary nutrients may act like psychoactive drugs, altering the manufacture of neurotransmitters, the brain's chemical messengers. Until fairly recently the brain was believed to be immune to all but the most drastic variations in diet because it is protected by the blood-brain barrier, a layer of specialized cells that keeps out many molecules circulating in the bloodstream. But now it has become clear that in order to synthesize neurotransmitters the brain requires precursor substances, dietary raw materials which it cannot manufacture by itself and which obviously cross the blood-brain barrier.

The precursor of the neurotransmitter serotonin, for example, is the amino acid tryptophan, a normal constituent of protein. Pure tryptophan bought at a pharmacy or health food store increases the amount of serotonin manufactured by the brain. Carbohydrate-rich foods also raise brain tryptophan and serotonin levels, in the following way: tryptophan normally competes with certain other amino acids for access to the mechanism that carries them across the blood-brain barrier. Carbohydrates trigger the secretion of insulin, which sweeps these competing amino acids out of the bloodstream and into muscle tissue. With its competition reduced, tryptophan enters the brain in greater quantities and accumulates more. This effect is countered by high-protein, low-carbohydrate foods like meat. Although they contain a small amount of tryptophan, they reduce tryptophan levels in the brain by introducing more competing amino acids. A neutral balance is achieved when the ratio of protein to carbohydrate is one-to-three, as in a bologna sandwich.

Serotonin is abundant in regions of the brain that govern the onset of sleep. Therefore, as might be expected, tryptophan causes drowsiness, and has been used as an aid to sleep. The dose can be kept lower if it is administered along with a high-carbohydrate, low-protein food. Tryptophan also dulls sensitivity to pain, and researchers have found it useful in treating chronic pain. Since some violent patients seem to have a deficiency of brain serotonin, tryptophan might also be useful in reducing aggression.

Sugar and Hyperactivity

Much is now known about the effects of carbohydrate-rich, protein-poor foods, and little support can be found for the common opinion that sugar causes or exacerbates hyperactivity in children. Most experiments show that sugar does not heighten activity levels even in children whose parents think it does. In normal adults, high-carbohydrate meals tend to produce fatigue and drowsiness about two hours after eating, despite a high blood level of glucose; the popular belief that hypoglycemia (low blood sugar) is a major cause of fatigue seems to be mistaken. Several studies also suggest impaired concentration and lowered mental test scores in adults and children after a carbohydrate meal.

Carbohydrate Snacking

Many overeaters prefer carbohydrates to other snack foods, and it is not only because they crave a sweet taste. Although their favorite foods are cake, candy, and similar sugar and fat mixtures, they also like bread and pasta. Patients with seasonal affective disorder (winter depression) and smokers undergoing withdrawal also crave carbohydrates. Rats as well as human beings gain weight during withdrawal from nicotine mainly because they eat more sweet carbohydrate-rich foods.

One recent study compared responses to high-carbohydrate food in two groups of overweight people: those who snacked mainly on carbohydrates and fat; and those who snacked on mixtures of carbohydrate, fat, and protein. After eating carbohydrates, snackers who normally ate protein felt more tired and more depressed; the mood of carbohydrate-and-fat snackers improved. This suggests that some people may have a deficiency in brain serotonin activity which they try to remedy by carbohydrate snacking.

Bulimics (binge eaters) say that their gorging reduces anxiety in the early stages but eventually causes guilt, depression, and a desire to purge. Many report a craving for carbohydrates. It is not clear that they actually prefer carbohydrate-rich foods, or that different foods have different effects on mood during and after a binge.

Tyrosine

Serotonin levels in the brain are reliably increased by tryptophan and carbohydrates. Dopamine (DA) and norepinephrine (NE), the catecholamine neurotransmitters, are a more complicated case. Their precursor is the amino acid tyrosine. Eating tyrosine raises the level of tyrosine in the brain, but not the level of DA and NE—unless nerve cells that use these transmitters happen to be firing rapidly. The conditions that make them fire rapidly, however, are common in psychiatric patients: stress, damage to DA neurons, and the use of antipsychotic drugs that block DA nerve receptors. Tyrosine may aid in preventing or reversing effects of uncontrollable stress. Rats subjected to uncontrollable stress in the laboratory become less active; they also show certain hormonal changes, and the level of NE in their brains becomes lower. All of these effects are reduced by extra tyrosine in the diet. Tyrosine is now being tested on people who are subject to intense or prolonged stress.

Choline and Lecithin

The influence of diet is especially complex in the synthesis of the neurotransmitter acetylcholine (ACh) from its precursor, choline. Pure choline is foul-tasting and foul-smelling. It is found in such foods as liver, soybeans, and eggs in the form of lecithin (phosphatidylcholine), which can also be bought as a nutritional supplement. It is still unclear whether dietary choline or lecithin increases the synthesis of ACh in the brain.

The brain itself also produces choline within its own neuronal membranes. Some researchers have speculated that in Alzheimer's disease and other forms of senile dementia that involve the degeneration of ACh neurons, the brain is cannibalizing its own neuronal membranes. So far, research has not shown that dietary choline or lecithin affects memory in the elderly. But sources of lecithin differ

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New Links . . .

greatly in their proportions of saturated and polyunsaturated fatty acids. Specific types of lecithin used selectively may yet prove to be useful in restoring memory, or at least slowing its loss. Choline has also been used to treat tardive dyskinesia, the movement disorder that results from prolonged use of antipsychotic drugs. Enough patients have shown some improvement to warrant further research.

Some day, unusual eating habits may be used to

diagnose underlying disturbances in brain activity. That would bring us closer to understanding how food intake and brain chemistry influence each other. At present foods are no substitute for drugs in psychiatric treatment, because their effects are weaker. But foods can be selected to keep the dose of a drug lower without losing its benefits. Moreover, a physician tempted to raise the dose of a prescribed drug because it is not working may want to consider first whether the patient's diet is reducing the drug's effect.

Bonnie Spring, PhD, is Professor of Psychology and Director of Clinical Training at Texas Tech. University.

IN BRIEF

Exploring Memory Through Drugs

Many researchers believe there are several distinct kinds of long-term memory, controlled by different brain mechanisms. Episodic memory is the recall of specific events. Semantic or knowledge memory represents experience in a more organized, systematic form, allowing the construction of concepts and the accumulation of factual knowledge. Brain disorders may affect different types of memory differently: for example, Korsakoff's syndrome, a form of amnesia found in some severe alcoholics, affects episodic more than semantic memory.

A recent experiment explores how these mental processes are influenced by the anti-anxiety drug diazepam (Valium®), which is known to impair memory. Ten experimental subjects were each tested twice, once after taking diazepam and once after taking a salt water placebo. First, as a test of attention, they were read a list of words and asked to indicate when they heard a word repeated. Then the experimenters tested their semantic memory by suggesting a conceptual category and asking them to generate a list of words belonging to it. After that they were asked to recall as many words as possible from the first list—a test of episodic memory. Finally, in a test of automatic or incidental episodic memory, they were given another list and asked to pick out the words that they had already heard.

Diazepam impaired attention and episodic memory, often very severely, but it had no effect at all on semantic memory. The same dose that impaired attention also impaired episodic memory of both the incidental and effortful kinds. The authors believe this suggests that attention and episodic memory are neurologically related, and semantic memory is controlled by a different mechanism. They point out that the pattern of memory disorganization produced by diazepam is the same one found in organic amnesias like Korsakoff's syndrome. As further evidence, they note that nerve

endings sensitive to diazepam are highly concentrated in the hippocampus, a brain region believed to be important for episodic memory.

Owen M. Wolkowitz, Herbert Weingartner, Karen Thompson, David Pickar, Steven M. Paul and Daniel W. Hommer. Diazepam-induced amnesia: a neuropharmacological model of an "organic amnesic syndrome." *American Journal of Psychiatry* 144:25-29 (January 1987).

Tics and Compulsions

The symptoms of obsessive-compulsive disorder (OCD) are unwanted, irrational, repetitive thoughts that impel the victim to ward off imaginary humiliations and dangers with meaningless repetitive actions: counting, checking, washing, touching things repeatedly in a certain order or performing certain complicated movements. The symptoms of Tourette's disease are tics (often very elaborate ones) and involuntary speech, especially obscenities and echoes. Tourette's disease and OCD run in the same families and often occur in the same patients, but usually one is regarded as a neurological and the other as a psychiatric disorder. Tics are distinguished from compulsions by the absence of intention.

In a recent study, 16 patients with Tourette's disease were compared to 16 with OCD. Of the Tourette's patients, 10 also had OCD; of the obsessive-compulsive patients, 5 had minor tics and one had Tourette's disease. In both groups tics began earlier than obsessive thoughts and compulsive behavior—at an average age of 8 in the Tourette's patients and 14 in the obsessive-compulsive patients. As compared with a control group of normal persons, both obsessive-compulsive and Tourette's patients had high rates of tics and OCD in their families. Psychiatric symptoms were more common and more serious among the Tourette's patients; for example, only they had a high rate of childhood hyperactivity and self-destructive behavior such as gnashing teeth and tearing hair.

Lack of intention did not always distinguish tics from compulsions. At least half of the patients with OCD could give only vague reasons for their compulsive actions, and tics sometimes seemed partly purposeful. For example, one man whose tic consisted of sniffing in, then out, five times explained that he "did everything by fives"; several patients said that their blinking or throat-clearing tics rid them of irritating sensations. According to the authors, the same genetic predisposition that causes some people to develop tics causes others to develop obsessions and compulsions, and still others to develop both.

Roger K. Pitman, Robert C. Green, Michael A. Jenike, and M. Marsel Mesulam. Clinical comparison of Tourette's disorder and obsessive-compulsive disorder. *American Journal of Psychiatry*, 144:1166-1171 (September 1987).

Smoking and Schizophrenic Patients

According to a study conducted in Montreal, schizophrenic patients who smoke are more likely to develop symptoms of tardive dyskinesia (TD), the disorder of body movement often caused by long-term use of antipsychotic drugs. Among 154 patients taking antipsychotic drugs, 47 of the 85 smokers (54 percent) but only 18 of the 69 nonsmokers (26 percent) had symptoms of TD. Female smokers were taking higher doses of drugs than female nonsmokers; men were taking the same dose of drugs whether they smoked or not. Smokers with TD and smokers without TD did not differ in the amount they smoked or the dose of drugs they took.

TD arises when antipsychotic drugs, by persistently blocking the neurotransmitter dopamine, produce a rebound effect of hypersensitivity in certain regions of the brain. The authors suggest that nicotine may raise the risk of TD by increasing dopamine activity. They note other studies showing that smoking affords some protection against the development of Parkinsonism, a disorder caused by dopamine deficiency. They suggest that drugs known to block the effects of nicotine might help in treating TD.

Ramzy Yassa, Samarthji Lal, Andras Korpassy, and Julie Ally. Nicotine exposure and tardive dyskinesia. *Biological Psychiatry*, 22:67-72 (January 1987).

LETTERS

To the Editor:

Thank you for publishing "The Case Against Deinstitutionalization" in the September issue of *The Harvard Medical School Mental Health Letter*. Would that more professionals presented this viewpoint.

Here in California, as in other states, an effort is being made to foist upon the mentally retarded the same policy that has been such a disaster for the mentally ill. Not only state hospitals, but even facilities in the community serving 50-100 people are being pressured to transfer clients to six-bed homes scattered through the community. This is done in the name of 'normalization.'

My husband and I are the parents of a thirty-five-year-old son who suffered brain damage as a result of premature birth. We would give our souls if he could be made normal, but the sad truth is that no pressure from the state and no longing of ours can change certain realities. We and many other parents of retarded children believe that our sons and daughters can best fulfill their potential, receive the care they need, and live in dignity if they are provided with a protected setting. For this view we are often criticized as 'selfish,' 'traditionalist,' 'stay-putters,' who are out of touch with 'progressive' thinking. We hear that we are part of the problem. We are even told that retarded people are entitled to the 'dignity of risk,' because risk is part of 'normal' life. We are also assured that experts agree on the desirability of deinstitutionalization. Of course that is not true, but published dissent is hard to come by. Hence our great appreciation of this article.

Juliette L. George
Stanford, California

To the Editor:

I read with interest the debate on deinstitutionalization beginning in the September, 1987 issue of *The Harvard Medical School Mental Health Letter*. Dr. Gralnick and Dr. Okin are excellent advocates, and I applaud your interest in looking at both sides of the issue.

I agree with Dr. Gralnick that both hospital and community mental health services are underfunded; I do not agree that "[patients'] suffering in our communities shows that deinstitutionalization has failed." Dr. Gralnick writes as though deinstitutionalization were all or nothing, right for all or wrong for all. In fact, many patients are doing fine in the community. Furthermore, we must discuss future policies, not past disagreements. The issue is not whether deinstitutionalization *was* right or wrong. People with severe mental illnesses are in our communities, and putting them back into hospitals for long periods of time is not feasible fiscally, politically, legally, or morally. We must address the needs of these people where they live now, by providing affordable housing, real jobs, 'normal' social activities, inexpensive medical care, case management, and mental health professionals who are trained to deal with chronic and severe mental illness.

Dr. Pamela Hyde, Director
Ohio Department of Mental Health
Columbus, Ohio

Determining Suicide Risk

What is the best way to determine the danger of suicide in a patient admitted to a hospital? We asked John T. Maltzberger, MD, Lecturer in Psychiatry, Harvard Medical School and Massachusetts General Hospital. He is the author of *Suicide Risk: The Formulation of Clinical Judgment*, New York University Press, 1986.

Clinicians must decide whether to admit suicidal patients to a mental hospital or send them home. They also have to decide whether to discharge hospitalized patients or hold them, and whether to warn others or not. Many clinicians base these decisions almost entirely on the patient's current mental state. In a long-term study of suicide and suicide attempts, my colleagues and I have shown the danger of that.

Most mental health professionals know that some patients mask serious depression with smiles and false cheer. Not all know that even in someone who is obviously severely depressed, *improvement* in mental state sometimes heightens the risk of suicide, because the patient is no longer paralyzed by misery. It is also easy to overlook the fact that many patients who commit suicide are not suffering from severe mood disorders. Among psychiatric inpatients, most suicides are schizophrenic; in general hospitals, some suicides are in a state of delirium from alcohol or other causes. Persecutory psychoses of all kinds may culminate in suicide: some patients kill themselves to escape imaginary enemies, others in response to hallucinated commands. And even if the psychosis clears, it may be followed by suicidal despair.

In judging the danger of suicide, mental health professionals should consider the clinical history before the patient's mental state. Psychiatric inpatient departments often fail to do this adequately because they concentrate on short-term care. Many tend to treat everyone alike, working toward early discharge unless a patient is so obviously disturbed or so explicit about suicidal intentions that continued supervision is plainly necessary.

One reason for this error is that so many inpatients are now given the diagnosis of borderline personality disorder. Although such patients often threaten or attempt suicide, they are notoriously difficult to treat in mental hospitals, and ordinarily should not be kept there long. Yet misdiagnosis or incomplete diagnosis is common in these cases. Many have mood disorders (major depression or bipolar disorder) instead of, or in addition to, borderline personality. For such patients a brisk discharge after a short stay may be dangerous; at least half of all successful suicides suffer from mood disorders. The demanding, provocative behavior that seems characteristically borderline may in fact be a sign of agitated depression. Patients suffering from symptoms compatible with the diagnosis of a major depressive episode should be handled cautiously even if they are formally diagnosed as schizophrenic, alcoholic, or borderline personalities. The danger is greatest when they are deluded or hallucinating.

Clinicians should also keep in mind that outside support helps suicidal patients to ward off murderous rage and feelings of loneliness, guilt, and worthlessness. Thus their mental state often improves in a hospital or clinic, where other people are present to help them—professionals, students, and other patients. If they are discharged because of that improvement, they lose the support and may quickly become suicidal again. Lack of external support is one of the best reasons for admitting suicidal patients to a hospital; for the same reason, they should usually not be discharged until they have established relationships to sustain them outside the hospital.

The type of support required depends on the patient's history. Some rely on family or friends, others on fellow workers or even on pets. Some use work itself rather than other people to sustain their self-esteem. Their capacity to excel at a task they value gives their lives meaning, despite isolation and doubts about their worth. Because depression interferes with work even more than with personal relationships, it is especially dangerous for these patients. They often have to be hospitalized when they fail at work, and discharge may be unsafe until they have a reasonable guarantee of a satisfactory job.

The goal of this Mental Health Letter is to interpret timely mental health information but its contents are not intended to provide advice for individual problems. Such advice should only be offered by a person familiar with the detailed circumstances in which the problem arises. We are interested in comments and suggestions about the content; unfortunately, we cannot respond to all inquiries.

Please address editorial inquiries only to: The Harvard Medical School Mental Health Letter, 74 Fenwood Road, Boston, MA 02115. Individual subscriptions \$39 annually, single copies \$4 each. Bulk subscriptions at reduced rates are available upon request. For subscription inquiries and orders write to: The Harvard Medical School Mental Health Letter, P.O. Box 885, Farmingdale, NY 11737. For Customer Service only call toll-free 1-800-227-5782.

Wechsler Memory Scale - Russell Revision - 1987 Scoring System

- I. Logical Memory Please read the following instructions to the patient:

"I AM GOING TO READ YOU A LITTLE SELECTION OF ABOUT FOUR OR FIVE LINES. LISTEN CAREFULLY BECAUSE WHEN I AM THROUGH, I WANT YOU TO TELL ME EVERYTHING I READ TO YOU. ARE YOU READY?"

After reading Paragraph A, say,

"NOW, WHAT DID I READ TO YOU? TELL ME EVERYTHING AND BEGIN AT THE BEGINNING."

Record verbatim everything that the patient says to you.

After the first selection is completed, say,

"NOW I'M GOING TO READ YOU ANOTHER LITTLE SELECTION AND SEE HOW MUCH MORE YOU CAN REMEMBER ON THIS. LISTEN CAREFULLY."

After reading paragraph B, record verbatim what the patient says.

Scoring of Logical Memory - Immediate Memory

1. Please refer to appendix #1 for description of which words will receive points. Follow this appendix very carefully, giving one point to only those content units that are described.
2. Add together the total number of units recalled on paragraph A, plus the total number of units recalled on paragraph B. This will yield the Total Raw Score.
3. These raw scores will then receive an age and education correction. You can look up the age and education correction on Table 2. Add this correction factor to the raw score.
4. Take the corrected score and look up the scaled score (rating) on Table 3. This will yield the Corrected Score Rating.
5. On Table 3, also look up the Percentage of Normal Score.

II. Visual Reproduction subtest - Immediate Memory

1. The following instructions are used:

"I AM GOING TO SHOW YOU A DRAWING. YOU WILL HAVE JUST 10 SECONDS TO LOOK AT IT; THEN I WILL TAKE IT AWAY AND LET YOU DRAW IT FROM MEMORY. DON'T BEGIN TO DRAW UNTIL I SAY, GO. READY?"

After exposing the card, card A for ten seconds, say,

"NOW DRAW IT, GO."

The same instructions are used for drawing #B.

For drawing #C, the instructions are:

"HERE IS ONE THAT IS A LITTLE HARDER. THIS CARD HAS TWO DRAWINGS ON IT. I WANT YOU TO LOOK AT BOTH OF THEM CAREFULLY - AGAIN YOU WILL HAVE ONLY TEN SECONDS TO LOOK AT THE CARD, THEN I WILL TAKE IT AWAY AND LET YOU MAKE BOTH DRAWINGS; THE ONE ON THE LEFT SIDE HERE (pointing to the space in which the subject is to make the drawing) AND THE RIGHT ONE HERE (pointing). READY?". Expose Card C for ten seconds, etc.

2. Please refer to appendix 2 for the scoring criteria. Please make special note of the sample drawings that are included. After following the scoring criteria listed in appendix 2, do the following: add up the total number of points for design A plus B plus C-1 plus C-2. This will give you the Total Raw Score.
3. Take the total raw score and correct it for age and education by referring to Table 2. This will give you the Corrected Score.
4. Turn to Table 3 and look up the corrected score and give it a scaled score (rating) .
5. Also look up the "percentage of normal."

III. Logical Memory - One-half hour delay

1. Thirty minutes after doing the Immediate Memory testing, say to the patient,

"I ASKED YOU A WHILE AGO TO REMEMBER SOME STORIES. I WOULD NOW LIKE YOU TO TELL ME THE FIRST STORY THAT I READ TO YOU." If the patient cannot remember the first story, say,

"DO YOU REMEMBER A STORY ABOUT A WASHERWOMAN?" At that point, copy verbatim everything the patient says. Then ask if s(he) can remember the second story. Copy verbatim what the patient says. If the patient cannot remember the second story, prompt him/her with:

"IT'S A STORY ABOUT A SHIP."

2. Then score each story up individually according to the criteria listed above, except the item used to prompt the subject is not included in the score. Subtract one point for each prompt for each story that is used.
3. Take the total number of points remembered from paragraph A and add it together with paragraph B, yielding a total raw score. Then take the total raw score and correct it for age and education by referring to Table 2, Verbal Memory, half-hour delay.
4. Take this corrected score and look up the rating on Table 3 and you get a rating for the corrected score. Also on Table 3, look up the (percentage of normal).
5. Then you need to derive a Percentage Retained Score. To do this, take the delayed corrected score and divide it by immediate corrected score times 100 to come up with a percentage.
$$\frac{\text{Delayed Corrected Score}}{\text{Immediate Corrected Score}} \times 100$$
6. Then return to Table 2 and correct for this percentage retained by looking at the age and education correction, take that corrected score and return to Table 3.
7. On Table 3, using the newly corrected percentage retained score, now look up the Corrected Percentage Retained Score on Table 3. Give this Corrected Percentage Retained Score a rating.

IV. Visual/Spatial Reproduction - Delayed Memory

After a half an hour of having shown the patient the Visual/Spatial designs, then say to the patient,

"A WHILE BACK I HAD YOU DRAW ME SOME DRAWINGS.
I WOULD NOW LIKE YOU TO DRAW ME FIGURE #1 IN THIS
SPACE HERE."

If the patient does not remember design A, prompt with,

"IT LOOKED LIKE FLAGS." Then go on to drawing B and say to the person,

"DO YOU REMEMBER THE DRAWING THAT FIT IN THIS SPACE?"

If the patient does not remember, then prompt with

"IT LOOKED LIKE SQUARES." Then go on to design C; if the patient does not remember, prompt with

"DO YOU REMEMBER ANOTHER DESIGN THAT LOOKED LIKE FLAGS?"

"DO YOU REMEMBER ANOTHER ONE THAT LOOKED LIKE
RECTANGLES?"

Scoring of Visual Reproduction Delayed Memory

1. Score using the scoring criteria outlined in the appendix #1
2. Deduct one point each time a prompt is used.
3. Add together the total number of points from designs A plus B plus C-1 plus C-2, subtracting the prompts that are used, from the total raw score.

4. Correct this raw score by referring to Table 2. Once you have corrected this raw score, go on to Table 3 and look up the scaled score (rating) for this corrected score.
5. Also record the Percentage of Normal Score.
6. You then need to derive the "percentage retained." To do this, you need to divide the Delayed corrected score by the Immediate corrected score times 100.
7. After doing this, return to Table 2 and correct this percentage retained by age and education norms listed.
8. Then turn to Table 3 and look up the percentage retained rating.

Additional Reminders

1. Remember, any Raw memory score of 0 is not corrected at all.
2. If you have both the person's education and IQ, then use the higher number for the correction unless you have a strong clinical reason for doing it otherwise. For example, let's say this is someone with a ninth grade education and they have a 120 IQ. Use the information from the 120 IQ to correct the raw scores.
3. Other additional points are that occasionally on a Visual Reproductions subtest, people will remember the designs but place them in the wrong box. Do not deduct any points for incorrect placement.

General concept: SC vs
Classification^{of} HV Detection: Cline

Jim,

Here is a rough draft of the article I've been working on.
The Discussion section is not yet completed. It
needs a considerable amt. of work in terms of
integrating the results.

Let me know what you think,
Alicia

P.S. Also, some of what is in the Discussion section
might really belong in the Intro.

METHODS

Over a period of one year, 33 patients with the diagnosis of either AIDS or AIDS-Related Complex were referred for neuropsychological evaluation to the Neuropsychology Service at San Francisco General Hospital. Fifteen patients (45%) were referred from the inpatient AIDS unit, 13 patients (39%) were referred from a locked psychiatric unit at SFGH and 5 patients (15%) were referred from the SFGH AIDS Outpatient Medical Clinic ~~or from private practitioners~~. Referral questions tended to cluster ^{ed} around three main issues: 13 referrals (39%) were for evaluation of HIV dementia versus a functional psychiatric disorder, 11 referrals (33%) were for evaluation of a psychotic process, specifically to evaluate for Bipolar Disorder versus Organic Affective Disorder and 9 referrals (27%) were non-specific with a general request to evaluate neuropsychological status. (7) ^{clinical} status suggested ^{neuro} ^{SS}.

Each patient was given a clinical interview and was administered neuropsychological screening measures sensitive to: fine motor speed; verbal fluency; attention and concentration; memory and problem-solving skills. It was our experience that the majority of patients fatigued easily, thus making it necessary that a limited, brief and focused testing approach be utilized.

Instruments selected included: Trail-Making Test (TMT); Wechsler Memory Scale-Russell Revision (WMS); Finger-Tapping Test (FTF); Controlled Oral Word Association Test (COWAT) and Shipley Institute of Living Scales (SILS). In addition, the nursing staff and treating physicians were interviewed regarding their observations of the patient. Medical charts were also reviewed, with particular attention to neurological signs, symptoms, medical and psychiatric history and ^{degree of} any ^{present} psychiatric symptoms noted.

Because the question of Bipolar Disorder versus Organic Affective Disorder was raised in 33% of the cases, the criteria for secondary mania, suggested by Krauthammer and Klerman (1) was considered. This criteria is as follows: "A psychiatric disorder following medical, pharmacologic or other organic dysfunction, lasting at least one week, and characterized by an elated and/or irritable mood and by behavior showing at least two of the following features: hyperactivity; pressured speech; flight of ideas; grandiosity; decreased sleep; distractibility and lack of judgment. Exclusionary criteria are: 1) a clear previous history of manic depressive or other affective disease, or 2) the co-existence of the manic syndrome with any symptomatology of confusional states."

RESULTS:

Information regarding demographic characteristics, risk factors and medical diagnosis for both the AIDs and the ARC groups is shown in Table 1. As summarized in Table 1, the age, educational levels, risk factors and length of time since diagnoses in both the AIDS group and ARC group were similar. Table 1 also summarizes the psychiatric history of all patients, both for themselves, as well as for their family of origin. "No psychiatric history" was defined as, "no previous history of psychiatric hospitalizations, no previous history of psychosis, no previous history of having been treated with antipsychotic medications." As Table 1 indicates, 88% of the patients had no history of major psychopathology for themselves and 81% of the sample had no history of major psychopathology ^{IN} for their family of origin.

or Major Mood
Affective Ill-
ness

Neuropsychological Deficits:

On the brief neuropsychological screening battery that was administered to the subjects, all subjects demonstrated impairment in at least one area. (See Table 2.) Particularly striking was the pattern of memory deficits identified. The Russell Scoring System was utilized. This scoring system helps to define not only the presence of memory impairment, but ^{also} the degree of impairment, as well. On an immediate verbal basis, 91% of all subjects demon-

strated impairment on immediate verbal memory, with 13% demonstrating mild impairment, 26% demonstrating moderate impairment and 22% demonstrating marked impairment and 30% with severe impairment. On 30 minute delayed verbal memory testing, 100% of the subjects were impaired. In addition to a greater percentage of patients being impaired on ^{this} the delayed memory task, the patients also demonstrated more severe impairment, with 6% having mild impairment, 18% moderate impairment, 41% having marked impairment and 35% having severe impairment. Delayed memory testing would appear to be more sensitive than immediate memory tests in detecting early memory impairment in AIDS spectrum patients. In addition, on the delayed memory task subject performance improved when provided with cues and prompting, suggesting greater difficulty in the retrieval of information rather than in the initial encoding and storage of information. On Trail-Making Test, Part B, a measure that taps into attention, concentration, speed of mental operations and visual/spatial scanning abilities and mental flexibility, 77% of all subjects were impaired. In addition to being slow on this task, 69% of the subjects also demonstrated shifting errors consistent with difficulty with mental flexibility. Relatively unimpaired was the Shipley Vocabulary IQ with the mean IQ for subjects computed to be 110 (bright normal range of intelligence). This is not surprising

since this vocabulary measure tends to be fairly robust in the face of cerebral dysfunction and ^{is generally seen to be a} ~~this~~ may be a good indicator of premorbid IQ. In contrast to ^{the} ~~this~~ vocabulary IQ is the Conceptualization Quotient of 76, which ^{Can we reference this?} ~~is suggestive of~~ impairment and deterioration in abstract reasoning abilities relative to the patients' expected premorbid intellectual status. Fine motor speed impairment was found in 66% of the subjects. Verbal fluency (as measured by the COWAT) was impaired with more than 50% of the subjects falling below the 35th percentile. This, of course, is much lower than would be expected in a well-educated group of patients. Interestingly ^{enough}, while rate of speech and the generation of a list of words on command in this sample was slower than would be expected, none of the subjects demonstrated obvious expressive speech problems during the course of normal conversation. ^{Anomic}.....tendencies were not evident.

Of particular interest was whether the individuals with AIDS versus ARC would differ in terms of the presence of impairment on the various cognitive measures. While the majority of subjects in both groups were impaired on most of the measures used, a higher percentage of impairment in the AIDS group was consistently revealed. Significant differences between the two groups on some of the cognitive measures were found. These are presented in Table 3. These results seem to suggest greater impairment on some

ARC definition

measures of speed in mental operations (TMT Part A), greater disruption of basic language skills on verbal fluency (COWAT) and greater impairment in abstract reasoning abilities for individuals with a diagnosis of AIDS. There were no significant differences between the groups on measures of delayed memory, fine motor speed or mental flexibility.

Psychiatric Symptoms:

Psychiatric symptoms that were noted in the patients' medical chart are summarized in Table 4. Depression was noted in the charts of 76% of the sample, with anxiety in 64%, impulsivity, poor judgment and emotional lability were frequently seen as well. Auditory hallucinations and flight of ideas were identified less frequently. The overall impression is that one or more psychiatric symptoms were noted in the charts of all patients.

Secondary Mania:

While psychiatric symptoms such as depression and anxiety are commonly found in individuals with terminal illnesses, some additional psychiatric symptoms were seen to be occurring with greater frequency than would have been expected, especially given the relative lack of psychiatric history in the majority of patients. These symptoms included the presence of hyperactivity, grandiosity, delusional thinking, euphoria, paranoia, circumstantial thinking, impulsivity and agitation. Ten patients

(30%) in the sample met the criteria for secondary mania as defined by Krauthammer and Klerman. ~~This subgroup of patients~~ ^{were} with secondary mania ~~was~~ significantly better educated, but did not differ on other demographic characteristics, nor were there significant differences between those patients with an AIDS diagnosis versus an ARC diagnosis. There was a positive correlation between secondary mania and length of time since receiving either a diagnosis of AIDS or ARC. Overall, the subgroup of patients with secondary mania did not differ significantly from the rest of the sample in terms neuropsychological functioning. However, on a few of the neuropsychological measures, the secondary mania group was significantly more impaired. This impairment was demonstrated on TMT Part B, fine motor speed, and verbal fluency. Not unexpectedly, psychiatric symptoms did differentiate the two groups. All significant differences are presented in Table 5.

DISCUSSION

Given the particular selection factors involved in this sample, the results obtained are not viewed as either comprehensive or easily generalizable. However, the consistency of findings across patients with either AIDS or ARC, who were referred from multiple sources, and who evidenced varying degrees of severity would suggest that the essential neuropsychological and psychiatric features present in this sample represent important elements of the HIV dementia complex.

Need a Transition sentence here

Neuropsychiatric Syndrome of HIV Dementia

Navia and Price () in their autopsy series of 70 patients with AIDS, concluded that at the time of death, ^{90%}~~70%~~ of the patients had clear evidence of HIV dementia on brain autopsy. Specifically, they ^{reported}~~found~~ abnormalities in the white matter and in the subcortical structures, particularly the basal ganglia and the thalamus, with a relative sparing of the cortex. These pathology results led Navia and Price to conclude that the HIV dementia might best be characterized as a subcortical dementia. Subcortical dementia is typically described as a clinical syndrome characterized by cognitive and motoric slowing, disturbance in attention, concentration and memory, difficulty with complex problem-solving and disturbance of mood and affect. () The constellation of cognitive ^{motor}~~deficits~~ found in this ^{present}~~sample~~ are all symptoms consistent with ~~the~~ subcortical dementia. Particularly striking ~~in this sample~~ is the slowness found on fine motor tasks, as well as generalized slowing on all cognitive measures. This, of course, is in contrast to the cortical dementias, such as Alzheimer's, which tends to manifest "normal psychomotor slowing speed throughout most of the clinical course ()." Beyond simple motoric slowing, motor system dysfunction is typically found in the subcortical

dementias, with predominant extrapyramidal symptoms often being present: bilateral hand tremors; dystonias; choreoform movements; dysmetria; myoclonic jerking; etc. It has now been well-documented, that AIDS spectrum patient typically complain of bilateral leg weakness, poor coordination, ataxic gait and bilateral hand tremors (). In fact, in this present study ~~---~~ subjects presented with bilateral hand tremors and ~~---~~ subjects were noted to have evidence of severe myoclonic jerking of the upper extremities, again lending support to an underlying subcortical etiology.

The pattern of memory deficits exhibited in this study appears to have both practical and theoretical implications. While mild immediate memory impairment was readily observed in the majority of patients, it was, ~~in fact~~, on 30 minute delayed memory conditions that virtually all subjects were impaired, ~~and~~ with 76% of the sample demonstrating marked to severe impairment. Traditional mental status exams do not explore for this type of memory dysfunction, and as a result may underestimate serious memory pathology in AIDS spectrum patients. The ability of patients in the study to be aided by memory cues, may, in fact, be another distinguishing feature of a subcortical dementia versus a cortical dementia. Typical memory problems in the cortical dementias are "a

product of encoding failure and are aided little by recall facilitation strategies ()." The commonly revealed disorders of language seen in broad spectrum dementing illnesses, such as Alzheimer's, has⁴ in part, been associated with word-finding problems, and the development of language comprehension deficits. On the other hand, subcortical dementia⁵ such as Huntington's chorea and Wilson's disease, have been noted to have an important lack of such cognitive difficulties.() In this sample of AIDS spectrum patients, specific language comprehension problems were rarely identified and word-finding deficits were not seen on clinical interview. Slowness on verbal fluency was apparent, but given the pattern discussed to this point, this specific difficulty appears to be associated with generalized slowing of all cognitive processes, rather than representing a specific language disorder per se.

Summary statement needed here.

Secondary Mania

A subset of patients in this present series demonstrated a constellation of psychiatric symptoms consistent with secondary mania. Grandiose delusions, euphoria and irritability were especially common.

wp/hi/#47

Jim,
I will be tying the 2^o Mania section in
to Research on Mania & Subcortical
Dementias
- where do we go from here?

Table 1 Background Data and Medical Diagnosis of AIDS & ARC Patients

Patient Data	AIDS (n=19)	ARC (n=14)
Age Range (Mean)	25-50 (37)	24-54 (35)
Sex	19 males	14 males
Education	14 years	14 years
<u>Risk Group:</u>		
Homosexual or Bisexual	16 (84%)	12 (86%)
Homosexual & IVDA	2 (10%)	2 (14%)
Unknown	1 (5%)	0 (0)
<u>Length of Time Since Diagnosis:</u>		
0 - 3 mo.	8 (42%)	5 (36%)
4 - 6 mo.	3 (16%)	3 (21%)
7 - 12 mo.	5 (26%)	4 (29%)
13 - 24 mo.	1 (5%)	2 (14%)
greater than 24 mo.	2 (20%)	0 (0)
<u>Criteria for AIDS Dx:</u>		
PCP only	11 (58%)	-
PCP & ks	2 (20%)	-
PCP & other	3 (16%)	-
Other AIDS Dx (MAI, ITP Systemic CMV)	3 (16%)	-
<u>Psychiatric History</u>		
No Psychiatric History	18 (95%)	11 (79%)
Schizophrenia	0 (0)	1 (7%)
Depression	1 (5%)	0 (0)
Drug Induced Psychosis	0 (0)	2 (14%)
<u>Psychiatric History in Family</u>		
No Psychiatric Hx	14 (74%)	13 (93%)
Depression	1 (5%)	0 (0)
Alcohol or Substance Abuse	4 (21%)	1 (7%)

Table 2 Neuropsychological & Neurological Test Findings
for All Subjects

Procedure	% of Subjects Impaired
TMT, Part A	74%
TMT, Part B	77%
WMS Verbal Imm.	91%
WMS Imm. Visual Reproduction	68%
WMS Delayed Verbal	100%
WMS Delayed Visual Reproduction	76%
Finger-Tapping Test	66%
CT Scan	45%

Procedure	$\bar{X}$	SD
COWAT Percentile	45	30.56
Shipley Vocabulary IQ	110	8.73
Shipley Conceptual IQ	76	16.27

Table 3 Differentiating Instruments: AIDS vs. ARC

Differentiating Tests	AIDS		ARC		
	X	S.D.	X	S.D.	
TMT, Part A Rating	3.5	1.3	2.2	1.5	*
COWAT Percentile	16.5	12.2	66.0	21.0	**
Shipley VOC IQ	103.80	7.4	117.0	1.15	**
Shipley CQ	64.6	6.7	89.50	13.6	**

t test * p <.05
 ** p <.01

Table 4 Frequency of Psychiatric Symptoms Noted for All Subjects

<u>Symptom</u>	<u>% Impairment</u>
Depression	68 76
Anxiety	47 64
Angry Outbursts	20 37
Emot. Lability	41 61
Circumstantial and Tangential Thinking	19 37
Visual Hallucinations	25 27
Auditory Hallucinations	0 13
Hyperactivity	24 30
Agitation	32 41
Grandiosity	16 22
Impulsivity	58 67
Pressured Speech	22 32
Flight of Ideas	11 16
Euphoria	32 25
Irritability	32 48
Delusional Thinking	26 29
Poor Judgment	67 62
Paranoia	21 28

Table 5 Differentiating Variables: Group I (Secondary Mania) vs.
Group II (Other)

Differentiating Variables	Group I		Group II	
	X	S.D.	X	S.D.
Education (years)	16.1	1.9	13.3	2.4
TMT B (seconds)	262.6	172.6	131.1	99.2
COWAT Percentile	8.0	11.3	50.8	28.4
Finger Tapping Test				

AIDS/ARC DEMOGRAPHIC INFORMATION

N = 33

Age: $\bar{x}$ = 36 (Range 24 to 54)

<u>Education</u>	<u>N</u>	<u>%</u>
College Grad. or Beyond	11	35
Some College	11	35
High School Grad.	6	19
Less Than High School	3	10

] 71

Racial Group

Caucasian	26	79
Black	5	15
Latino	1	3
Asian	1	3

AIDS/ARC DEMOGRAPHIC INFORMATION

N = 33

<u>Risk Group</u>	<u>N</u>	<u>%</u>
Gay Male	28	85
Both Gay Male and IVDA	4	12
No Known Risk Group	1	3
<u>Diagnosis</u>		
AIDS	19	58
ARC	14	42

AIDS DEMOGRAPHICS

N = 19

<u>AIDS Diagnosis</u>	<u>N</u>	<u>%</u>
PCP Only	11	58
PCP and KS	2	11
PCP and Other	2	11
CNS Infection	1	5
Other AIDS Dx	3	16

<u>Length of Time Since AIDS Diagnosis</u>	<u>N</u>	<u>%</u>
0 to 3 mos.	8	42
3 to 6 mos.	3	16
7 to 12 mos.	5	26
13 to 24 mos.	1	5
25 to 36 mos.	1	5
More than 36 mos.	1	5

ARC DEMOGRAPHICS

N = 14

<u>Length of Time Since ARC Diagnosis</u>	<u>N</u>	<u>%</u>
0 to 3 mos.	5	36
3 to 6 mos.	3	21
7 to 12 mos.	4	29
13 to 24 mos.	2	14

AIDS/ARC DEMOGRAPHICS

N = 33

<u>Psychiatric History</u>	<u>N</u>	<u>%</u>
No Psychiatric History	29	88
Schizophrenia	1	3
Depression	2	6
Drug Induced Psychosis	1	3

<u>Psychiatric History In Family</u>		
No Psychiatric History	25	81
Depression	1	3
Alcohol or Substance Abuse	5	16

AIDS/ARC Test Findings & Psychiatric Symptoms

NEUROPSYCHOLOGY TEST FINDINGS

PSYCHIATRIC SYMPTOMS

Percentage of subjects impaired		% imp.	
Trail Making A	74	Depression	76
Trail Making B	77	Anxiety	64
WMS - Imm. Verbal	91	Angry Outbursts	37
WMS - Delay Verbal	100	Emot. Lability	61
WMS - Imm. Vis. Sp.	78	C + T Thinking	37
WMS - Delay Vis. Sp.	82	Visual Hall.	27
Motor Speed - Dom. Hand	60	Auditory Hall.	13
Motor Speed - Non Dom. Hand	47	Hyperactivity	30
CT Scan	45	Agitation	41
		Grandiosity	22
		Impulsivity	67
		Pressured Speech	32
		Flight of Ideas	16
		Euphoria	25
		Irritability	48
		Confusion + DisOr.	45
		Delusional Thinking	29
		Poor Judgement	62
		Paranoia	28

	x	sd	
COWAT %ile -	45	30.56	= 92 IQ
Shipley Vocabulary IQ -	110	8.73	
Shipley Conceptual IQ -	76	16.27	
Shipley Full Scale IQ -	106	10.86	

N = 33

50% of people fell below 35 IQ → 85 IQ