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#### Social Support

Low	Moderate	High
Good support, stable committed relationships;	Some relationships; commitment to patient	No support or unstable relationships
caregiver(s) able to provide assistance	tentative; emotional or geographical factors	

#### Financial/Insurance

Low	Moderate	High
Stable access to health care( insurance); work	Limited resources and insurance; good	Very limited access to health
history; good resources; adequate income to	cognitive ability to problem solve; motivation	care/medications; limited cognitive ability to
meet needs	to seek employment post-transplant/remain	problem solve; no work history; inadequate
	employed; limited income to meet needs	income to meet needs

#### Compliance

Low	Moderate	High
Good understanding of medical situation; hx	Struggles with understanding of medical	Unable to self-manage; caregiver not available
of good follow through on medical	situation; reports of non-compliance;	or unreliable; avoids medical treatment; high
recommendations; ability to self-manage; able	questionable ability to self-manage; needs	risk behaviors;
to manage meds and tx plan	assistance to manage meds and treatment	

#### **Functional Status**

Low	Moderate	High
Active; exercises; independent	Requires partial care; uses assistive device for mobility/hearing; vision loss	Requires assistance with ADLs; sedentary; dependent; current health issues that impact QOL

#### **Cognitive Function**

Low	Moderate	High
No evidence of cognitive decline/memory	Current (or history of) mild mental	Moderate to severe mental retardation OR
deficits; executive functions (ability to	retardation/ impairments in adaptive	frank dementia or severe cognitive
organize and follow through with new	functioning, with/out alternative/adaptive	impairment; unable to self-manage; caregiver
information) seem intact; no current/historical	learning plans, such as IEP; OR mild	not available or reliable; resides in nursing
mental retardation/impairments in adaptive	cognitive/memory deficits; questionable	facility, or would require long-term care post-
functioning; no current or historical	ability to self-manage, needs some assistance	txp to manage post-txp routine.
alternative/adaptive learning plans, such as	or supervision to manage meds and	
IEP	treatment; caregiver available and capable.	

#### Mental Health

Low	Moderate	High
No current or past hx of mental illness;	Past hx of mental illness	Active, untreated mental illness
No current symptoms Intact mental status	Current tx for mental illness, symptoms well managed	Chronic recurrence of mental illness Non-compliance with tx
No family hx of mental illness	Compliance with past treatment	Altered mental status
No past abuse, neglect, loss, or other trauma	Treated/resolved hx of abuse, neglect, loss or	Untreated hx of abuse, neglect loss, or other
	other trauma	trauma
		Anti-social behavior (recurrent legal issues)

#### Coping

Low	Moderate	High
Identifiable healthy coping skills	Presence of some healthy coping mechanisms	No identifiable healthy coping mechanisms
Hx of coping well with stress	Hx of occasional difficulty coping with stress	Presence of unhealthy coping mechanisms
Insightful, able to identify needs and seek		Strong hx of difficulty coping with stress
assistance		

#### Substance Abuse

Low	Moderate	High
No use or limited use of alcohol	Hx of abuse or dependency of alcohol or drug	Alcohol or drug dependency within past 6
No drug use, including tobacco	Abstinence greater than 6 months; some	months
No evidence of hx of abuse/dependency	involvement in treatment; some insight	Recent dependency without SA treatment /
	Hx of legal or other serious consequences	lack of insight
	related to substance abuse	Recent legal or other serious consequences
		related to substance abuse

#### Legal Issues

Low	Moderate	High
Never any legal issues	Unresolved/pending legal issues; previous DUI	previous incarceration; pending incarceration

#### Understanding of transplant process

Low	Moderate	High
Realistic; aware of risks and benefits	Some knowledge gaps or denial; generally	Unrealistic; little understanding of transplant
	good understanding	as a treatment

#### Motivation for transplant

Low	Moderate	High
Self-motivated for transplant as part of	Uncertain of desire for transplant; shows little	Applied for transplant because of others
continuum of care	motivation	interest in transplant; not motivated

## • <u>ADLQ rating tool</u>

### ADLQ

Instructions: Circle one number for each item

#### SELF-CARE ACTIVITIES

#### 1. Eating

- 0. No problem
- 1. Independent, but slow or some spills
- 2. Needs help to cut or pour; spills often
- 3. Must be fed most foods
- Don't know

#### 2. Dressing

- 0. No Problem
- 1. Independent, but slow and clumsy
- 2. Wrong sequences, forgets items
- Needs help with dressing
- 4. Don't Know

#### 3. Bathing

- 0. No problem
- 1. Bathes self, but needs to be reminded
- Bathes self with assistance
- 3. Must be bathed by others
- Don't know

#### 4. Elimination

- 0. Goes to bathroom independently
- 1. Goes when reminded; some accidents
- 2. Needs assistance with eliminations
- 3. Has no control over either bowl or bladder
- 4. Don't know

#### 5. Taking pills or medicine

- 0. Remembers without help
- 1. Remembers if dose is kept in a special place
- 2. Needs spoken or written reminders
- 3. Must be given medications by others
- 4. Does not take medications or don't know

#### 6. Interest in personal appearance

- 0. Same as always
- 1. Interested if going out, but not at home
- 2. Allows self to be groomed, or does so on request
- Resists efforts of caretaker to clean and groom
- 4. Don't know

#### HOUSEHOLD CARE

- 7. Preparing meals, cooking
  - 0. Plans and prepares meals without difficulty
  - 1. Some cooking, but less than usual, less
    - variety
  - 2. Gets food only if it's already been prepared
  - Does nothing to prepare meals
  - 4. Never did this activity or don't know

#### 8. Setting the table

- 0. No problem
- 1. Independent, but slow or clumsy
- 2. Forgets items or puts them in wrong place
- 3. No longer does this activity
- 4. Never does this activity or don't know

#### 9. House keeping

- 0. Keeps house as usual
- 1. Does at least half or his/her job
- 2. Occasional dusting or small jobs
- No longer keeps house
- 4. Never did this activity or don't know

#### 10. Home maintenance

- 0. Does all tasks usual for him/her
- 1. Does at least half of usual tasks
- 2. Occasionally rakes or some other minor job
- 3. No longer does any maintenance
- 4. Never did this activity or don't know

#### 11. Home repairs

- Does all usual repairs
- 1. Does at least half or usual repairs
- 2. Occasionally does minor repairs
- 3. No longer does any repairs
- 4. Never did this activity or don't know

#### 12. Laundry

- 0. Does laundry as usual (Same routine)
- 1. Does laundry less frequently
- Does laundry only if reminded; leaves out detergent, steps
- 3. No longer does longer
- 4. Never did this activity or don't know

#### Sticker here

#### EMPLOYMENT AND RECREATION

#### 13. Employment

- 0. Continues to work as usual
- Some mild problems with routine responsibilities
- Works at an easier job or part-time; threatened with loss of job
- 3. No longer works
- 4. Never worked or retired before illness or don't know

#### 14. Recreation

- Same as usual
- Engages in recreational activities less frequently
- Has lost some skills necessary for recreational activities (bridge, golf); needs coaxing to participate
- 3. No longer pursues recreational activities
- Never engaged in recreational activities or don't know

#### 15. Organizations

- Attends meetings, takes responsibilities as usual
- 1. Attends less frequently
- Attends occasionally; has no major responsibilities
- 3. No longer attends
- Never participated in organizations or don't know

#### 16. Travel

- 0. Same as usual
- 1. Gets out if someone else drives
- 2. Gets out in wheelchair
- 3. Home- or House- bound
- 4. Don't know

#### SHOPPING AND MONEY

- 17. Food shopping
  - 0. No problem
  - 1. Forgets items or buys unnecessary items
  - 2. Needs to be accompanied while shopping
  - 3. No longer does shopping
  - 4. Never had this responsibility or don't know

#### 18. Handling cash

- 0. No problem
- Has difficulty paying proper amount, counting
- 2. Loses or misplaces money
- 3. No longer handles money
- 4. Never had this responsibility or don't know

#### 19. Managing Finances

- 0. No problem paying bills, banking
- 1. Pays bills late; some trouble writing checks
- 2. Forgets to pay bills; has trouble balancing checkbook; needs help from others
- 3. No longer manages finances
- 4. Never had responsibility for this activity or don't know

#### TRAVEL

#### 20. Public transportation

- 0. Uses public transportation as usual
- 1. Uses public transportation less frequently
- 2. Has got lost using public transportation
- 3. No longer uses public transportation
- Never used public transportation regularly or don't know

#### 21. Driving

- 0. Drives as usual
- 1. Drives more cautiously
- Drives less careful; has got lost while driving
- 3. No longer drives
- 4. Never drove or don't know

#### 22. Mobility around neighborhood

- Same as usual
- 1. Goes out less frequently
- 2. Has gotten lost in the immediate
- neighborhood 3. No longer goes out unaccompanied
- This activity has been restricted in the past or don't know

#### 23. Travel outside familiar environment

- 0. Same as usual
- Occasionally gets disoriented in strange surrounding
- Gets very disoriented but is able to manage if accompanied
- 3. No longer able to travel
- 4. Never did this activity or don't know

#### **COMMUNICATION**

#### 24. Using telephone

- 0. Same as usual
- 1. Calls a few familiar numbers
- 2. Will only answer phone (wont make calls)
- 3. Does not use telephone at all
- 4. Never had a telephone or don't know

#### 25. Talking

- 0. Same as usual
- 1. Less talkative, has trouble thinking of words or names
- 2. Makes occasional errors in speech
- 3. Speech is almost unintelligible
- 4. Don't know

#### 26. Understanding

- 0. Understands everything that is said as usual
- 1. Asks for repetition
- Have trouble understanding conversations or specific words occasionally
- Does not understand what people are saying most of the time
- 4. Don't know

#### 27. Reading

- 0. Same as usual
- 1. Reads less frequently
- 2. Has trouble understanding or remembering what he/she has read
- 3. Has given up on reading
- 4. Never read much or don't know

#### 28. Writing

- Same as usual
- 1. Writes less often; makes occasional spelling errors
- 2. Signs names but no other writing
- 3. Never writes
- 4. Never wrote much or don't know

	# of questions answered	Total Points possible (# questions x3)	Actual Total score	% Impairment (actual score/total points possible x 100)
Self-care Activities				
Household Care				
Employment and Recreation				
Shopping and Money				
Travel				
Communication				
Total:				

# • Mini Mental Status Exam

/13/12

MMSE.jpg (806×809)

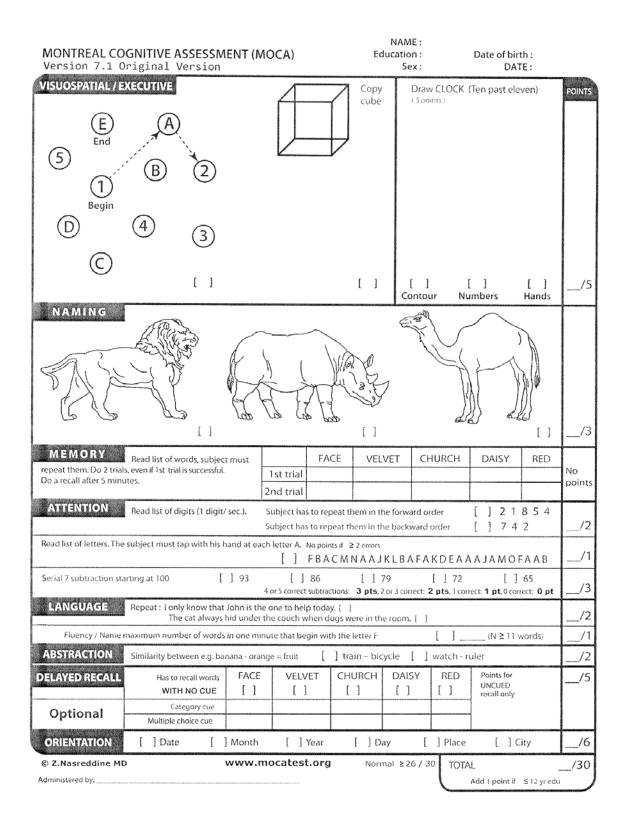
### The Mini-Mental State Exam

Patient		Examiner	Date
Maximum	Score		
5 5		<b>Orientation</b> What is the (year) (season) (date) (day) (month)? Where are we (state) (country) (town) (hospital) (floor)	?
3	( )	Registration Name 3 objects: I second to say each. Then ask the pai all 3 after you have said them. Give 1 point for each Then repeat them until he/she learns all 3. Count to Trials	h correct answer.
5	( )	Attention and Calculation Serial 7's. I point for each correct answer. Stop after 5 Alternatively spell "world" backward.	5 answers.
3	( )	<b>Recall</b> Ask for the 3 objects repeated above. Give 1 point for e	ach correct answer.
2 1 3 1 1		Language Name a pencil and watch. Repeat the following "No ifs, ands, or buts" Follow a 3-stage command: "Take a paper in your hand, fold it in half, and put it Read and obey the following: CLOSE YOUR EYES Write a sentence. Copy the design shown.	t on the floor."
		Total Score ASSESS level of consciousness along a continuum Alert Drowsy Stup	

eurologynerd.com/pictures/MMSE.jpg

1/

### • Montreal Cognitive Assessment



**WEBSITE** Copies of the PHQ family of measures, including the GAD-7, are available at the website: www.phqscreeners.com

Also, translations, a bibliography, an instruction manual, and other information is provided on this website.

# QUESTIONS NOT ADDRESSED IN THIS INSTRUCTION DOCUMENT

For further questions, please send an e-mail to <u>questions@phqscreeners.com</u>

# QUESTIONS REGARDING DEVELOPMENT,

ACKNOWLEDGMENTS AND USE The PHQ family of measures (see Table 1, page 3), including abbreviated and alternative versions as well as the GAD-7, were developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. All of the measures included in Table 1 are in the public domain. No permission is required to reproduce, translate, display or distribute.

- Generalized Anxiety Disorder Questionnaire (GAD 2 & GAD 7)
- Patient Health Questionnaire (PHQ 2 & PHQ 9)

# GAD-7 Anxiety

Over the last two weeks, how often have you been bothered by the following problems?		Not at all	Several days	More than half the days	Nearly every day
1. Feeling	nervous, anxious, or on edge	0	1	2	3
2. Not bein worrying	g able to sleep or control	0	1	2	3
3. Worrying things	too much about different	0	1	2	3
4. Trouble	relaxing	0	1	2	3
5. Being sc	restless that it is hard to sit still	0	1	2	3
6. Becomin	g easily annoyed or irritable	0	1	2	3
<ol> <li>Feeling afraid, as if something awful might happen</li> </ol>		0	1	2	3
	Column totals	; +	+	+	=
				Total score	
If you checked any problems, how difficult have they made it for you to do your work, take care of things at home, or get along with other people?					take care of
Not difficult at all	Somewhat difficult	Very difficul	t	Extremely d	ifficult

Source: Primary Care Evaluation of Mental Disorders Patient Health Questionnaire (PRIME-MD-PHQ). The PHQ was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke, and colleagues. For research information, contact Dr. Spitzer at <u>ris8@columbia.edu</u>. PRIME-MD® is a trademark of Pfizer Inc. Copyright© 1999 Pfizer Inc. All rights reserved. Reproduced with permission.

# Scoring GAD-7 Anxiety Severity

This is calculated by assigning scores of 0, 1, 2, and 3 to the response categories, respectively, of "not at all," "several days," "more than half the days," and "nearly every day." GAD-7 total score for the seven items ranges from 0 to 21.

0-5: mild anxiety

6-10: moderate anxiety

11-15: moderate anxiety

17-21: severe anxiety

# Patient Health Questionnaire—PHQ-9

Name:	Date of Birth :	Today's Date:

Fill in the boxes with pen or pencil to mark your answers.

#### A. Over the last 2 weeks, how often have you been bothered by any of the following problems?

	Not at all 0	Several days 1	More than half the days 2	Nearly every day 3
1. Little interest or pleasure in doing things				
2. Feeling down, depressed, or hopeless				
3. Trouble falling/staying asleep, sleeping too much				
4. Feeling tired or having little energy				
5. Poor appetite or overeating				
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down.				
7. Trouble concentrating on things, such as reading the new spaper or watching television.				
8. Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual.				
9. Thoughts that you would be better off dead or of hurting yourself in some way.				
Total Score =	+	+	+	

#### B. If you have been bothered by <u>any</u> of the 9 problems listed above, please answer the following:

How difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somew hat Difficult	Very Difficult	Extremely Difficult

This health survey was adapted from the PRIME-MD® Patient Health Questionnaire © 1999, Pfizer Inc. Reproduced with permission. For research information, contact Dr. Robert L. Spitzer at rls8@columbia.edu.

Gray, A., Humberson, A. et al. Society for Transplant Social Workers 2012

# The Brief Coping Scale

## **Brief COPE**

The items below are an abbreviated version of the COPE Inventory. We have used it in research with breast cancer patients, with a community sample recovering from Hurricane Andrew, and with other samples as well. At present, none of that work has been published, except for an article reporting the development of the Brief COPE, which includes information about factor structure and internal reliability from the hurricane sample (citation below). The Brief COPE has also been translated into French and Spanish (see below), as separate publications.

We created the shorter item set partly because earlier patient samples became impatient at responding to the full instrument (both because of the length and redundancy of the full instrument and because of the overall time burden of the assessment protocol). In choosing which items to retain for this version (which has only 2 items per scale), we were guided by strong loadings from previous factor analyses, and by item clarity and meaningfulness to the patients in a previous study. In creating the reduced item set, we also "tuned" some of the scales somewhat (largely because some of the original scales had dual focuses) and omitted scales that had not appeared to be important among breast cancer patients. In this way the positive reinterpretation and growth scale became positive reframing (no growth); focus on and venting of emotions became venting (focusing was too tied to the experiencing of the emotion, and we decided it was venting we were really interested in); mental disengagement became self-distraction (with a slight expansion of mentioned means of selfdistraction). We also added one scale that was not part of the original inventory--a 2-item measure of self-blame--because this response has been important in some earlier work.

You are welcome to use all scales of the Brief COPE, or to choose selected scales for use. Feel free as well to adapt the language for whatever time scale you are interested in. Citation: Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine*, 4, 92-100. [abstract]

Following is the BRIEF COPE as we are now administering it, with the instructional orientation for a presurgery interview (the first time the COPE is given in this particular study). Please feel free to adapt the instructions as needed for your application.

Scales are computed as follows (with no reversals of coding):

Self-distraction, items 1 and 19 Active coping, items 2 and 7 Denial, items 3 and 8 Substance use, items 4 and 11 Use of emotional support, items 5 and 15 Use of instrumental support, items 10 and 23 Behavioral disengagement, items 6 and 16 Venting, items 9 and 21 Positive reframing, items 12 and 17 Planning, items 14 and 25 Humor, items 18 and 28 Acceptance, items 20 and 24 Religion, items 22 and 27 Self-blame, items 13 and 26

I have had many questions about combining scales into "problem focused" and "emotion focused" aggregates, or into an "overall" coping index. I have never that in my own use of the scales. There is no such thing as an "overall" score on this measure, and I recommend no particular way of generating a dominant coping style for a give person. Please do NOT write to me asking for instructions to for "adaptive" and "maladaptive" composites, because I do not have any such instructions. I generally look at each scale separately to see what its relation is to other variables. An alternative is to create second-order factors from among the scales (see the

1989 article) and using the factors as predictors. If you decide to do that, I recommend that you use your own data to determine the composition of the higher-order factors. Different samples exhibit different patterns of relations.

If you can not figure out from these instructions how to examine your data, please consult with your own statistical person rather than sending me questions.

If you are interested in a <u>Spanish version</u> of the Brief COPE. If you are interested in a <u>French version</u> of the Brief COPE. If you are interested in a <u>German version</u> of the Brief COPE. If you are interested in a <u>Greek version</u> of the Brief COPE. If you are interested in a <u>Korean version</u> of the Brief COPE.

Brief COPE

These items deal with ways you've been coping with the stress in your life since you found out you were going to have to have this operation. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.

2. I've been concentrating my efforts on doing something about the situation I'm in.

- 3. I've been saying to myself "this isn't real.".
- 4. I've been using alcohol or other drugs to make myself feel better.
- 5. I've been getting emotional support from others.
- 6. I've been giving up trying to deal with it.
- 7. I've been taking action to try to make the situation better.
- 8. I've been refusing to believe that it has happened.
- 9. I've been saying things to let my unpleasant feelings escape.
- 10. I've been getting help and advice from other people.
- 11. I've been using alcohol or other drugs to help me get through it.

12. I've been trying to see it in a different light, to make it seem more positive.

- 13. I've been criticizing myself.
- 14. I've been trying to come up with a strategy about what to do.
- 15. I've been getting comfort and understanding from someone.
- 16. I've been giving up the attempt to cope.
- 17. I've been looking for something good in what is happening.
- 18. I've been making jokes about it.
- 19. I've been doing something to think about it less, such as going to movies,

watching TV, reading, daydreaming, sleeping, or shopping.

- 20. I've been accepting the reality of the fact that it has happened.
- 21. I've been expressing my negative feelings.
- 22. I've been trying to find comfort in my religion or spiritual beliefs.

23. I've been trying to get advice or help from other people about what to do.

- 24. I've been learning to live with it.
- 25. I've been thinking hard about what steps to take.
- 26. I've been blaming myself for things that happened.
- 27. I've been praying or meditating.
- 28. I've been making fun of the situation.

### Carver

Original version of the COPE

University of Miami, Department of Psychology P.O. Box 248185, Coral Gables, FL 33124-0751 Phone: 305-284-2814 Fax: 305-284-3402 Comments: webmaster@psy.miami.edu

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# **CAGE**

Self-assessment tests and screening tools can be the key to identifying, understanding, and getting support for alcohol abuse problems. They are not designed to provide a diagnosis. If you think you or someone you know may have an alcohol problem, please consult a physician for a full evaluation.

The goal of screening, therefore, is to determine whether a person should receive a more thorough evaluation.

The scoring is confidential and only for your eyes. The answers to the questions are scored 0 for "no" and 1 for "yes", with a total score of 2 or greater considered indicative of an alcohol or drug problem.

The CAGE Questionnaire for alcohol:

- Have you ever felt you should cut down on your drinking?
- Have people annoyed you by criticizing your drinking?
- Have you felt bad or guilty about your drinking?
- Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover (eye-opener)?

# DSM-IV criteria for abuse vs. dependence

## Diagnostic Criteria for Substance Abuse

A. A maladaptive pattern of substance use leading to clinically significant impairment or distress, as manifested by one (or more)

of the following, occurring within a 12-month period:

1. recurrent substance use resulting in a failure to fulfill major

role obligations at work, school, or home

2. recurrent substance use in situations in which it is physically hazardous

3. recurrent substance-related legal problems

4. continued substance use despite having persistent or recurrent social or interpersonal problems caused or exacerbated by the effects of the substance

**B.** The symptoms have never met the criteria for substance dependence for this class of substance.

### Diagnostic Criteria for Substance Dependence

A maladaptive pattern of substance use, leading to clinically significant impairment or distress, as manifested by three (or more) of the following, occurring at any time in the same 12-month period:

- 1. tolerance
- 2. withdrawal
- 3. the substance is often taken in larger amounts or over a longer period than was intended
- 4. there is a persistent desire or unsuccessful efforts to cut down or control substance use
- 5. a great deal of time is spent in activities necessary to obtain the substance
- 6. important social, occupational, or recreational activities are given up or reduced
- 7. the substance use is continued despite knowledge of having a persistent or recurrent physical or psychological problem that is likely to have been caused or exacerbated by the substance

### Sample Questions for Evaluating Substance Use based on DSM Criteria for Abuse and Dependence:

#### DSM Diagnosis for Substance Abuse: 1 (or more) of 4

1. Has recurrent substance use impacted your ability to be able to fulfill your obligations at work, school or home (such as repeated absences or poor work performance, work/school related suspensions, neglect of children/household)? Y Ν

2. Have you continued using despite having recurrent social or interpersonal problems, caused by or exacerbated by the effects of the substance (such as arguments with family about consequences of intoxication or physical fights)? Y Ν

3. Have you used recurrently in situations that are physically hazardous (such as driving an automobile or operating a machine when impaired)? Y

4. Have you had recurrent substance-related legal problems?

#### DSM Diagnosis for Substance Dependence: 3 (or more) of 7

1. Have you increased the amount of the substance you use to achieve the same level of intoxication or effect, or experienced a lesser effect with continued use of the same amount? Y N 2. Have you ever experienced withdraw from using , or used a similar substance to relieve or avoid withdrawal? Y N 3. Do you often drink or use more than you intend to, or drink or use for a longer period of time than you intended? Y N

4. Have you felt a persistent desire to cut down your use or have you had unsuccessful attempts to cut down or control your use?

5. Do you feel like you spend a lot of time in activities necessary to obtain the substance, use the substance, or recover from its effects? Y

6. Has your use caused you to give up or reduce any important activities in your life, such as your involvement in work, social or recreational activities?

Y Ν

Ν

Y N

Ν

Ν

Y

7. Have you continued using despite knowing you have a persistent physical or psychological problem that was likely to have been caused or exacerbated by the substance?

Y N

# **CMS** Guidelines

- CMS a qualified Social Worker is expected to complete an assessment focused on the individual's suitability for transplant.
- Must address:
  - Social, personal, housing, financial, & environmental supports
  - Coping abilities & strategies
  - Understanding of the risks & benefits of transplant
  - Ability to adhere to a therapeutic regiment

- Mental health history, including substance use and how it may impact the success or failure of organ txp.

- Of note, the psychosocial evaluation is required to be completed and the assessment closed BEFORE the patient is discussed at your Transplant Selection Committee.
- Also, when a patient is transplanted, a social worker is expected to have at least 1 chart note or more as needed on the patient within every 7 days as needed during their initial transplant hospitalization.

## **UNOS Data Requirements**

- 1. Marital status
- 2. Number of pregnancies

3. Citizenship -US citizen or if not please specify:
- Non-U.S. Citizen/ U.S. Resident - Non-U.S. Citizen/Non-U.S. Resident, Traveled to U.S. for Reason Other Than Transplant

- Non-U.S. Citizen/Non-U.S. Resident, Traveled to U.S. for Transplant

- Note: If Non-U.S. Citizen/Non-U.S. Resident, Traveled to U.S. for Reason Other Than Transplant is selected, Year of Entry to the U.S will be required.

- 4. Highest education level
- 5. Working for income,
  - if Yes part time or full time
  - if only part time, why?

(retired, disabled, demands of treatment, inability to find work, etc)

• 6. Race: (entire list below of choices - if you could be as specific as you can, that will help)

# American Indian or Alaska native

Eskimo Aleutian Alaska Indian American Indian or Alaska Native: Other American Indian or Alaska Native: Not Specified/Unknown

### Asian

Asian Indian/Indian Sub-Continent Chinese Filipino Japanese Korean Vietnamese Asian: Other Asian: Not Specified/Unknown

#### Black or African American

African American African (Continental) West Indian Haitian Black or African American: Other Black or African American: Not Specified/Unknown

#### Hispanic/Latino

Mexican Puerto Rican (Mainland) Puerto Rican (Island) Cuban Hispanic/Latino: Other Hispanic/Latino: Not Specified/Unknown

#### Native Hawaiian or other Pacific Islander

Native Hawaiian Guamanian or Chamorro Samoan Native Hawaiian or Other Pacific Islander: Other Native Hawaiian or Other Pacific Islander: Not Specified/Unknown

#### White

European Descent Arab or Middle Eastern North African (non-Black) White: Other White: Not Specified/Unknown

# Addendum Appendix:

### Caregiver Commitment Example:

#### Patient and Care Partner Commitment

Date:

Name: Me	dical Record#:

Social Worker: \_\_\_\_\_

I am aware as a \_\_\_\_\_\_\_transplant candidate that I have a responsibility before and after my transplant in order to have the best outcome, to work cooperatively with the transplant team, and not to jeopardize my transplant success. These responsibilities include: compliance with medical testing/procedures that are recommended by the transplant team, lab work, medication compliance, and complete abstinence from alcohol and all other addictive substances. I also will need to have adequate care partner(s) and financial means to care for myself before and after transplant.

I agree to maintain and stay connected with the \_\_\_\_\_ Transplant Program and follow all recommendations before and after my transplant. This includes:

- 1. Compliance: I understand that I will need to be compliant with all medical recommendations for testing, procedures, lab work, and medications. I will notify the transplant team of any medical concerns or updates on medical treatments, and if I am admitted to another hospital.
- 2. Financial Responsibilities: All patients must have insurance and prescription coverage for transplant. You may also need to plan for travel, lodging, meals, and other miscellaneous out of pockets expenses incurred while residing in \_\_\_\_\_area. These expenses are estimated at \$10,000-\$12,000 over the course of the first year. You are expected to do fundraising if you are not able to afford these costs. You are responsible for looking into insurance and prescription coverage, as well as travel/lodging benefits, and will notify the social worker or financial coordinator with any changes or updates with your financial situation.
- 3. Social Support: All patients must have a care partner (or team of people) for assistance both before and after transplant. A care partner should be over the age of 21 years old, have average reading skills, good judgment, sober, and reliable. Patients will need a care partner available for the first 8-12 weeks after discharge from the hospital.

- a. Care partner(s) responsibilities include:
  - Attend the pre-transplant coordinator class
  - Read the transplant binder after patient is listed for transplant
  - Attend post transplant coordinator education class during post transplant hospitalization
  - Provide transportation for the patient to medical appointment and to get lab work completed
  - Assist the patient with their activities of daily living and with medications
- 4. For a non-complicated transplant, Patient's residing more than one hour from the Hospital will need to plan to stay locally for 2-4 weeks post transplant (after discharge from the hospital). If you reside more than 4 hrs from \_\_\_\_\_you can expect to stay locally 4-8 weeks. You will need your care partner(s) with you at all times during this period. Patient's that have a more complicated medical situation may have to stay longer. Your surgeon will advise you when it is safe to return home.

My goal is to be a successful transplant recipient. I willingly take part in my healthcare treatment before and after transplant by doing whatever is necessary to build and maintain my health. I have read and understand the above responsibilities and I agree to accept and carry them out. I know that failure to maintain my responsibilities may jeopardize my success after transplant.

Patient Signature:

As the care partner I also agree to the above responsibilities in order assist the patient in their care before and after transplant.

Care Partner Signature:

Care Partner Signature:

Social Worker Signature:

### Records ?

#### Adult Heart Transplant Candidate Registration Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 03/31/2015

Note: These worksheets are provided to function as a guide to what data will be required in the online TIEDI<sup>®</sup> application. Currently in the worksheet, a red asterisk is displayed by fields that are required, independent of what other data may be provided. Based on data provided through the online TIEDI<sup>®</sup> application, additional fields that are dependent on responses provided in these required fields may become required as well. However, since those fields are not required in every case, they are not marked with a red asterisk.

Provider Information
Recipient Center:

Candidate information	
Organ Registered:	Date of Listing or Add:
Last Name: * First Name: * Previous Surname:	MI:
SSN:	Gender: * C Male C Female
HIC:	DOB:*
State of Permanent Residence: <sup>*</sup> Permanent ZIP Code: <sup>*</sup> Is Patient waiting in permanent ZIP code:	· YES · NO · UNK
Ethnicity/Race: (select all origins that apply)	
American Indian or Alaska Native American Indian Eskimo Aleutian Alaska Indian American Indian or Alaska Native: Other American Indian or Alaska Native: Not Specified/Unknown	Asian Asian Indian/Indian Sub-Continent Chinese Filipino Japanese Korean Vietnamese Asian: Other Asian: Not Specified/Unknown
Black or African American          African American         African (Continental)         West Indian         Haitian         Black or African American: Other	Hispanic/Latino Mexican Puerto Rican (Mainland) Puerto Rican (Island) Cuban Hispanic/Latino: Other

Black or African American: Not Specified/Unknow	/n Hispanic/Latino: Not Specified/Unknown		
Native Hawaiian or Other Pacific Islander	White		
Native Hawaiian	European Descent		
Guamanian or Chamorro	Arab or Middle Eastern		
Samoan	North African (non-Black)		
Native Hawaiian or Other Pacific Islander: Other	White: Other		
Native Hawaiian or Other Pacific Islander: Not Specified/Unknown	White: Not Specified/Unknown		
	C US Citizen		
	Non-US Citizen/US Resident		
Citizenship:**	Non-US Citizen/Non-US Resident, Traveled to US for Reason Other Than Transplant		
	Non-US Citizen/Non-US Resident, Traveled to US for Transplant		
Year of Entry to the U.S.			
	NONE		
	GRADE SCHOOL (0-8)		
	HIGH SCHOOL (9-12) or GED		
	ATTENDED COLLEGE/TECHNICAL SCHOOL		
Highest Education Level:*	ASSOCIATE/BACHELOR DEGREE		
	POST-COLLEGE GRADUATE DEGREE		
	N/A (< 5 YRS OLD)		
	IN INTENSIVE CARE UNIT		
Medical Condition at time of listing:	HOSPITALIZED NOT IN ICU		
	NOT HOSPITALIZED		
Patient on Life Support:*	C YES C NO		
	Extra Corporeal Membrane Oxygenation		
	Intra Aortic Balloon Pump		
	Prostaglandins		

	Intravenous Inotropes		
	Other Mechanism, Specify		
Specify:			
	NONE		
	C LVAD		
Patient on Ventricular Assist Device: 🕷	C RVAD		
	🥌 ТАН		
	C LVAD+RVAD		
VAD Brand1:			
Specify:			
VAD Brand2:			
Specify:			
Functional Status: *			
	No Limitations		
	C Limited Mobility		
Physical Capacity:	Wheelchair bound or more limited		
	Not Applicable (< 1 year old or hospitalized)		
	C Unknown		
Working for income: *	C YES C NO C UNK		
If No, Not Working Due To:			
	Working Full Time		
	Working Part Time due to Demands of Treatment		
If Yes:	Working Part Time due to Disability		
	Working Part Time due to Insurance Conflict		
	Working Part Time due to Inability to Find Full Time Work		
	Working Part Time due to Patient Choice		

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Working Part Ti		g Part Time Reason Unknown			
Working, Part		g, Part Time vs. Full Time Unknown			
6		Within One Grade Level of Peers			
	C Delayed	Delayed Grade Level			
Academic Progress:	Special	Special Education			
	Not App	licable < 5 years old/ High School graduate or GED			
	Status U	Jnknown			
	Full acad	demic load			
	Reduced	d academic load			
Academic Activity Level:	Unable t	to participate in academics due to disease or condition			
	Not App	blicable < 5 years old/ High School graduate or GED			
		Jnknown			
Previous Transplants:					
Organ	Date	Graft Fail Date			
transplants by calling 800-978-4334 or	r by emailing unethelpdesk@un	UNet Help Desk to confirm more than three previous nos.org.			
Previous Pancreas Islet Infusion:**	G YES G	NO 🦳 UNK			
Source of Payment:					
Primary: *					
Specify:					
Secondary:					
Clinical Information: AT LISTING					
Height: 🔻	ft.	in. cm ST=			
Weight:*	Ibs	kg ST=			
BMI:	kg/m <sup>2</sup>				
ABO Blood Group:					
Primary Diagnosis: *					

Specify:			
General Medical Factors:			
	No		
	Туре І		
Diabetes: *	Туре II		
Diabetes: *	C Type Other		
	Type Unknown		
	Diabetes Status Unknown		
	No dialysis		
	G Hemodialysis		
Dialysis:	Peritoneal Dialysis		
	Dialysis Status Unknown		
	Dialysis-Unknown Type was performed		
	No		
Peptic Ulcer:	Yes, active within the last year		
replic older.	Yes, not active within the last year		
	C Unknown		
	No angina		
	Stable angina - strenuous activity results in angina		
	Stable angina - ordinary physical activity results in angina		
Angina:	Stable angina - no rest angina; does have angina with less than ordinary activity		
	Stable angina - angina with any physical activity or at rest		
	Unstable angina		
	Unknown if angina present		
Drug Treated Systemic Hypertension:	G YES G NO G UNK		
Symptomatic Cerebrovascular Disease:*	C YES C NO C UNK		

Symptomatic Peripheral Vascular Disease:	C YES C NO C UNK		
Drug Treated COPD:	C YES C NO UNK		
Pulmonary Embolism:	C YES C NO C UNK		
Any Previous Transfusions:	YES NO UNK		
Any previous Malignancy:*	YES NO UNK		
	Skin Melanoma		
	Skin Non-Melanoma		
	CNS Tumor		
	Genitourinary		
	Breast		
Specify Type:	Thyroid		
	Tongue/Throat/Larynx		
	Leukemia/Lymphoma		
	Liver		
	Other, specify		
Specify:			
Most Recent Serum Creatinine:*	mg/dl ST=		
Total Serum Albumin:	g/dl ST=		
I			

Heart Medical Factors:	
Sudden Death:	C YES C NO C UNK
Antiarrhythmics:	C YES C NO C UNK
Amiodarone:	C YES C NO C UNK
Implantable Defibrillator: 🕷	YES NO UNK
Infection Requiring IV Drug Therapy within 2/wks prior to listing:	
Exercise Oxygen Consumption:*	ml/min/kg ST=

Most Recent Hemodynamics:

Inotropes/Vasodilators:

PA (sys) mm/Hg: <b>≭</b>		ST=	C YES C NO
PA (dia) mm/Hg:都		ST=	C YES C NO
PA (mean) mm/Hg: <mark>≭</mark>		ST=	YES NO
PCW (mean) mm/Hg: *		ST=	C YES C NO
CO L/min: 🕷		ST=	YES NO
History of Cigarette Use: *	YES NO		
	<b>0</b> -10		
	11-20		
	<b>©</b> 21-30		
If Yes, Check # pack years:	<b>6</b> 31-40		
	<b>6</b> 41-50		
	Unknown pack years		
	C 0-2 months		
	G 3-12 months		
	C 13-24 months		
Duration of Abstinence:	25-36 months		
	6 37-48 months		
	49-60 months		
	>60 months		
	Continues To Smoke		
	Unknown duration		
Other Tobacco Use:	YES ONO UNK		

Prior Cardiac Surgery (non-transplant): *	C YES C NO C UNK
If yes, check all that apply:	<ul> <li>CABG</li> <li>Valve Replacement/Repair</li> <li>Congenital</li> <li>Left Ventricular Remodeling</li> </ul>
Specify:	Other, specify
Prior Lung Surgery (non-transplant):	C YES C NO C UNK
If yes, check all that apply:	<ul> <li>Pneumoreduction</li> <li>Pneumothorax Surgery-Nodule</li> <li>Pneumothorax Decortication</li> <li>Lobectomy</li> <li>Pneumonectomy</li> <li>Left Thoracotomy</li> <li>Right Thoracotomy</li> <li>Other, specify</li> </ul>
Specify:	

### Records ?

#### Adult Kidney Transplant Candidate Registration Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 03/31/2015

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Provider Information	
Recipient Center:	

Candidate Information	
Organ Registered:	Date of Listing or Add:
Last Name: * First Name: * Previous Surname:	MI:
SSN:	Gender: * C Male C Female
HIC:	DOB:*
State of Permanent Residence:* Permanent ZIP Code:* Is Patient waiting in permanent ZIP code:  Y	'ES C NO C UNK
Ethnicity/Race:* (select all origins that apply)	
American Indian or Alaska Native American Indian Eskimo Aleutian Alaska Indian American Indian or Alaska Native: Other American Indian or Alaska Native: Not Specified/Unknown	Asian Asian Indian/Indian Sub-Continent Chinese Filipino Japanese Korean Vietnamese Asian: Other Asian: Not Specified/Unknown
Black or African American <ul> <li>African American</li> <li>African (Continental)</li> <li>West Indian</li> <li>Haitian</li> <li>Black or African American: Other</li> </ul>	Hispanic/Latino <ul> <li>Mexican</li> <li>Puerto Rican (Mainland)</li> <li>Puerto Rican (Island)</li> <li>Cuban</li> <li>Hispanic/Latino: Other</li> </ul>

Black or African American: Not Specified/Unknov	wn Hispanic/Latino: Not Specified/Unknown
Native Hawaiian or Other Pacific Islander	White
Native Hawaiian	European Descent
Guamanian or Chamorro	Arab or Middle Eastern
Samoan	North African (non-Black)
Native Hawaiian or Other Pacific Islander: Other	White: Other
Native Hawaiian or Other Pacific Islander: Not Specified/Unknown	White: Not Specified/Unknown
	G US Citizen
	Non-US Citizen/US Resident
Citizenship:**	Non-US Citizen/Non-US Resident, Traveled to US for Reason Other Than Transplant
	Non-US Citizen/Non-US Resident, Traveled to US for Transplant
Year of Entry to the U.S.	
	NONE
	GRADE SCHOOL (0-8)
	HIGH SCHOOL (9-12) or GED
Highest Education Level:*	ATTENDED COLLEGE/TECHNICAL SCHOOL
ingliest Education Level.	ASSOCIATE/BACHELOR DEGREE
	POST-COLLEGE GRADUATE DEGREE
	N/A (< 5 YRS OLD)
	UNKNOWN
	IN INTENSIVE CARE UNIT
Medical Condition at time of listing:	G HOSPITALIZED NOT IN ICU
	NOT HOSPITALIZED
Functional Status: *	
	No Limitations
Physical Capacity:	C Limited Mobility
,	Wheelchair bound or more limited

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	<ul><li>Not Applicabl</li><li>Unknown</li></ul>	e (< 1 year old or hospitalized)	
Working for income: * If No, Not Working Due To:	C YES C NO	C UNK	
If Yes:	<ul> <li>Working Part</li> <li>Working Part</li> <li>Working Part</li> <li>Working Part</li> <li>Working Part</li> <li>Working Part</li> </ul>	Time Time due to Demands of Treatment Time due to Disability Time due to Insurance Conflict Time due to Inability to Find Full Time Work Time due to Patient Choice Time Reason Unknown	
Academic Progress:	<ul> <li>Delayed Grad</li> <li>Special Education</li> </ul>	ation e < 5 years old/ High School graduate or GED	
Academic Activity Level:	<ul> <li>Reduced acad</li> <li>Unable to par</li> <li>Unable to par</li> <li>Not Applicable</li> </ul>	<ul> <li>Unable to participate regularly in academics due to dialysis</li> <li>Not Applicable &lt; 5 years old/ High School graduate or GED</li> </ul>	
Previous Transplants:			
Organ	Date	Graft Fail Date	
	s are listed here. Please contact the UNet 34 or by emailing unethelpdesk@unos.org	Help Desk to confirm more than three previous g.	

Previous Pancreas Islet Infusion:**	C YES C NO C UNK
Source of Payment:	
Primary: *	
Specify:	
Secondary:	
Clinical Information: AT LISTING	
Height: *	ft. in. cm <b>ST</b> =
Weight:*	lbs kg ST=
BMI:	kg/m <sup>2</sup>
ABO Blood Group:	
Primary Diagnosis: *	
Specify:	
General Medical Factors:	
	No
	Туре І
	Туре II
Diabetes: *	C Type Other
	C Type Unknown
	Diabetes Status Unknown
	No dialysis
	Hemodialysis
Dialysis:	Peritoneal Dialysis
	Dialysis Status Unknown
	Dialysis-Unknown Type was performed
	No
Pontio Illoon	Yes, active within the last year
Peptic Ulcer:	
	Yes, not active within the last year

	C Unknown
	No
	Yes, and documented Coronary Artery Disease
Angina:	Yes, with no documented Coronary Artery Disease
	Yes, but Coronary Artery Disease unknown
	Status Unknown
Drug Treated Systemic Hypertension:	C YES C NO C UNK
Symptomatic Cerebrovascular Disease:	C YES C NO C UNK
Symptomatic Peripheral Vascular Disease: 🕷	C YES C NO C UNK
Drug Treated COPD: *	C YES C NO C UNK
Any previous Malignancy: 🕷	C YES C NO C UNK
	Skin Melanoma
	Skin Non-Melanoma
	CNS Tumor
	Genitourinary
	Breast
Specify Type:	Thyroid
	Tongue/Throat/Larynx
	Lung
	Leukemia/Lymphoma
	Liver
	Other, specify
Specify:	
Most Recent Serum Creatinine:	mg/dl ST=
Total Serum Albumin: 🕷	g/dl ST=

	C YES C NO C UNK	
Exhausted Peritoneal Access: *	C YES C NO C UNK	
Age of Diabetes Onset:	yrs	ST=

## Records ?

### Adult Liver Transplant Candidate Registration Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 03/31/2015

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Provider Information	
Recipient Center:	

Candidate Information	
Organ Registered:	Date of Listing or Add:
Last Name: * First Name: * Previous Surname:	MI:
SSN:	Gender:** C Male C Female
HIC:	DOB:*
State of Permanent Residence:* Permanent ZIP Code:* Is Patient waiting in permanent ZIP code:  YES	
Ethnicity/Race: (select all origins that apply)	
American Indian or Alaska Native American Indian Eskimo Aleutian Alaska Indian American Indian or Alaska Native: Other American Indian or Alaska Native: Not Specified/Unknown	Asian Asian Indian/Indian Sub-Continent Chinese Filipino Japanese Korean Vietnamese Asian: Other Asian: Not Specified/Unknown
Black or African American African American African (Continental) West Indian Haitian Black or African American: Other	Hispanic/Latino <ul> <li>Mexican</li> <li>Puerto Rican (Mainland)</li> <li>Puerto Rican (Island)</li> <li>Cuban</li> <li>Hispanic/Latino: Other</li> </ul>

Black or African American: Not Specified/Unknow	wn Hispanic/Latino: Not Specified/Unknown
Native Hawaiian or Other Pacific Islander	White
Native Hawaiian	European Descent
Guamanian or Chamorro	Arab or Middle Eastern
Samoan	North African (non-Black)
Native Hawaiian or Other Pacific Islander: Other	White: Other
Native Hawaiian or Other Pacific Islander: Not Specified/Unknown	White: Not Specified/Unknown
	US Citizen
	Non-US Citizen/US Resident
Citizenship:**	Non-US Citizen/Non-US Resident, Traveled to US for Reason Other Than Transplant
	Non-US Citizen/Non-US Resident, Traveled to US for Transplant
Year of Entry to the U.S.	
	NONE
	GRADE SCHOOL (0-8)
	HIGH SCHOOL (9-12) or GED
	ATTENDED COLLEGE/TECHNICAL SCHOOL
Highest Education Level: <sup>₩</sup>	ASSOCIATE/BACHELOR DEGREE
	POST-COLLEGE GRADUATE DEGREE
	N/A (< 5 YRS OLD)
	IN INTENSIVE CARE UNIT
Medical Condition at time of listing:	6 HOSPITALIZED NOT IN ICU
	NOT HOSPITALIZED
Patient on Life Support:*	🧉 YES 🌀 NO
	Ventilator
	Artifical Liver
	Other Mechanism, Specify

Specify:	
Functional Status: *	
	No Limitations
	Limited Mobility
Physical Capacity:	Wheelchair bound or more limited
	Not Applicable (< 1 year old or hospitalized)
	C Unknown
Working for income: *	YES NO UNK
If No, Not Working Due To:	
	Working Full Time
	Working Part Time due to Demands of Treatment
	Working Part Time due to Disability
If Yes:	Working Part Time due to Insurance Conflict
ii 165.	Working Part Time due to Inability to Find Full Time Work
	Working Part Time due to Patient Choice
	Working Part Time Reason Unknown
	Working, Part Time vs. Full Time Unknown
	Within One Grade Level of Peers
	C Delayed Grade Level
Academic Progress:	Special Education
	Not Applicable < 5 years old/ High School graduate or GED
	Status Unknown
	Full academic load
	Reduced academic load
Academic Activity Level:	C Unable to participate in academics due to disease or condition
	Not Applicable < 5 years old/ High School graduate or GED

Status Unknown			
Previous Transplants:			
Organ	Date	Graft Fail Date	
The three most recent transplants are listed here. Please contact the UNet Help Desk to confirm more than three previous transplants by calling 800-978-4334 or by emailing unethelpdesk@unos.org.         Previous Pancreas Islet Infusion:**			
Source of Payment:			
Primary: *			
Specify:			
Secondary:			
Clinical Information: AT LISTING			
Height:*	ft. in.	cm ST=	
Weight:*	lbs	kg ST=	
BMI:	kg/m <sup>2</sup>		
ABO Blood Group:			
Primary Diagnosis: **			
Specify:			
Secondary Diagnosis:			
Specify:			
General Medical Factors:			
	No		
	Type I		
	Type II		
Diabetes:*	C Type Other		
	Type Unknown		
	Diabetes Status	s Unknown	
	No dialysis		

	C Hemodialysis
Dialysis:	C Peritoneal Dialysis
	CAVH: Continuous Arteriovenous Hemofiltration
	CV VH: Continuous Venous/Venous Hemofiltration
	Dialysis Status Unknown
	Dialysis-Unknown Type was performed
	No
Peptic Ulcer:	Yes, active within the last year
	Yes, not active within the last year
	C Unknown
	No
	Yes, and documented Coronary Artery Disease
Angina:	Yes, with no documented Coronary Artery Disease
	Yes, but Coronary Artery Disease unknown
	Status Unknown
Drug Treated Systemic Hypertension:	
Symptomatic Cerebrovascular Disease:	C YES C NO C UNK
Symptomatic Peripheral Vascular Disease:	C YES C NO C UNK
Drug Treated COPD:	YES NO UNK
Pulmonary Embolism:	C YES C NO C UNK
Any previous Malignancy: 🔭	C YES C NO C UNK
	Skin Melanoma
	Skin Non-Melanoma
	CNS Tumor
	Genitourinary

	Breast	
	Thyroid	
	Tongue/Throat/Larynx	
Specify Type:	Leukemia/Lymphoma	
	Liver	
	Hepatocellular Carcinoma	
	Other, specify	
Specify:		
Most Recent Serum Creatinine:	mg/dl ST=	
Liver Medical Factors		
Variceal Bleeding within Last Two Weeks:	C YES C NO C UNK	
Previous Upper Abdominal Surgery: *	● YES ● NO ● UNK	
Spontaneous Bacterial Peritonitis:	C YES C NO C UNK	
History of Portal Vein Thrombosis: *	C YES C NO C UNK	
History of TIPSS:*	C YES C NO C UNK	

## Records ?

#### Adult Lung Transplant Candidate Registration Worksheet

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 03/31/2015

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Provider Information	
Recipient Center:	

Candidate Information			
Organ Registered:		Date of Listing or Add:	
Last Name: * First Previous Surname:	Name:*	MI:	
SSN:		Gender: *	Male Female
HIC:		DOB:*	
State of Permanent Residence:* Permanent ZIP Code:* Is Patient waiting in permanent ZIP o	code: C YES		
Ethnicity/Race: <sup>*</sup> (select all origins that apply)			
American Indian or Alaska Native American Indian Eskimo		Asian □ Asian Indian/Indian Sub-Contin □ Chinese	ient
Aleutian			
Alaska Indian		Japanese	
American Indian or Alaska Nativ		Korean	
American Indian or Alaska Nativ Specified/Unknown	e: Not	☐ Vietnamese ☐ Asian: Other ☐ Asian: Net Orea ife ditud	
		Asian: Not Specified/Unknown	
Black or African American		lispanic/Latino Mexican	
African (Continental)		Puerto Rican (Mainland)	
West Indian		Puerto Rican (Island)	
Haitian			
Black or African American: Othe	r	Hispanic/Latino: Other	

Black or African American: Not Specified/Unknow	vn Hispanic/Latino: Not Specified/Unknown
Native Hawaiian or Other Pacific Islander	White
Native Hawaiian	European Descent
Guamanian or Chamorro	Arab or Middle Eastern
Samoan	North African (non-Black)
☐ Native Hawaiian or Other Pacific Islander: Other	White: Other
Native Hawaiian or Other Pacific Islander: Not Specified/Unknown	White: Not Specified/Unknown
	US Citizen
	Non-US Citizen/US Resident
Citizenship: <b>₩</b>	Non-US Citizen/Non-US Resident, Traveled to US for Reason Other Than Transplant
	Non-US Citizen/Non-US Resident, Traveled to US for Transplant
Year of Entry to the U.S.	
	NONE
	GRADE SCHOOL (0-8)
	HIGH SCHOOL (9-12) or GED
Highest Education Level: <sup>₩</sup>	ATTENDED COLLEGE/TECHNICAL SCHOOL
righest Education Level.	ASSOCIATE/BACHELOR DEGREE
	POST-COLLEGE GRADUATE DEGREE
	N/A (< 5 YRS OLD)
	IN INTENSIVE CARE UNIT
Medical Condition at time of listing:	HOSPITALIZED NOT IN ICU
	NOT HOSPITALIZED
Patient on Life Support:*	• YES • NO
	Extra Corporeal Membrane Oxygenation
	Intra Aortic Balloon Pump
	Prostacyclin Infusion

	Prostacyclin Inhalation
	Inhaled NO
	Ventilator
	Other Mechanism, Specify
Specify:	
Functional Status: <b>*</b>	
	No Limitations
	Limited Mobility
Physical Capacity:	Wheelchair bound or more limited
	Not Applicable (< 1 year old or hospitalized)
	C Unknown
Working for income: *	YES ONO UNK
If No, Not Working Due To:	
	G Working Full Time
	Working Part Time due to Demands of Treatment
	Working Part Time due to Disability
	Working Part Time due to Insurance Conflict
If Yes:	Working Part Time due to Inability to Find Full Time Work
	Working Part Time due to Patient Choice
	Working Part Time Reason Unknown
	Working, Part Time vs. Full Time Unknown
	Within One Grade Level of Peers
	C Delayed Grade Level
Academic Progress:	Special Education
	Not Applicable < 5 years old/ High School graduate or GED
	Status Unknown

	Full academic los	ad
	Reduced academ	nic load
Academic Activity Level:	Unable to partici	pate in academics due to disease or condition
	Not Applicable <	5 years old/ High School graduate or GED
	Status Unknown	
Previous Transplants:		
Organ	Date	Graft Fail Date
The three most recent transplants transplants by calling 800-978-43.	are listed here. Please contact the UNet He 34 or by emailing unethelpdesk@unos.org.	lp Desk to confirm more than three previous
Previous Pancreas Islet Infusion	n:**	UNK
Source of Payment:		
Primary: 🕷		
Specify:		
Secondary:		
Clinical Information: AT LIST	ING	
Height: 🕷	ft in.	cm ST=
Weight:*	lbs	kg ST=
BMI:	kg/m <sup>2</sup>	
ABO Blood Group:		
Primary Diagnosis: 🕷		
Specify:		
General Medical Factors:		
	No	
	Туре І	
	Туре II	
Diabetes: *	C Type Other	
	C Type Unknown	
	<b>7</b> 1	

	No dialysis
	Hemodialysis
Dialysis:	Peritoneal Dialysis
	Dialysis Status Unknown
	Dialysis-Unknown Type was performed
	No
Peptic Ulcer:	Yes, active within the last year
	Yes, not active within the last year
	C Unknown
	No
	Yes, and documented Coronary Artery Disease
Angina:	Yes, with no documented Coronary Artery Disease
	Yes, but Coronary Artery Disease unknown
	Status Unknown
Drug Treated Systemic Hypertension:	C YES C NO C UNK
Symptomatic Cerebrovascular Disease:	C YES C NO C UNK
Symptomatic Peripheral Vascular Disease:	C YES C NO UNK
Any previous Malignancy: <sup>₩</sup>	YES ONO UNK
	Skin Melanoma
	Skin Non-Melanoma
	CNS Tumor
Specify Type:	Genitourinary
	Breast
	Thyroid
	Tongue/Throat/Larynx

	Lung
	Leukemia/Lymphoma
	Liver
	Other, specify
Specify:	
Most Recent Serum Creatinine:	mg/dl ST=
Total Serum Albumin:	g/dl ST=

Lung Medical Factors		
Pulmonary Status:		
FVC:	%predicted	ST=
FeV1:	%predicted	ST=
pCO2:	mm/Hg	ST=
FeV1(L)/FVC(L):		ST=
O2 Requirement at Rest:	L/min	ST=
IV Treated Pulmonary Sepsis Episode >= 2 in last 12 months:	🔍 yes 🧖 no 💭 unk	
Corticosteroid Dependency >= 5mg/day:	G YES G NO G UNK	
Six minute walk distance:	# of feet	
Pan-Resistant Bacterial Lung Infection: <b>*</b>	G YES G NO G UNK	
Infection Requiring IV Drug Therapy within 2/wks prior to listing:	G YES G NO G UNK	

Heart/Lung Medical Factors:	
Most Recent Hemodynamics:	Inotropes/Vasodilators
PA (sys) mm/Hg: ╈	ST=
PA (dia) mm/Hg: <sup>ж</sup>	ST=
PA (mean) mm/Hg: <del>淋</del>	ST=
PCW (mean) mm/Hg: *	ST=
	ST=

CO L/min:*	C YES C NO
History of Cigarette Use: *	YES NO
	0-10
	11-20
	21-30
If Yes, Check # pack years:	31-40
	41-50
	○ >50
	Unknown pack years
	0-2 months
	G 3-12 months
	13-24 months
	<b>25-36 months</b>
Duration of Abstinence:	<b>37-48 months</b>
	49-60 months
	○ >60 months
	Continues To Smoke
	Unknown duration
Other Tobacco Use:	YES NO UNK
Prior Cardiac Surgery (non-transplant): *	YES NO UNK
	CABG
	Valve Replacement/Repair
If yes, check all that apply:	Congenital
	Left Ventricular Remodeling
	Other, specify
Specify:	
Prior Lung Surgery (non-transplant):	YES NO UNK

	Pneumoreduction
	Pneumothorax Surgery-Nodule
	Pneumothorax Decortication
	Lobectomy
If yes, check all that apply:	Pneumonectomy
	Left Thoracotomy
	Right Thoracotomy
	Other, specify
Specify:	

Patient Name			_ Clinic #		
Rater		Date			
Psychosocial Assessment	of Candidates for Tra	Insplantation (PAC	Т)		
Initial Rating of Candidate Quality (u	se categories 1-4 only for thos	e patients you think shoul	d be accepted for surgery)		
0	1	2	3	4	
	orderline, acceptable nder some conditions	acceptable with some reservations	good candidate	excellent candidate	
I. SOCIAL SUPPORT 1. Family or Support System St	ability				
1 2	3	4	5		
No strong interpersonal ties or highly		nships, some problems	stable, committed relationships, strong	unable to rate	
unstable relationships 2. Family or Support System Ava	evident		family commitment; good mental health supporters	1 111	
	a since		_		
12	3	4	5		
support unavailable	geographical factors	imited by emotional or S	in town with patient thru process, emotionally supportive	unable to rate	
II. PSYCHOLOGICAL HEALTH 3. Psychopathology, Stable Perso	onality Factors				
12	3	4	5		
severe ongoing psychopathology (e. schizophrenia, recurrent depression personality disorder		ty or adjustment/coping ificant reactive anxiety, on)	well-adjusted	unable to rate	
4. Risk for Psychopathology					
1 2	3	4	5		
strong family history of major psychopathology, previous significar psychiatric history in patient	periods of poor copi		no history of major psychopathology ir family, self, no periods of poor coping	unable to rate	
III. LIFESTYLE FACTORS					
5. Healthy Lifestyle, Ability to Sus	tain Change in Lifestyle				
1 2	3	1	5		
sedentary lifestyle; major dietary		ge; may require further	major, sustained changes in lifestyle,	unable to rate	
problems; ongoing smoking; reluctat to change			no major risk factors, willing to change		
6. Drug and Alcohol Use					
12	3	4	5		
dependence, reluctant to change	moderate, non-daily discontinue	use, willing to	abstinence or rare use	unable to rate	
7. Compliance with Medications a	and Medical Advice				
1 2	3	4	5		
unreliable compliance; unconcerned does not consult physician		neds; near adequate ilant usually consults	knowledgeable re meds; vigilan;t keep records; consults physician	s unable to rate	
IV. UNDERSTANDING OF TRANS 8. Relevant Knowledge and Rece					
1 2	3	4	5		
no idea of what is involved; views transplant as cure, no long-range pic	some knowledge ga	aps or denial, generally	able to state risks and benefits; realisti	c unable to rate	
Final Rating of Candidate Quality (Use categories 1-4 only for those particular of the second					
	1 orderline, acceptable under ome conditions	2 acceptable with some reservations	good candidate	4 excellent candidate	
Which of the above items contribute	d most heavily to your final rat	ing? (Circle) 1 2	3 4 5 6 7 8		

List any factors that went into your final rating other than those included above:

## TRANSPLANT EVALUATION RATING SCALE (TERS)

Category	Level	Criteria
Prior psychiatric historyAxis I	1	No significant current or past Axis I diagnosis
	2	Current diagnosis of adjustment disorder, related to health status; previous acute Axis I disorder, treated and now resolved or in long-term remission; current sub-diagnostic symptoms of an Axis I disorder
	3	Current Axis I diagnosis (other than adjustment disorder related to health status); continuing symptoms related to a chronic Axis I diagnosis
Prior psychiatric		
historyAxis II	1	No significant Axis II personality features or diagnosis; sub- diagnostic Cluster C (Avoidant, Dependent, Obsessive
Compulsive,		Passive Aggressive) symptom pattern
	2	Cluster C Axis II diagnosis; subdiagnostic Cluster A/B symptoms (A = Paranoid, Schizoid, Schizotypal; B = Antisocial, Borderline, Histrionic, Narcissistic)
	3	Cluster A/B diagnosis
Substance Use/Abuse	1	No history of heavy use/abuse of ETOH or drugs; true social drinking; very limited drug experimentation
	2	History of significant ETOH/drug use/abuse; successfully treated or stopped without treatment before or at the time of current diagnosis
	3	History of ETOH/drug use/abuse that was stopped only after significant time since current diagnosis (i.e., became too sick to use substances); ongoing ETOH/drug use/abuse

Health Behaviors	1	Practiced good health behaviors (exercise, diet, smoking, stress management) before developing illness
	2	Changed health behaviors only after current diagnosis was made
	3	Continues to practice poor health behaviors
Compliance	1	Appropriately compliant with medical regimen/advice throughout treatment
	2	Only partially compliant or compliant only with difficulty throughout treatment
	3	Noncompliant until very recent past or continues to be noncompliant
Quality of family/		
social support	1	Good-Excellent: Friends/family members present and available; willing to focus on patient's needs
	2	Poor-Fair: Some separation difficulties; some conflict and dependency problems
	3	Dysfunctional: Enmeshed or disengaged boundaries; extremely conflictual; focused on individuals' needs at expense to the patient
Prior history of coping	1	Good-Excellent: Adapts to problems and changes flexibly. Has extensive repertoire of coping behaviors
	2	Poor-Fair: Some flexibility in coping repertoire and some variations in coping responses, with general limitations. Some negativistic patterns of responding when under stress
	3	Profoundly poor: Decompensation under stress; negativistic patterns; rigid style; history of self-destructive behaviors; limited repertoire of coping behaviors; impulsive and/or aggressive responses

Coping with disease and treatment	1	Resolution of feelings about diagnosis. Considers treatment options with realistic balance of hope and concern for future
	2	Denial; lack of clarity; ambivalence over treatment choice
	3	Extreme denial; confusion over disease course; severe ambivalence about treatment
Quality of affect	1	Appropriate fears; some anxiety; appropriate sadness
	2	Moderate fears and anxiety; moderate depression
	3	Generalized anxiety; moderate-severe depression; extreme fears and anger
Mental status		
(Past and present)	1	No cognitive impairment or disorder of attention; normal sleep- wake cycle; normal activity level and responsiveness
	2	Some past or current impairment in cognitive function, attention, sleep-wake cycle, activity level, and/or responsiveness
	3	Global disorder of cognitive functions (perception, thinking, memory, or orientation), attention (awareness and consciousness; difficulties with mobilizing, shifting, sustaining, and directing attention; hyper- or hypoalert); severe disruption of normal sleep- wake cycles; reduced or heightened activity level and responsiveness (movements, speech)

## **TERS SCORE SHEET**

		Date:			
Category	Patient Rating		Weight		Weighted Score
Prior Psychiatric History Axis I		X	4	=	
Prior Psychiatric History Axis II		X	4	=	
Substance Use/Abuse		X	3	=	
Health Behaviors		X	2.5	=	
Compliance		X	3	=	
Quality of Family/ Social Support		X	2.5	=	
Prior History of Coping		X	2.5	=	
Coping with Disease and Treatment		X	2.5	=	
Quality of Affect		X	1.5	=	
Mental Status		X	1	=	
TOTAL					

**Note:** Patient ratings on each category are 1, 2, or 3, based on criteria listed in attached scale. Total is the sum of the weighted scores.

## The Transplant Evaluation Rating Scale

## A Revision of the Psychosocial Levels System for Evaluating Organ Transplant Candidates

ROBERT K. TWILLMAN, PH.D., CORINNE MANETTO, PH.D. David K. Wellisch, Ph.D., Deane L. Wolcott, M.D.

Psychosocial criteria play an important role in evaluating organ transplant candidates. The Transplant Evaluation Rating Scale (TERS) classifies patients' level of adjustment in 10 aspects of psychosocial functioning that are thought to be important in adjusting to transplantation. On the basis of pretransplant psychiatric consultations, 35 liver transplant recipients received retrospective TERS ratings. Results showed significant correlations between TERS scores and visual analogue scale ratings of five outcome variables at 1–3 years posttransplant. Significant interrater reliability was also found. The TERS represents a promising instrument for transplant candidate selection as well as a valuable tool for further research.

The number of liver transplants performed annually has increased steadily in the United States, rising from 62 in 1982 to 2,524 in 1990 (personal communication, U.S. Department of Health and Human Services, 1990). This pattern of rapid growth is largely attributable to improved outcomes resulting from advances in surgical and immunosuppressive technology and should continue as patients with a wider variety of liver diseases are treated with liver transplants.<sup>1</sup> In addition, recent improvements in the success rate of liver transplantation

as a treatment for alcohol-related cirrhosis will exponentially increase the pool of potential recipients.<sup>2-5</sup> The pressure to transplant more and more patients will result in increasing competition for organs, necessitating decisions on which patients are to receive this precious, limited resource.<sup>1,2,6-11</sup>

Currently, the screening process to help select among many candidates for a few organs typically involves consideration of a variety of psychosocial factors. Among these are the patient's psychological condition (e.g., personality characteristics, presence of any psychiatric disorder, coping resources and strengths, etc.), social support, financial status, and history of compliance.<sup>1,4,5,10,12</sup> Two recent surveys indicate that 99% of responding cardiac transplant programs<sup>13</sup> and 100% of responding liver transplant programs (Levenson, personal communication, January 28, 1991) use some form of psychosocial assessment in their candidate selection processes. Further, roughly two-thirds

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Received November 25, 1991; revised January 15, 1992; accepted January 22, 1992. From the Pittsburgh Cancer Institute and the Western Psychiatric Institute and Clinic, Pittsburgh, PA; the Cedars-Sinai Comprehensive Cancer Center, Los Angeles, CA; and the University of California, Los Angeles. Address reprint requests to Dr. Twillman, The University of Kansas Cancer Center, 3901 Rainbow Blvd., Kansas City, KS 66160-7820.

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of the programs surveyed report routinely having each patient interviewed by a mental health professional to determine suitability for transplantation. Thus, it is apparent that psychosocial assessment of potential candidates for organ transplantation plays some role in virtually every heart and liver transplant program responding to surveys.

Despite this widespread use of psychosocial screening, it remains somewhat unclear which criteria are considered important in these evaluations, how differences in various aspects of psychosocial functioning are weighed in making the ultimate decision on the suitability of the patient for transplantation, and the extent to which pretransplant psychosocial characteristics predict the medical and psychosocial outcomes of the procedure. It has been shown that psychosocial factors have some ability to predict the psychosocial outcomes of transplantation;<sup>14,15</sup> however, the surveys of Levenson<sup>13</sup> (and personal communication, January 28, 1991) indicate that, with the exception of severe active psychopathology (especially alcohol and other drug abuse), there is little agreement on which factors should constitute absolute or even relative contraindications for transplantation.

These varying standards have resulted in a call for the development of reliable and valid psychometric instruments for use in the transplantation screening process.<sup>1,11,16-18</sup> Such instruments could offer important data from both clinical and research standpoints as well as guard against the dangers of personal bias in the selection of candidates for transplantation.<sup>1,6-9,11,19</sup> A small number of articles in the literature document attempts to develop such an instrument. In one such study, the Psychosocial Assessment of Candidates for Transplant (PACT)<sup>11</sup> has displayed acceptable interrater reliability, but it apparently has not been evaluated for predictive or other types of validity.

A second rating scale, the Psychosocial Levels System (PLS),<sup>20</sup> has displayed interrater reliability and limited convergent validity. In their retrospective study of patients undergoing bone marrow transplants (BMTs) at the University of California, Los Angeles (UCLA), Futterman et al.<sup>20</sup> derived global summary scores reflecting overall adjustment by using the PLS to rate psychiatric consultation reports made when the patients entered the hospital for transplants. These summary scores were highly correlated with retrospective global ratings of the psychosocial adjustment of each patient by the inpatient consulting psychologist. These retrospective therapist ratings were further correlated with the frequency of psychiatric interventions recorded in each patient's chart, although frequency of interventions was not correlated with the instrument-derived summary scores.

To foster further research into the relative impact of psychosocial factors on organ transplant outcome and posttransplant quality of life, particularly in solid organ transplants, the Transplant Evaluation Rating Scale (TERS) has been devised. This instrument, a revision of the PLS,<sup>20</sup> elicits general ratings of patients on a number of biopsychosocial variables, weights each variable according to its theorized relative impact on outcome, and provides a single summary score that indicates a patient's current level of functioning as well as a weighted score for each variable. In revising the PLS to increase its relevance to solid organ transplant evaluations and increase specificity to promote reliability, five changes were made: the Prior Psychiatric History subscale from the PLS was divided into separate subscales for DSM-III-R Axis I and Axis II; Substance Use/Abuse, Compliance, and Health Behaviors subscales were added; and the Proneness to Anticipatory Anxiety subscale was dropped. In addition to these revisions, the weights for the individual subscales were revised by using the same method described in a study by Futterman et al.<sup>20</sup>

It was hypothesized that this revised instrument would display acceptable interrater reliability and a significant degree of predictive validity when referenced to a variety of posttransplant outcomes in a population of liver transplant recipients.

#### METHODS

#### Subjects

Forty subjects were selected from among the 137 adult (age  $\geq$  18 years) patients receiving orthotopic liver transplants (OLTs) at the UCLA Medical Center in 1987 and 1988. Selected patients had been diagnosed with either chronic active hepatitis (CAH; n = 39 in total pool) or primary biliary cirrhosis (PBC; n = 26 in total pool). Within each diagnostic group, 20 subjects were randomly selected, without regard for their surgical outcome or current medical status. Demographic characteristics of the sample at the time of the present study are shown in Table 1. There were no statistically significant demographic differences between the patients selected and those not selected. Among the CAH patients, 14 were diagnosed with type non-A,non-B hepatitis, 5 with type B, and 1 with an undetermined type.

#### Procedure

At UCLA, all patients being considered for OLT are interviewed by a psychiatrist as part of the transplant evaluation procedure. Initial psychiatric consultation (IPC) reports are generated for each patient, and the psychiatrist participates in the candidate selection meetings. To conduct the present study, IPCs were collected for each patient in the sample from the consulting psychiatrist. The IPCs could not be located for 5 of the patients. There is no reliable anecdotal information available to suggest that these patients differ in any systematic way from the remaining 35; 2 were male CAH patients (mean age = 47.5), whereas the remaining 3 were female PBC patients (mean age = 44.3), indicating that they do not differ significantly in terms of these demographic factors from other patients in their subgroups. Thus, it was possible for psychosocial ratings to be completed for 35 of the original 40 subjects. Of these 35 remaining subjects, 26 were alive at the time of the study (1–3 years post-OLT).

After the IPCs were collected, a team of three raters (R.T., C.M., and D.K.W.) divided them so that each IPC was read by two raters. The raters were all experienced in work with transplant patients and did not complete ratings on patients known to them personally. After reading each IPC, the raters classified each patient on each of the 10 individual subscales comprising the TERS.

The TERS is a revision of the conceptual PLS, which was developed at UCLA.<sup>20</sup> In the TERS, patients are categorized into three levels of psychosocial functioning on each of 10 biopsychosocial variables felt by the authors to be important in adaptation to transplantation. Table 2 shows an outline of these variables, the criteria for classifying subjects into the three levels within each variable, and the ad hoc weights assigned by the authors to reflect their opinion of the relative importance of each variable in outcome of OLT. In revising the instrument, new weights for the variables were developed by a process identical to that described in Futterman et al.<sup>20</sup> The 10 variables were rank-ordered by each of the first three authors, who then met to produce a single list of rank-ordered variables based on a combination of their rankings. Reflecting on their previ-

Characteristic	CAH Subjects $n = 20$	PBC Subjects $n = 20$	Total Sample N = 40
Age at transplant, mean ± SD	47.2 ± 12.4	49.2 ± 7.3	47.9 ± 9.5
Men/women	10/10	0/20	10/30
Alive/deceased at study	16/4	15/5	31/9

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ous BMT experiences, each individual then assigned weights to each variable, bearing in mind the importance of the variables relative to each other. The three raters then met to discuss their results and to reach agreement on a final set of ad hoc weights, producing those given in Table 2.

Thus, each patient received 10 separate ratings from each of two raters as well as a weighted summary score derived by multiplying the patient's rated level on each subscale (1, 2, or 3) by the assigned weight of the subscale and then summing across the 10 subscales. When discrepancies were found in the initial set of ratings, each rater reread the IPC and rerated the patient on the subscales in dispute while remaining blind to initial ratings of both raters. Remaining discrepancies after this process (which totaled 11 [3%] of 350 total ratings) were resolved by having the third rater read the IPC and rate the subject on the disputed subscale, blind to earlier ratings; the majority opinion was recorded as the result. These 11 discrepancies were distributed as follows: 2 on the Axis I subscale, 2 on Axis II, 1 on Ouality of Family/Social Support, 3 on Coping With Disease and Treatment, and 3 on Mental Status. The wide distribution of these discrepancies suggests that their existence may have had more to do with the information available in the IPCs than with unclear rating criteria.

While subjects were being rated on their psychosocial functioning at the time of pre-OLT evaluation, the UCLA Liver Transplant Coordinator was asked to complete a series of Visual Analogue Scale (VAS) ratings reflecting the coordinator's perception of the transplant patient's current functioning in five areas: overall success of the OLT, level of compliance, level of substance use/abuse, health behaviors, and quality of life. For each, the coordinator was asked to mark on a 100-mm line the patient's current performance. These ratings were completed with the rater blind to both the characteristics under examination and the ratings of the patients. These ratings were completed on the 28 surviving patients from among the 35 whose IPCs were rated.

Interrater reliability was evaluated by use of the kappa statistic. This statistic indicates the degree of agreement between raters and ranges from -1 to 1. A kappa statistic of 1 means perfect agreement between the raters; a statistic of 0 indicates agreement equal to the rate expected by chance. Thus, if the 95% confidence interval for the kappa statistic does not cover 0, it can be concluded that there is a significantly greater rate of agreement than that expected by chance.

#### RESULTS

#### **TERS Ratings**

The distribution of scores for the subject pool on the TERS reflects, in the authors' clinical experience, an accurate picture of the population of patients receiving OLTs at UCLA. Because of the active participation of psychiatry in the screening of patients before acceptance for OLT, there may be a skew in the population favoring patients who are relatively well-functioning from a psychosocial standpoint. The weighted summary scores on the TERS ranged from the minimum possible, 26.5, to 71.5 (maximum 79.5), with a mean  $\pm$  SD of 33.49  $\pm$  10.78. The distribution is shown in Figure 1.

#### Interrater Reliability

Kappa statistics for the TERS ratings can be found in Table 3; they indicate a significantly greater rate of agreement than that expected by chance, suggesting that subjects can be rated reliably by multiple raters on the basis of the criteria given.

Effects of Demographic Variables on TERS Scores

A series of *t*-tests was conducted to investigate the impact of gender and diagnostic group on TERS ratings, comparing these groups not only on the weighted TERS summary score, but

## Transplant Evaluation Rating Scale

Psychosocial Characterist and Weight	ic Level 1	Level 2	Level 3
Prior psychiatric history: DSM-III-R Axis I Weight = 4.0	None	Current adjustment disorder, due to health; previous Axis I disorder, treated and now resolved; current significant symptoms of Axis I disorder	Current Axis I diagnosis (not adjustment disorder due to health); continuing symptoms of chronic Axis I disorder
Prior psychiatric history: DSM-III-R Axis II Weight = 4.0	No diagnosis; sub- diagnostic symptoms of DSM-III-R cluster C disorder	Cluster C Axis II diagnosis; subdiagnostic symptoms of cluster A or B disorder	Cluster A or B Axis II diagnosis
Substance use/abuse Weight = 3.0	No history of heavy use/abuse of alcohol or drugs; true social drinking; very limited drug experimentation	History of significant use/abuse; successful treatment or stopped before current diagnosis	History of use/abuse stopped only after significant time since current diagnosis; ongoing use/abuse
Compliance Weight = 3.0	Appropriately compliant throughout treatment	Only partially compliant or compliant only with difficulty throughout treatment	Noncompliant until very recently or still noncompliant
Health behaviors Weight = 2.5	Practiced good health behaviors (exercise, no smoking, diet, etc.) before developing illness	Changed health behaviors only after diagnosis was made	Continues to practice poor health behaviors
Quality of family/social support Weight = 2.5	Good-excellent: friends/ family members present and available; willing to focus on patient's needs	Fair-good: some separation difficulties; some conflict or dependency problems	Fair-poor: enmeshed or disengaged boundaries; extreme conflicts; focused on individuals' needs at patient's expense
Prior history of coping Weight = 2.5	Good-excellent: adapts to problems and changes flexibly; has extensive repertoire of coping behaviors	Fair-good: some flexibility in coping repertoire and some variations in coping responses, with general limitations; some negativistic patterns of responding when under stress	Fair-poor: decompen- sation under stress; negativistic patterns; rigid style; history of self-destructive behaviors; impulsive and/or aggressive responses
Coping with disease and treatment Weight = 2.5	Resolution of feelings about diagnosis; considers treatment options with realistic balance of hope and concern for future	Denial; lack of clarity; ambivalence over treatment choice	Extreme denial; confusion over disease course; severe ambivalence about treatment
Quality of affect Weight = 1.5	Appropriate fears; some anxiety; appropriate sadness	Moderate fears and anxiety; moderate depression	Generalized anxiety; severe depression; extreme fears and anger
Mental status (past and present) Weight = 1.0	No cognitive impairment or disorder of attention; normal sleep-wake cycle; normal activity level and responsiveness	Some past or current impairment in cognitive function, attention, sleep-wake cycle, activity level, and/or responsiveness	Global disorder of cognitive functions, attention; severe disruption of sleep-wake cycles; reduced or heightened activity level and responsiveness

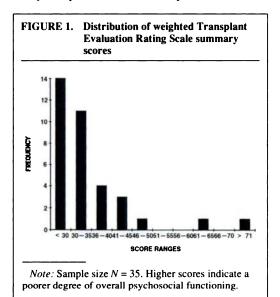
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on each individual subscale as well. No significant differences in any of these ratings were found between men and women. Between diagnostic groups, only mental status was significantly different (mean = 1.56 for CAH patients, 1.12 for PBC patients; t = 2.64, P = 0.014); however, there was a trend for CAH patients to display higher scores on Axis I (mean = 1.44 vs. 1.12; t = 1.97, P = 0.060). Although the most parsimonious interpretation of these results is that disease status of the patients is related to their mental status and Axis I scores, this can only be proven through further research.

#### **Relation of TERS Scores to Outcome**

Comparisons of weighted TERS summary score, individual subscale scores, and age were made between the 31 patients who were alive 1–3 years post-OLT and the 9 patients who had



died. None of these t-tests reached statistical significance, although there was a trend for the deceased patients to be older (mean = 52.67 vs. 46.45 years; t = 1.75; P = 0.089). This overall pattern is not surprising because, with the exception of one patient who died 9 months posttransplant (shortly after undergoing a second transplant), all the deceased patients died (all of sepsis) within the first 75 days post-OLT. The mean time to death for all 9 decedents was 68 days; this is reduced to 41 days when the one outlier is eliminated. Thus, these deaths are most likely attributable to perioperative complications, and it is unlikely that any of these patients (other than the one 9-month survivor) had left the hospital. Thus, it seems unlikely that psychosocial factors had a significant impact on survival in this sample.

Table 4 contains the results of correlational analyses between the weighted TERS summary score and the VAS ratings of the liver transplant coordinator. For the 28 surviving patients, there are highly significant correlations between the pretransplant TERS score and levels of compliance, substance abuse, and health behaviors, as well as a significant correlation between the TERS and quality of life, all when measured 1-3 years post-OLT. When only the CAH patients are considered, the correlations between the TERS and compliance, substance use, and health behaviors become even stronger, reaching the r = 0.70 level for all three and the r =0.80 level for two. In this subsample, there is no longer a significant correlation between the TERS and quality of life, although a very significant correlation is found with overall success of the OLT. Finally, for the PBC subjects, the relationships are less striking overall, although there are still significant correlations

Rating Team	Percentage of "Hits"	Kappa	95% Confidence Interval Minimum	95% Confidence Interval Maximum
Team 1 $(n = 25)$	86	0.585	0.461	0.708
Team 2 $(n = 3)$	77	0.407	0.209	0.605
Team 3 $(n = 7)$	71	0.513	0.229	0.797
Total	83			

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with health behaviors and quality of life and significant trends for compliance and substance use. In these last two cases, the correlation coefficients still reach approximately the r = 0.50 level, suggesting that a significant correlation might be found if the sample were somewhat larger than 13. (With similar distributions of scores and correlation coefficients, perhaps as few as an additional five subjects would lower the *P*-level to < 0.05.) Thus, overall, these correlations suggest that the TERS score is a highly significant predictor of several facets of psychosocial outcome of OLT, especially when the subjects in question come to transplant because of sequelae of CAH.

#### DISCUSSION

With the increasing use of OLT as a treatment for a wider variety of diseases, there is increased competition for the available supply of donor organs. One factor that has been considered frequently in decisions on who should receive a transplant is psychosocial functioning. Because using psychosocial criteria increases the potential for personal bias and results in the frequent reliance on clinical judgment alone, which may be less than optimal, it will be increasingly important for evaluators and decision makers in this field to use methods that have demonstrated empirical reliability and validity. One potential solution to these problems is the use of structured psychometric instruments. We believe that the TERS is the first such instrument to provide evidence of its reliability and predictive validity.

The data presented here suggest that this simple rating scale, used in conjunction with a psychosocial history interview typically employed in the evaluation of transplant candidates, displays significant interrater reliability. It is therefore ideal for a situation in which individual candidates within one program may be evaluated by different mental health professionals. In fact, the high degree of interrater agreement found in the ratings of the subjects in this investigation is somewhat surprising, considering that 1) the ratings were based on IPCs written up to 3 years before the instrument was first designed; 2) the IPCs were not designed to specifically address these variables; and 3) the raters did not personally know the patient being rated. Given these factors, it would seem likely that a prospective replication of this study, in which interviewers could use the framework provided by the TERS as a guideline in formulating the topics of their evaluation, would provide an equally high or higher rate of interrater agreement.

The predictive validity displayed by the TERS is also vital if the instrument is ultimately to be useful in screening transplant candidates. The purpose of evaluating candidates psychosocially is to try to determine which individuals are at greatest risk for noncompliance or other behaviors that would jeopardize the success of

		All Subjects (N = 28)		Subjects n = 15)	<b>PBC Subjects</b> $(n = 13)$	
Variable	r	P	r	P	r	Р
VAS success of OLT	-0.227	0.245	-0.585	0.022	0.246	0.418
VAS compliance	-0.636	< 0.001	-0.799	< 0.001	-0.492	0.087
VAS substance use	0.643	< 0.001	0.709	< 0.001	0.537	0.059
VAS health behaviors	-0.671	< 0.001	-0.807	< 0.001	-0.555	0.049
VAS quality of life	-0.415	0.028	-0.273	0.326	-0.579	0.038

thotopic liver transplant. Higher score on Transplant Evaluation Rating Scale indicates poorer overall psychosocial functioning. Higher scores on VAS substance use scale indicate greater substance use. For all other VAS variables, higher scores indicate more positive outcomes. VAS scores on variables rated by transplant coordinator.

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their transplant. Once this has been accomplished, these patients, depending on the individual program's policies, can be placed lower on the priority list for transplant. They also can be treated using early, secondary psychosocial interventions designed to decrease their risk of a less favorable transplant outcome through modifying the factors that place them at risk. In this study, the TERS provides evidence, although admittedly preliminary, of its ability to predict patients' levels of compliance, health behaviors, and substance abuse for as long as 1-3 years after their transplants. Given that these three variables represent significant sources of graft-damaging behaviors, the ability to predict them is essential.

The TERS's slightly diminished ability to predict overall success of the patients' transplant and quality of life at 1–3 years post-OLT suggests that behavioral factors represent only a portion of the total contribution to these two global outcome variables. In fact, the demonstration that the TERS is significantly correlated with success of the transplant in the CAH subjects and with quality of life in both the PBC subjects and the total sample is surprising given the presumed overwhelming biological determinants of OLT outcome.

In evaluating these results, a number of shortcomings must be considered. First, the sample for this preliminary pilot study is small, suggesting that some of these findings might not hold if a greater number and variety of patients were included. With the current interest in performing OLTs in patients with alcoholrelated cirrhosis, in which the behavioral risks are presumed to be much greater than in patients with CAH and PBC, the predictive power of the TERS and other instruments would be much more vital. However, the magnitude of the correlation coefficients is such that, for some relationships, as much as 64% of the variance in the outcome ratings is accounted for by the TERS score. Considering the relative restriction in the range of TERS scores imposed by both the limited sample size and the effects of the prescreening performed in the candidate evaluation process at UCLA, correlations of this magnitude are impressive. Given these factors, the magnitude of the relations found is very encouraging for further research.

A second potential source of difficulty in generalizing these results to the clinical situation is the use of liver transplant coordinator ratings as the outcome variables. By definition, these are the subjective perceptions of one member of the health care team. Therefore, they may or may not accurately reflect the "true" situation (in terms of the behavioral outcomes) or the opinions of others involved in each individual case (especially the patient and/or the physicians). Certainly, future investigations of the predictive validity of the TERS should use additional sources of outcome data. However, the rater for these outcome variables was blind to subject ratings, including the specific biopsychosocial variables considered in the TERS. In addition, there is no reason to believe that the transplant coordinator should be any more biased than the patient or the physicians involved, albeit in different ways. We felt it was important to include these coordinator ratings as outcome variables to attempt to balance the inherent subjectivity of the VAS outcome ratings with the objectivity of a rater who has seen hundreds of OLT recipients over a period of years.

Other potential criticisms of these results could not be addressed within the limitations of the present study. For instance, the weights used to determine the summary score were assigned in an ad hoc manner, based on the clinical experience of the authors as to their importance in determining the outcomes of interest; this is the common procedure when a new scale is first derived. Statistically derived weights should be helpful in improving the relationships between the TERS score and outcome variables, such as quality of life and overall success of the OLT, but must be replicated on a much larger sample. In the course of determining such weights, it might be discovered that some of the psychosocial characteristics assessed here are superfluous, and the instrument can be shortened. The retrospective nature of the present study represents another potential concern in the generalization of these results. As mentioned above, a prospective study should have a favorable impact on the interrater reliability of the TERS scores, as the structure provided by the instrument could be used to guide the psychosocial assessment interview. The chances that a prospective study would find a significantly different picture of the instrument's predictive validity should be relatively limited, since the only influences operating on this factor should be the changes in reliability and modifications in the outcome (dependent) variables used. A prospective study may unfortunately muddy the picture somewhat, because individuals identified as high risks on the basis of their TERS scores may be the intentional or unintentional targets of greater psychosocial intervention. This, by definition, attempts to keep them in the lowest level of psychopathology possible and ideally prevents them from decompensating during the hospitalization into more psychopathology and a higher (worse) level on the TERS. This mandates a prospective study, and one is planned.

improve the state of clinical practice and research methodology in the important area of psychosocial influences on the outcome of organ transplantation. It provides clinicians with a means of organizing their informationgathering efforts, weight the data collected, and derive a single summary score reflecting the patient's overall level of adjustment. Should its reliability and validity be confirmed in further studies, the TERS can become a valuable instrument enabling consultants to organ transplant programs to predict patients' psychosocial adjustment. Psychosocial consultants will be able to diagnose and intervene earlier, thus reducing stress levels on patients, their families, and the staff members who care for them.

The authors wish to acknowledge the following individuals: Deborah Besbris, R.N., for ratings of transplant outcome; Ann Futterman, Ph.D., for assistance in devising the test instrument; Jerry Lee, Ph.D., for assistance with data analysis; and Grayson Norquist, M.D., for providing access to psychiatic consultation reports.

In summary, the TERS is an early effort to

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## Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT) Assessment Long Form©

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#### **DEMOGRAPHIC INFORMATION**

Type of transpl	ant proposed: [] E	BMT [] Heart [] Hea	art/Lung [] Intestinal	[] Kidney [] Liver	[]Lung []LVAD []"Fulmi	
Name of Intervi	ewer:					
Date of evaluation:			tion:	Present:		
			onfidentiality reviewed	ntiality reviewed [] Informed consent obtained		
Patient:				MRN:		
DOB:		Age:	Gender: [] Male	[] Female		
Address:		Phone:				
Relationship :	status: [] Sing		Married [] Sep	arated []	Common-law	
p	[] =		[] Widowed		[] Lesbian	
Ethnicity:	[ ] Caucasian [ ] South Asian	[ ] African American [ ] Other:		[] Hispanic/Latino		
Languages spoken: Fait		Faith	n system:			
			Drimony core D	hysisian		

#### **PSYCHOSOCIAL TRANSPLANT MEDICINE - SUMMARY OF FINDINGS & RECOMMENDATIONS:** S.I.P.A.T. score: \_\_\_\_\_

**Psychosocial Recommendations:** 

Note: grey-out sections in the body of the forms represent the essential elements of the SIPAT scoring instrument .

#### **HISTORY OF PRESENTING ILLNESS**

(Brief chronological medical Hx pertinent to transplant, previous surgeries, hospitalizations, first experience with medications, "transplant")

SOCIAL HISTORY
Developmental History:         Born:       The ofchildren.
Raised by:
Parental relationships during Childhood Mother:
Father:
[] The patient reports good parental relationships during his/her early childhood.
Educational History: Highest level of education obtained?
Primary language:
Can patient read, write, and understand English? [] Yes [] No If No, why?
[] Patient is literate[] Patient does not know how to read[] Patient has limited literacy[] English is not patient's primary language[] Hx of special education or developmental delay
<b>Employment History:</b> [] Employed [] Disabled [] Unemployed [] Retired [] Homemaker [] Self-employed Current occupation:
Spouse/partner employed? [] Yes [] No If Yes, where?
Financial & Insurance History: Financial source(s):
Insurance source(s):
[] No financial concerns [] Financial concerns [] Insurance concerns [] Resource education provided [] Referred to transplant financial coordinator

Relationship History & Current Supportive Relations	hips (Duration/brief de	escription	n/why ended/childre	n):
1.				
2.				
3.				
4.				
SUPPORT SYSTEM				
Living Space and Current Living Situation [SIPAT#8]:				
Who lives in your household [SIPAT#6]?				
Who will be involved as patient's caregiver support team?	Primary:		·	
	Secondary:			
RELATIONSHIP STABILITY       [SIPAT#7]:         [] Strong/stable relationship       [] Domestic violence         [] Evidence of current relationship discord       [] Sexual issues report	[] Major sources o ted [] Hx of relationshi			
Do caregiver(s) have a realistic understanding of caregiver role	and responsibilities?	[]Yes	[] No	
[] SH&C Caregiver Agreement reviewed and signed.	[] Further caregiving counse	eling, educati	ion & teaching warranted.	
RELOCATION [SIPAT#8]				
Will the patient have to relocate post-transplant?		[]Yes	[] No	
Has the patient been explained the post-transplant relocation re	equirements?	[] Yes	[] No	
Has the patient been explained housing options?		[]Yes	[] No	
Has the patient identified an acceptable relocation plan?		[]Yes	[ ] No	
Are there any barriers that prevent patient from being able to re If yes, please explain:	elocate?	[]Yes	[] No	
SELF-MANAGEMENT WITH MEDICAL TREATM	ENT [SIPAT#3,4,5,7,	, <b>13]</b> [ ] Unab	le to assess due to:	
Medical Treatment: Has patient had difficulty following doctor's recommendations o [] Yes [] No If Yes, explain:				
Has patient had difficulty attending medical appointments or co [] Yes [] No If Yes, explain:	mpleting tests?			
Has patient experienced difficulties taking their medications?				
Has patient experienced side effects from their medications? [] Yes [] No If Yes, explain how you have managed	ged them:			
	count them out daily patient did not bring list of r	[ rx	[] use alternative system	
Who manages the patient's medications?				
Who is in charge of scheduling clinic appointments?				
How involved is the patient in his/her own care?				

#### UNDERSTANDING OF ILLNESS & TRANSPLANT PROCESS [SIPAT#1, 2]

[] Unable to assess due to:	
When did patient first learn they might require a transplant?	
What does patient think may have caused their organ failure?	
Has the patient met anyone who has had an organ transplant? [] Yes [] No If Yes, whom & when?	
Has patient been provided transplant education/teaching? [] Yes [] No If Yes, from whom & when?	
What education/teaching materials has patient received?         [] Transplant Education Manual (SH&C)       [] Partnering With Your Transplant Team (DHHS)       [] Psycho-education         [] What Every Patient Needs to Know (UNOS)       [] Other	
Has patient/caregiver read them? [] Yes [] No If No, explain why?	
Knowledge about transplant process & procedure? (indicate areas where patient is knowledgeable)       [] unknown length of wait time         [] selection process       [] waitlist status       [] unknown length of wait time         [] dry runs       [] length/course of hospitalization       [] rehab/recovery         [] benefits/risks of transplant       [] immune-suppression therapy       [] relocation         [] post-transplant follow-up       [] personal monitoring & surveillance	
WILLINGNESS/DESIRE FOR TRANSPLANTATION: [SIPAT#3] - Who suggested the transplant?	
- How did you react?	
- How do you feel about it now?	
- Why are you pursuing it?	
- Who seems to be pushing for it more: you, your family, doctors?	
Does patient have any concerns about the transplant surgery? [] Yes [] No If Yes, explain:	
*Is patient aware of the Living Donor Program? (*KIDNEY, LIVER & BMT ONLY) [] Yes [] No If Yes, what is there understanding?	
[] Has not received sufficient information [] Has not read education materials [] Asked appropriate/meaningful questions [] Lim of understanding [] Reasonable level of understanding [] Good level of understanding [] Further counseling, education teaching warranted	ited level on &
PSYCHOLOGICAL HEALTH [] Unable to assess due to:         Past Psychiatric History [SIPAT#9, 10, 11]         History of Abuse: [] Verbal [] Physical [] Sexual [] Domestic Violence         [] There is no Hx of verbal, physical, sexual or domestic violence.         [] History of ANTISOCIAL BEHAVIOR, EXPLAIN:         Hx of any significant past psychological symptom, diagnosis or treatment? OR any past psychiatric hospitalizations, prior mental health of	contact?
Hx of personality traits, self-destructive or aggressive behavior? [SIPAT#11]	
History of psychotropic medication use (name of Rx, effect, date-length-reason for use, Rx'd by?, reason for d/c?):	
Hx of adverse cognitive reactions to medical illness or its treatment? (e.g., confusion, delirium, dementia-like symptoms) [SIPAT#10]	
Hx of adverse psychological reactions to medical illness or its treatment? (e.g., adjustment disorder, depression, mania)	
[] The patient has never been seen, treated or diagnosed by a psychiatrist, psychologist or mental health professional. S/he has no prior history of psychiatric hospitalizations, suicidal attempts or self-injurious behaviors.	

SU	BSTANCE USE HISTORY [SIPAT#14, 12, 13, 17, 15] [] Unable to assess due to:
	Onset of Use Date/Habitual Use Date/Problem Current Use (amount/frequency/problem?)
1.	Alcohol:
[] []/	CAGE Score:/ 4. Administered AUDIT AUDIT score:/40 AUDIT interpretation:
Doe	s patient currently consume alcohol? [] Yes [] No Amount of "standard drinks" per occasion?
Cur	rent alcohol consumption: [] "light" [] "moderate" []" heavy"
Ear	's?[] Yes[] NoDrinking throughout the night?[] Yes[] Nockouts?[] Yes[] NoMinor withdrawal symptoms?[] Yes[] Noy AM drinking[] Yes[] NoDT's?[] Yes[] NoDH-related arrests[] Yes[] NoETOH withdrawal seizures?[] Yes[] No
Has	alcohol use ever affected your: work: [] Yes [] No family: [] Yes [] No relationships: [] Yes [] No
	es, explain:
	your doctor ever requested you to stop drinking? [] Yes [] No If Yes, when:
	lence of alcohol abuse?       [] Yes       [] No         Alcohol dependence?       [] Yes       [] No
Dat	e of last use:
	Onset of Use Date/Habitual Use Date/Problem Current Use (amount/frequency/problem?) Date of last use
2.	Tobacco:
3.	Marijuana (PO, inhaled):
4.	Cocaine (IN, IV):
5.	Psychostimulants (PO, IV, IN):
6.	Heroin (IN, IV):
7.	Hallucinogens:
8.	Prescription Medications:
9.	Others:
[]A	dministered DAST DAST score: DAST interpretation:
Pre	vious alcohol or drug treatment? (include times and dates & why they terminated)
Any	history of recidivism?
Has	the patient use any substances after learning of their renal or other serious medical problems?
Ave	rage Length of Sobriety after Completion of Treatment?
	the patient continue to use ANY substance of abuse (including ETOH & THC) after learning of their medical condition/organ are?

MENTAL STATUS [SIPAT#9,10,11] [] Unable to assess due to:
Description:         [] The patient was found sitting in the waiting room accompanied by
Inappropriate Flat Blunted Unhappy Apathetic Anhedonic Dysphoric Grandiose Tense Panicky Labile Anxious Excited Manic Hypomanic
Thought Content:         [] The thought content was appropriate to questions. The patient denies any suicidal ideation, homicidal ideation, or death wish. There are no signs of psychosis irrational fears, obsessions or phobias. Or         Suicidal Ideation       Homicidal Ideation       Paranoid Ideation       Suspiciousness       Phobias       Obsessions       Delusions         Hypochondriasis       Ideas of Reference       Magical Thinking       Grandiosity       Hyper-religiosity       Thought: insertion       Withdrawal       Broadcasting       Blocking         Thought Process:       [] The thought process was goal directed and coherent. Or       Rambling       Circumstantial       Tangential       Neologisms       Flight of Ideas         Ambivalence       Perseveration       Clang Associations       Clang Associations       Or         [] Perceptions:       []       Perceptions:       Imagical Ill/Hall       Depersonalization       Derealization
Neuro-Vegetative Functions: Energy: [] Energy level is good. The patient is able to perform most usual functions. [] Poor. Unable to carry out most of his/her usual functions. [] Fatigued most of the time.
Sleep:       [] Sleep pattern was reported as intact and regular, with no initial, middle or late insomnia. Or         [] Difficulties falling asleep       [] Awakening too early in the morning         [] Awakening many times during the night & difficulty falling back to sleep       [] Nightmares         [] Difficulty falling asleep even with sleep medications
Appetite: [] Appetite is reported to be intact, with no significant changes in weight.         [] Decreased appetite with an associated weight loss of lbs.         [] Increased appetite with an associated weight gain of lbs.         Intelligence         [] Intelligence and general information appeared appropriate to the level of education.         [] Impaired.
Cognition: [] Cognition appears relatively intact. [] Impaired – formal psychiatric evaluation is recommended.
Abstraction [] Abstraction was good; with similarities and proverbs interpreted correctly. [] Impaired.
Judgment [] Judgment capacity appeared adequate, with appropriate response to a simple hypothetical situation. [] impaired.
Insight
[] Psychological insight into current circumstances was good. [] Impaired
IMPRESSION REGARDING PATIENT'S OPENNESS AND TRUTHFULNESS DURING EVALUATION [SIPAT#12]

(Especially in relation to available records, conversations with other members of the Transplant team or healthcare team and support):

#### **PSYCHIATRIC DIAGNOSTIC IMPRESSION:**

[] Psychiatric consult recommended – FOR PSYCHOLOGISTS AND SW's ONLY.

# **Stanford Integrated Psychosocial Assessment for Transplant**

(SIPAT)

Stanford University Medical Center

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Patient's Name:	Date:
Patient's MR#:	Total Score:
SIPAT Examiner:	

#### A. PATIENT'S READINESS LEVEL

#### I. Knowledge & Understanding of Medical Illness Process (that caused specific organ failure)

- 0) Excellent Understanding: High degree of self-directed learning and excellent knowledge of treatment risks & benefits.
- 1) Good Understanding: Patient & support system are fully aware of the cause of illness & contribution to current health status.
- 2) Moderate Understanding: Patient has modest knowledge despite teaching/material provided.
- 3) Limited Understanding: Patient only has rudimentary knowledge despite of years of illness & extensive teaching by providers.
- 4) Poor Understanding: Extreme denial or indifference evident.

#### II. Knowledge & Understanding of the Process of Transplantation

- 0) Excellent Understanding: High degree of self-directed learning and excellent knowledge of treatment risks & benefits.
- 1) Good Understanding: Patient & support have studied & understood provided literature Or A patient who just found out about his/her condition and no education has been provided.
- 2) Moderate Understanding: Patient has modest knowledge despite teaching/material provided.
- 3) Limited Understanding: Patient only has rudimentary knowledge despite of intensive teaching by providers.
- 4) Poor Understanding: Extreme denial or indifference evident.

#### III. Willingness/Desire for Treatment (Transplant)

- 0) Excellent: Patient highly motivated & directly involved in his/her medical care.
- 1) Good: Patient expresses interest but actions only acceptable at best.
- 2) Moderate: Patient appears ambivalent; only passively involved in process.
- 3) Limited: Family member or MD more interested in Transplant process than patient.
- 4) Poor: Family member or MD pushing patient to participate in the Transplantation evaluation process.

#### IV. Treatment Compliance/Adherence (Pertinent to medical issues)

- 0) Excellent: Full compliance & effective self-management.
- 2) Good: Patient may be challenging, but fully compliant.
- 4) **Moderate:** Only partial compliance, requires multiple efforts and persuasion from the Transplant team and/or family.
- 6) Limited: Only compliant after the development of complications.
- 8) **Poor:** Evidence of significant treatment non-adherence with negative impact in patient's health (i.e., Treatment non-adherence/compliance; continued substance use after learning of illness).

#### V. Lifestyle Factors (Including diet, exercise, fluid restrictions; and habits according to organ)

- 0) Able to modify & sustained needed changes- self initiated.
- 1) Patient is reluctant but compliant with recommended changes.
- 2) Patient complies with recommended changes only after much prompting and encouragement from support & Transplant team.
- 3) Patient complies with recommended changes only after the development of complications.
- 4) Unhealthy diet & sedentary lifestyle. Reluctant to change. (i.e., non-adherence with recommended restrictions; continued substance use after learning of illness).

## **Stanford Integrated Psychosocial Assessment for Transplant** (SIPAT)

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#### **B. SOCIAL SUPPORT SYSTEM**

#### VI. Availability of Social Support System

- Excellent: Several family, significant others &/OR friends have been identified and are actively engaged as part of 0) the support system. Excellent back-up system in place.
- **Good:** Only one support person has been identified & appears engaged. A back-up system has not been confirmed. 2)
- **Moderate:** The patient's identified support system appears unreliable or inconsistent. No reasonable backup 4) system identified.
- Limited: Patient identified support system, but support person appear conflicted, uncertain or uncommitted. No 6) reasonable backup system identified.
- 8) Poor: Patient unable to identify reliable support system, or identified caregiver has failed to present to clinic.

#### VII. Functionality of Social Support System

- 0) Excellent: Support members have demonstrated initiative in learning & already committed to and engaged in patient's care. They are ready to help.
- Good: A limited support system has already committed to and has had limited engagement in the patient's care. 2) They may need some work before they are ready for transplantation.
- Moderate: Patient's identified system seems to have medical or social problems themselves which may impair 4) their ability to reliably assist the patient.
- Limited: Identified support system has problems which may prevent them for being appropriate -OR- identified 6) person(s) express doubts/hesitation/conflict.
- 8) Poor: Patient has suffered due to unreliable support system -OR- team has not been able to effectively work with support.

#### VIII. Appropriateness of physical living space & environment

- **Excellent:** Patient has permanent and adequate housing. 0)
- 1) **Good:** Patient has some stable arrangement albeit not optimal.
- 2) Moderate: Reported arrangement is only temporary & tenuous.
- 3) **Limited:** Unable to confirm reported arrangement or perceived to be inappropriate.
- 4) **Poor:** Non-existent: Patient has no stable living arrangements **–OR–** lives in environment that doesn't promote Transplant health.

### C. PSYCHOLOGICAL STABILITY & PSYCHOPATHOLOGY

#### IX. Presence of Psychopathology (other than personality disorders & organic psychopathology)

- 0) None: No history of psychiatric problems
- History of Mild Psychopathology (i.e. Adjustment disorder). Usually a self-limited problem without significant 2) impact on functioning. No treatment needed. No History of SI/SA.
- History of Moderate Psychopathology. Treatment has been effective, good compliance. No History of SI/SA at 4) present; although possible or + History SI/SA in past.
- History of severe psychopathology. Patient has needed multiple psychiatric hospitalizations in the past or 6) History of SI/SA.
- 8) Extreme History of psychopathology present (i.e., History of multiple Psych Hosp; Treatment with ECT; History of multiple SI/SA). Patient is in need for acute psychiatric intervention before proceeding.

#### IXa. Assessment of Depression (Use clinical judgment; Patient Health Questionnaire [PHQ] or Beck Depression Inventory [BDI], if available)

- No Clinical Depression; or PHQ < 5; or BDI = 0 13. 0)
- **Mild** Clinical Depression; or PHQ = 5 9; or BDI= 14 19. 1)
- Moderate Clinical Depression; or PHQ = 10 19; or BDI = 20 28. 2)
- Зĺ **Severe** Clinical Depression; or PHQ  $\ge$  20; or BDI = 29 – 63.
- IXb. Assessment of Anxiety (Use clinical judgment; Generalized Anxiety Disorder questionnaire [GAD-7] or Beck Anxiety Inventory [BAI], if available)
  - 0)
  - **No** Clinical Anxiety; or GAD-7 < 5; or BAI = 0 7. **Mild** Clinical Anxiety; or GAD-7 = 5 9; or BAI = 8 15. 1)
  - **Moderate** Clinical Anxiety; or GAD-7 = 10 14; or BAI = 16 25. 2
    - **Severe** Clinical Anxiety; or GAD-7  $\ge$  15; or BAI = 26 63.

Gray, A., Humberson, A. et al.

#### Society for Transplant Social Workers 2012

Score P2:\_\_\_\_\_\_\_74

# **Stanford Integrated Psychosocial Assessment for Transplant**

#### (SIPAT)

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# X. History of Organic Psychopathology or Neurocognitive Impairment (i.e., illness or medication induced psychopathology)

- **0)** None: No history of disease or treatment induced psychiatric problem.
- 1) History of Mild Organic Psychopathology.
- 3) History of Moderate Organic Psychopathology.
- 5) History of Severe Organic Psychopathology.

#### Xa. Assessment of Cognitive Functioning (Use clinical judgment or use MMSE, if available)

- **0)** Cognitive Functioning Within Normal Limits; or MoCA / MMSE  $\geq$  26.
- **1)** Borderline Level of Cognitive Functioning; or MoCA / MMSE = 22 25.
- 2) Impaired Cognitive Functioning; or MoCA / MMSE < 22.

#### XI. Influence of Personality Traits vs. Disorder

- **0)** None; No history of significant personality disorder or psychopathology.
- 1) History of **mild** personality traits or psychopathology in response to illness, medical treatment or psychosocial stressors.
- 2) History of moderate personality traits or psychopathology in response to illness, medical treatment or psychosocial stressors. Treatment, if needed, has been effective. Patient with good compliance, no characterological interference with treatment. No history of SI/SA.
- **3)** History of **severe** personality psychopathology or traits in response to illness, medical treatment or psychosocial stressors. Patient has needed multiple psychiatric hospitalizations in the past. History of SI/SA.
- 4) Extreme character pathology present in response to illness, medical treatment or psychosocial stressors. Patient is in need for acute psychiatric intervention before proceeding.

#### XII. Effect of Truthfulness vs. Deceptive Behavior in Presentation

- 0) No evidence of deceptive behavior by history or at present.
- 2) Patient has not volunteered some negative information, but truthfully answered direct questioning.
- 4) Patient has not been fully forthcoming with negative information, but provides it on confrontation.
- 6) Patient has not been fully forthcoming with negative information. Information obtained only from external sources.
- 8) There is clear evidence of deceptive behavior as evidence by records, collateral information or testing.

#### XIII. Overall Risk for Psychopathology (including items IX – XII)

- 0) None or minimal: No history of personal or familial psychiatric problems; no psychiatric complications to illness, medical treatment or psychosocial stressors.
- 1) Low: History of acceptable coping with previous medical challenges or psychosocial stressors.
- 2) Mild: History of poor coping with previous medical challenges or psychosocial stressors.
- 3) Moderate: Patient has experienced significant psychiatric complications to medical illness, interventions or treatment –OR– Presence of moderate psychopathology in family of origin.
- 4) Severe: History of significant psychopathology present in family of origin –OR– Patient has experienced severe psychiatric complications to medical.

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### D. LIFESTYLE & EFFECT OF SUBSTANCE USE

#### XIV. Alcohol Use/Abuse/Dependence (Use clinical judgment or use AUDIT, if available)

- **0)** None: No history of alcohol use. No risk: Audit = 0.
- 2) ALCOHOL USE NO ABUSE: History of minimal alcohol use which has caused no social or medical problems (i.e., no abuse). If requested by the team the patient promptly discontinued all alcohol use. Low Risk: Audit < 7.
- 4) MODERATE ALCOHOL ABUSE: History of moderate alcohol abuse evidenced by excessive drinking and possible deleterious bodily or social effects. Pt quit use as soon as patient learned of disease or when first told by MD. Patient may have required treatment/intervention in order to achieve sobriety. Mild Risk: Audit = 8 15.
- 6) DEPENDENCE OR SEVERE ABUSE: History of severe alcohol abuse or dependence. Patient required treatment/ intervention in order to achieve sobriety (or refused Treatment); or continued to use after disease progressed, developing medical complications. Moderate Risk: Audit = 16 – 19.
- 8) DEPENDENCE OR EXTREME ABUSE: History of extreme alcohol abuse & multiple relapses despite of warning and/or treatment. Patient continued to drink until just prior to presentation or only quit drinking when too sick to continue. High Risk: Audit > 20.

#### XV. Alcohol Use/Abuse/Dependence - Risk for Recidivism

- **0)** None: No history of Alcohol use.
- 1) Low Risk.
- 2) Moderate Risk.
- 3) High Risk.
- 4) Extreme Risk: History of recidivism after prior treatment or after an extended period of sobriety.

# XVI. Substance Use/Abuse/Dependence – Including Prescribed & Illicit Substances (Use clinical judgment or use DAST, if available)

- 0) None: No history of illicit substance Use; or abuse of prescribed substances.
- 2) History of minimal substance abuse. Quit use as soon as patient learned of disease or when first told by MD. DAST= 1 − 2.
- 4) MODERATE SUBSTANCE ABUSE: History of moderate substance abuse, but quit use as soon as patient learned of disease or when first told by MD. Patient may have required treatment/intervention in order to achieve remission. DAST= 3 5.
- 6) DEPENDENCE OR SEVERE ABUSE: History of dependence or severe abuse. Patient required treatment/intervention in order to achieve sobriety (or refused treatment/intervention); or continued to use after disease progressed, developing medical complications. DAST= 6 8.
- 8) DEPENDENCE OR EXTREME ABUSE: History of dependence or extreme substance; History of multiple relapses despite of warning and/or treatment. Patient continued to use until just prior to presentation or only quit when too sick to continue. DAST = 9 10.

### XVII. Substance Use/Abuse/Dependence – Including Prescribed & Illicit Substances -Risk for Recidivism

- **0)** None: No history of illicit substance Use; or abuse of prescribed substances.
- 1) Low Risk.
- 2) Moderate Risk.
- 3) High Risk.
- 4) Extreme Risk: History of recidivism after prior treatment or after an extended period of sobriety.

#### XVIII. Nicotine Use/Abuse/Dependence

- **0)** None: No history of Nicotine Use/Abuse.
- 1) Quit >6 months ( " " test).
- 3) Quit <6 months ( " " test).
- 5) Still currently smoking (per admission, accessory source report, or "+" test).

Score P4:\_

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SIPAT <u>TOTAL Score</u> (add scores for pp 1 – 4) :	
SIPAT Score Interpretation	
0 - 6	Excellent candidate
	Recommend to list without reservations.
7 – 20	Good candidate
	Recommend to list- although monitoring of identified risk factors may be required.
21 – 39	Minimally Acceptable Candidate
	Recommend to list under certain conditions- identified risk factors must be satisfactorily
	addressed before representing for consideration.
40 – 68	High Risk candidate, significant risks identified
	Recommend deferral while identified risks are satisfactorily addressed.
<ul> <li>&gt; 69 Poor Candidate</li> <li>&gt; Surgery not recommended while identified risk factors continue to be present.</li> </ul> Considerations for Final Psychosocial Recommendations: Overall numbers of Risk Factors (RF): Absolute Severe High Moderate/Low	
1. The patient has at least 1 absolute contraindication? Yes No	
If the answer to the above question is yes please refer to guidelines and consider deferment/decline. If none present proceed to next question.	
2. The patient has at least 2 high risk, relative contraindications? Yes No	
3. The patient has at least 3 moderate/low, relative contraindications? Yes No	
4. Patient failed to meet abstinence contract? Yes No	
5. Listed patient who failed a toxicology screening test? Yes No N/A	
6. Listed patient who is not compliant? Yes No	
7. The patient has active/unstable psychiatric symptoms in need of treatment or questionable psych history	
waiting clarification	on? Yes No
If the answer to any question #2-7 is yes, refer to guidelines for final recommendation. If none present proceed to SIPAT interpretation.	

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See example form attached on next page for Liver Recipient Patients that demonstrates the information gathered by UNOS.

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