



Data Collection Worksheet

Please Note: The Data Collection Worksheet (DCW) is a tool to aid integration of a PhenX protocol into a study. The PhenX DCW is not designed to be a data collection instrument. Investigators will need to decide the best way to collect data for the PhenX protocol in their study. Variables captured in the DCW, along with variable names and unique PhenX variable identifiers, are included in the PhenX Data Dictionary (DD) files.

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Patient Name: _____ Date: _____

Rater: _____

Psychosocial Assessment of Candidates for Transplantation (PACT)

Initial Rating of Candidate Quality

(Use categories 1-4 only for those patients you think should be accepted for surgery)

0	1	2	3	4
Poor surgery candidate	Borderline candidate acceptable under some conditions	Acceptable with some reservations	Good candidate	Excellent candidate

I SOCIAL SUPPORT

1) Family or Support System Stability

1	2	3	4	5
No strong interpersonal	Some stable relationships;		Stable, committed	[] Unable to

ties or highly
unstable
relations

some
problems
evident

relationships
strong family
commitment;
good mental
health in
supporters

rate

2) Family or Support System Availability

1

2

3

4

5

Support
unavailable

Support
availability
limited by
emotional or
geographical
factors

In town with
patient
through
process;
emotionally
supportive

[] Unable to
rate

II PSYCHOLOGICAL HEALTH

3) Psychopathology, Stable Personality Factors

1

2

3

4

5

Sever ongoing
psychopathology
(e.g.,
schizophrenia,
recurrent
depression,
personality
disorder)

Moderate
personality or
adjustment/coping
problems (e.g.,
significant
reactive anxiety,
situational
depression)

Well-
adjusted

[] Unable
to rate

4) Risk for Psychopathology

1

2

3

4

5

Strong family history of major psychopathology; previous significant psychiatric history in patient

Periods of poor coping; some psychological sensitivity to medications; some family history of major psychopathology

No history of major psychopathology [] Unable to rate in family, self, no periods of poor coping

III LIFESTYLE FACTORS

5) Healthy Lifestyle, Ability to Sustain Change in Lifestyle

1

2

3

4

5

Sedentary lifestyle; major dietary problems; ongoing smoking; reluctant to change

Some lifestyle change; may require further education to reduce risk

Major, sustained changes in lifestyle; no major risk factors; willing to change [] Unable to rate

6) Drug and Alcohol Use

1

2

3

4

5

Dependence, reluctant to change

Moderate, non-daily use; willing to discontinue

Abstinence or rare use [] Unable to rate

7) Compliance with Medications and Medical Advice

1	2	3	4	5	
Unreliable compliance; unconcerned; does not consult physician		Knowledgeable re: meds; near adequate compliance; not vigilant, usually consults physician		Knowledgeable re: meds; vigilant; keeps records; consults physician	[] Unable to rate

IV UNDERSTANDING OF THE PROCESSES OF TRANSPLANT AND FOLLOW UP

8) Knowledge and Education

1	2	3	4	5	
No idea of what is involved; views transplant as cure, no long range picture		Some knowledge gaps or denial; generally good understanding		Able to state risks and benefits; realistic	[] Unable to rate

Final Rating of Candidate Quality (Do not average above responses)

0	1	2	3	4
Poor surgery candidate	Borderline candidate acceptable under some conditions	Acceptable with some reservations	Good candidate	Excellent candidate

Which of the above items contributed most heavily to your final rating? 1 2 3 4 5 6 7 8

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

PACT Scoring Instructions

Following a comprehensive interview with the patient, including mental status examination, complete the PACT by rating the patient first with an initial impression and then along the eight dimensions described. Finally, indicate a final rating of candidate quality. Your final rating should take into account your ratings on the eight items but should not be an average.

On the following pages is a description of each of the final rating categories. Here is some additional information regarding each of the eight dimensions rated on the PACT.

1. **Family or Support System Stability:** look for recent losses, family conflict, separations, other signs of support system instability.
2. **Family or Support System Availability:** consider distance of family from transplant center, necessity of spouse continuing to work or provide child care during hospitalization, emotional distance, other demands on family (elder care, care for disabled family member).
3. **Psychopathology, Stable Personality Factors:** Most personality disorders would rate a 1 or 2, 3 at most.
4. **Risk for Psychopathology:** Look for history of postoperative psychosis or psychological reactions to steroids and other medications, rate a substance abuse history with symptoms in remission greater than 6 months also on this scale.
5. **Healthy Lifestyle:** Take into account type of disease - cardiac risk factors should be weighted more heavily for cardiac patients. Do not rate down for exercise if disability prevents the patient from participating in previously high levels of physical activity.

6. Drug and Alcohol Use: Rate use within the past 6 months. Abstinence for two weeks is not a 5. Use judgment based on amounts used, length of use, etc.
7. Compliance with Medications and Medical Advice: Rate actual compliance more heavily than knowledge on this scale, but do not rate a 5 unless patient is both knowledgeable and compliant. Look for reasons patient might miss medication, how patient would handle situation if developing side effects, systematic recording or use of pill sorter box. Also consider general health vigilance, medical appointment keeping, follow-up with recommended care for chronic or potentially recurring conditions.
8. Relevant Knowledge and Receptiveness to Education: Look for knowledge of prognosis without transplant, knowledge of survival rates, knowledge re rejection, effects of immunosuppression, length of hospital stay, requirements of the patient in follow-up period.

Final Rating, PACT

Listed below are broad general descriptions of patients who fall into each of the final rating categories on the PACT. These descriptions are intended to provide the clinician with some guidance in making final ratings. In arriving at a final rating, the eight items are not necessarily equally weighted. For example, a patient may score well in all areas except one and obtain a very low final rating due to the importance of that single area. Alternately, other patients will "lose points" due to an accumulation of minor problems in a number of areas. New raters should compare their ratings with an expert in order to develop a clinical sense of the implicit norms employed in making PACT ratings.

4, Excellent Candidate

Describes a patient who is recommended for transplant with no reservations. Patient is free of psychopathology and has good coping abilities. Family support is excellent. Patient lifestyle is consistent with active enhancement and maintenance of health following surgery. Patient is compliant with medications and collaborative with physicians. Has good knowledge regarding transplant. In addition, patient has qualities such as "will to live", optimism and confidence that are neither narcissistic (sense of entitlement) nor rooted in pathological denial of the risks of transplant surgery. This rating should be reserved for the best of candidates, and, as a rule of thumb, will not usually be assigned to more than ten percent of all candidates evaluated for transplant.

3, Good Candidate

Describes a patient who is recommended for transplant with at most minor reservations. Patient is free of psychopathology and has good coping abilities. Family support is good. Patient lifestyle is consistent with maintenance of health

following surgery. Patient is compliant with medications and collaborative with physicians. Has fair to good knowledge regarding transplant.

2, Acceptable Candidate with Reservations

Describes a patient who is recommended for transplant with some reservations. Patient may display some psychopathology or inadequacy in coping abilities, but not at a level to preclude ability to understand what is required or to form an alliance with physicians and the transplant team. Family support may range from weak to good. Patient may have had difficulty in implementing recommended lifestyle change such as smoking cessation or adherence to diet. Patient is generally compliant with medications and collaborative with physicians. Has fair to good knowledge regarding transplant.

1, Borderline Candidate, May be Acceptable Under Some Conditions

Implies conditional acceptance of the patient for transplant surgery, e. g., patients may be accepted on the condition that they display certain lifestyle changes or ability to comply with medications while waiting for transplant, or patients may be accepted on the condition they agree to participate in psychotherapy. Describes a patient who is recommended for transplant with major reservations. Patients may display significant treatable psychopathology or inadequacy in coping abilities, to the point where it is questionable whether they are able to understand what is required or to form an alliance with physicians and the transplant team. Family support may range from weak to good. Patients may have had difficulty in implementing recommended lifestyle change such as smoking cessation or adherence to diet. Patients may display pathological denial of the seriousness of their illnesses. Patients may have had difficulty with compliance with medications and collaboration with physicians. Knowledge regarding transplant may range from poor to good.

0, Poor Candidate, Transplant Not Recommended

A patient for whom transplant is seen as contraindicated on psychosocial grounds. Patient may be displaying serious psychopathology not amenable to treatment. Patient may continue significantly maladaptive habits or lifestyle such as alcohol abuse or tobacco dependence. Patient may have a history of poor compliance and failure to cooperate with physicians, which may include AMA hospital discharges. Patient knowledge regarding transplant may range from poor to good. Family support may range from weak to strong. Patients are seen as being unable to cooperate adequately with their care following surgery.