

Informed Consent in Clinical Neuropsychology Practice

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Overview: Complications arising from patient-provider interactions remains a primary source of ethical complaints or violations. One ethical issue that has a direct bearing on the patient-provider relationship is informed consent. The origin of informed consent in clinical venues has been a direct outgrowth of more than a century of legal precedents, advances in professional ethics, and progressive moral development. Informed consent allows patients to explore options and to take responsibility for their own welfare through consideration of the costs and benefits associated with the services and procedures offered to them and alternatives to those services. Informed consent is integral to patient autonomy and self-determination. Informed consent is decidedly the starting point for the patient-provider relationship and the genesis of the three key elements of ethical behavior: autonomy, nonmaleficence, and beneficence.

Historically, in comparison to the provision of psychotherapy services, formal consent procedures have been used less often in the context of neuropsychological services. Early attempts to apply the 1992 Ethics Code (American Psychological Association, 1992) to neuropsychology opined that informed consent procedures were not needed for assessment procedures. Also, there were no binding legal precedents that required informed consent for psychological services, though such precedents were well established within the medical community. Although the 1992 APA Ethics Code could be viewed by some as ambiguous, informed consent was a standard of care for at least some providers of neuropsychological services during the past decade. The Canadian Code of Ethics for Psychologists (CPA, 1991) had already made explicit the need for informed consent for "any psychological services," including assessment. Statutes for many states, which are arguably more binding to licensed psychologists, do not typically differentiate assessment from treatment activities, viewing all activities as psychological services. In 1997, Johnson-Greene and his colleagues (1997) commented on the need for informed consent in neuropsychological evaluations and offered recommendations for its content and conveyance. Overall, there has been a growing awareness of the need for neuropsychologists to candidly inform their patients about intended services and potential beneficial and deleterious effects. Consistent with such developments, the APA's revised Ethical Principles and Code of Conduct now incorporates more explicit requirements for informed consent in the conduct of psychological assessment.

Modifications in the APA Ethics Code and Current Standards for Informed Consent

The 2002 edition of the APA Ethics Code (APA, 2002), effective June 1, 2003, contains several changes that impact informed consent for neuropsychological assessment. The revised code specifies the need for informed consent for "assessments, evaluations, or diagnostic services," albeit with several notable exceptions in which patient assent represents the appropriate standard of care, addressing these issues in three sections: a) section 3.10 in Human Relations, section 4.2 discussing the Limits of Confidentiality, and section 9.03 on Informed Consent in Assessments.

What constitutes full disclosure in informed consent is less ambiguous than in previous versions of the APA Ethics Code. Section 9.03 states that consent should include: a) an explanation of the nature and purpose of the assessment, b) fees, c) involvement of third parties, and d) limits of confidentiality. The patient/client should also be provided with sufficient opportunity to ask questions and receive answers. Although not explicitly required by the revised Ethics Code, there may be good practical and ethical reasons to provide information concerning the referral source; foreseeable risks, discomforts, and benefits; and time commitment, as such elements may well be intrinsic to consent that really is adequately informed. Where mandatory reporting requirements exist (Section 4.05), such as those associated with the motor vehicle administration in some states, the limits of confidentiality and involvement of these agencies should be anticipated in neurological populations and discussed with patients as a possible limitation of confidentiality at the outset of an evaluation. As outlined in section 4.05 (a), the disclosure is technically limited to the minimum necessary to achieve the purpose. There are also several other special circumstances requiring informed consent, including the use of interpreters (9.03 c) and recording audiovisual information (section 4.03).

Informed consent is not required in some instances in which assent, as defined as the absence of objection to assessment procedures, would be considered sufficient. Such situations include the following: a) testing is mandated by law or governmental regulations, b) informed consent is implied because testing is conducted as a routine educational, institutional, or organizational activity; or c) where the purpose of testing is to evaluate decisional capacity. Section 3.1 outlines the requirements for patients' assent. Specifically, psychologists must still: a) provide an appropriate explanation, b) consider such persons' preferences and best interests, c) obtain appropriate permission by a legally authorized person if permitted or required by law; and d) seek patients' assent. There is also a need to use language that is "reasonable understandable" in such instances. Patients can or should be informed of their right to revoke consent without penalty or prejudice, though they seldom do. Though one could presume that evaluation of decisional capacity is a goal in every evaluation of a neurologically impaired patient, it would appear that this exclusion only applies when there is a reasonable expectation that a patient would be unable to give informed consent resulting in a primary *a priori* goal of the assessment to determine decisional capacity.

Additional Considerations

The APA Ethics Code (APA, 2002), much like its predecessor, does not have explicit guidelines for informed consent for children. However, it is assumed that children are included in Section 3.10, which refers to persons who are legally incapable of giving informed consent. Clearly, children should be entitled to the same considerations noted above under patient assent. That is, they should be provided with basic information about the procedures, their preferences should be noted, and their assent should be documented along with the consent of their parent(s) and/or legal guardian. Forensic cases should often be viewed in a similar vein where a normal doctor-patient relationship does not exist but where the basic components of patient assent would be expected. Person in forensic may also be precluded from receiving an explanation of their test results normally afforded to patients under section 9.10, which should be explained in advance of any evaluative procedure.

Consent in the patient's primary language to ensure proper communication and comprehension of information as well as consideration of cultural factors relevant to the consent process is essential. Inasmuch as true informed consent requires an understanding of the information that might impact consent as opposed to mere exposure to such information, and given the impaired populations with

which practitioners often work, neuropsychologists are generally encouraged to ascertain their patient's understanding of pertinent information through probing questions. The patient's accuracy can be used as a further indication of their understanding and may reveal areas requiring additional clarification. Only then can there be a high level of assurance that accurate comprehension of the risks and benefits of an evaluation have been achieved. Neuropsychologists are also generally encouraged to describe the comparative risks and benefits of procedures, including the possible alternative option to do nothing.

The APA Ethics Code (APA, 2002) does not explicitly state whether the patient's consent must be written or oral. Section 3.1 (d) states that "psychologists appropriately document written or oral consent, permission, and assent." While it may be practical and commonplace to obtain written consent in most outpatient settings, patients found in inpatient settings may be less amenable to written consent because of the acuity of their illness, psychiatric disturbance, or other factors. Also, in the acute care hospital setting neuropsychology would be undoubtedly one of the few professions seeking written consent because the hospital ordinarily has patients sign consent to treatment upon admission to the hospital. Therefore, it is recommended that neuropsychologists strive for written consent, either through presentation of their own documents or through the documents provided by an intermediary like a hospital admitting department, but that oral consent be accepted depending on the circumstances of the case.

Informed consent can be viewed as a flexible entity whose content is partly dependent on the particular set of circumstances associated with a specific patient (Fischer, Johnson-Greene, Barth, 2002). Since no two assessments are exactly alike, and thus there may be a need for some modification of ancillary information while core pieces of the informed consent package would generally remain constant. A flowchart can be found in Appendix 1, which outlines the process of determining consent content and conveyance. A sample informed consent document can be found in Appendix 2.

Summary of Informed Consent in Neuropsychological Evaluation

Autonomy and self-determination are promoted when patients have a proper understanding of the anticipated goals of an evaluation. Ironically, some patients may refuse to be evaluated who could otherwise benefit from neuropsychological consultation, though obviously it is the patient's right to exercise this prerogative assuming that they have intact decisional capacity and there is no mandate for the assessment. There current professional standard would appear to be an explicit requirement that neuropsychologists inform their patients about the nature and purpose of an evaluation and provide other pertinent data outlined above. Generic statements about the need to assess cognitive ability would probably be inadequate in most evaluative cases depending on the situation and the patient's capacity to understand and comprehend this information, and additional information of the type described above will need to be provided. Active steps should also be taken, such as probing questions, to assure that patients have a satisfactory grasp of the pertinent information.

In summary, the National Academy of Neuropsychology, in line with the revised APA Ethical Principles and Code of Conduct, strongly encourages neuropsychologists to provide informed consent to patients seeking services and views its conveyance as a basic professional and ethical responsibility. Neuropsychologists are also required to provide additional information to patients to be fully compliant state and federal laws, such as the Health Information Portability and Accountability Act (HIPAA).

References

American Psychological Association (1992). Ethical Principals of Psychologists and Code of Conduct. <u>The American Psychologist</u>, 47, 1597-1611.

American Psychological Association (2002). Ethical Principals of Psychologists and Code of Conduct. APA Web Site.

Fischer, J., Johnson-Greene, D., & Barth, J. (2002). Evaluation, diagnosis, and interventions in clinical neuropsyclogy in general and with special populations In S. Bush and M Drexler (Ed.s.) <u>Ethical Issues in Clinical Neuropsychology</u>Lisse: Swets and Zeitlinger publishers.

Johnson-Greene, D., Hardy-Morrais, C., Adams, K. M., Hardy, C., Bergloff, P. (1997). Informed consent and neuropsychological assessment: Ethical considerations and proposed guidelines. <u>The Clinical Neuropsychologist</u>, 11, 454-460.

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Appendix 1: Flowchart for Informed Consent

No

INITIAL CONTACT

Special Referral Situations

- a. Mandated by law or governmental regulations
- b. Routine educational, institutional, or organizational activity where consent is implied
- c. Evaluation of decisional capacity

Yes

Obtain Patient's Assent for Assessment Procedure

- a. Explain nature and purpose of the assessment
- b. Use language that is reasonably understandable to the person being assessed
- c. Consider patient's preferences and best interests
- d. Take reasonable steps to protect patient's rights and welfare
- e. Obtain substitute consent from authorized person when permitted or required by law*
- f. Document written or oral assent

*Note. When substitute consent from authorized persons is unavailable contact the Department of Social Services in your state.

Consider Assessment Characteristics

Patient Competency

Patient presumed or

known to be competent

Yes

a. Source of referral

No

- b. Referral question(s) and goal of the assessment
- c. Anticipated uses of assessment
- d. Inpatient or outpatient setting?
- e. Involvement of third parties?
- f. Special legal mandates or circumstances?
- g. Special limits of confidentiality?
- h. Use of interpreter?
- i. Recording of voice or images?

Obtain Patient's Consent for Assessment Procedure

- a. Content
 - 1.Referral source
 - 2. Purpose of the assessment
 - 3. Foreseeable risks, discomforts, and benefits
 - 4. Fees and testing time
 - 5.Limits of confidentiality
 - 6.Involvement of third parties
- b. Provide opportunity for patient to ask questions and receive answers
- c. Ask probing questions to assess understanding
- d. Document written or oral consent (varies depending on situation)

Appendix 2: Sample Informed Consent

Please note that this is a general template for informed consent that may not apply to your specific jurisdiction. It is recommended that psychologists seek advice from personal council to determine if this consent is appropriate for their specific jurisdictions.

Referral Source : You have been referred for a new thinking abilities) by	ropsychological assessment (i.e., evaluation of your name of referral source).
Nature and Purpose of Assessment: The goal of neuropsychological assessment is to determine if any changes have occurred in your attention, memory, language, problem solving, or other cognitive functions. A neuropsychological assessment may point to changes in brain function and suggest possible methods and treatments for rehabilitation. In addition to an interview where we will be asking you questions about your background and current medical symptoms we may be using different techniques and standardized tests including but not limited to asking questions about your knowledge of certain topics, reading, drawing figures and shapes, listening to recorded tapes, viewing printed material, and manipulating objects. Other specific goals and anticipated uses of the information we gather today includes the following: Foreseeable Risks, Discomforts, and Benefits: For some individuals assessments can cause fatigue, frustration, and anxiousness. Other anticipated risks, discomforts, and benefits associated with this assessment includes the following:	
Limits of Confidentiality: Information obtained do be released only with your written permission. The confidentiality including: a) a statement of intent to abuse of children or vulnerable adults; and c) iss foreseeable limits to confidentiality for this assessment.	here are some special circumstances that can limit harm self or others, b) statements indicating harm or uance of a subpoena from a court of law. Other
I have read and agree with the nature and purpose of this assess opportunity to clarify any questions and discuss any points of co	ment and to each of the points listed above. I have had an oncern before signing.
Patient Signature	Date
Parent/Guardian or Authorized Surrogate (if applicable)	Date
Witness Signature	Date