



The ADC Lumbar Puncture Survey

John C. Morris, MD

Friedman Distinguished Professor
of Neurology

KnightADRC
Alzheimer's Disease Research Center

WASHINGTON
UNIVERSITY
ST. LOUIS



Rationale

- Success rates for lumbar puncture (LP) for research/clinical purposes vary widely across country, culture, and center
- What influences consent for LP?
 - Perceptions of site personnel?
 - Patient experience (e.g., LP headache)?
 - Other?



Aims

- Document current experience and use of LP at each ADC
- Examine current experience and perceptions regarding LP for all ADC personnel who request consent for LP
- Determine characteristics of the patients/research volunteers who do or do not agree to undergo LP
- Determine the patient/research volunteer's experience with LP to allow complications to be assessed
- Over 2 y, obtain a qualitative and quantitative database of the experience of ADC personnel and all patient/research volunteers who are requested to have an LP

Current Status (3-13-13)

- ADC LP Experience form completed by all 27 ADCs
- 20 ADCs participating in completion of Requestor and Patient survey components
 - 59 Requestor forms completed
 - 214 Patient/Initial forms completed
 - » 179 agreed to LP
 - » 35 refused LP
 - 129 Patient /Follow-up forms completed

Preliminary Results – I.

- Reasons LP collected (at ADCs currently performing LP):
 - Research 100%
 - Diagnosis 62.5%
 - Industry-supported study 70.8%
- Asking for and agreement to LP:

Purpose of LP	Percent Asked	Percent Agreeing*
Research	40.1%	64.0%
Diagnosis	6.4%	83.9%

*Among those asked to have an LP

Preliminary Results – II.

- Characteristics of LP Requestors:

Female	53.2%
Age	45.0 y
Race	
Caucasian	80.9%
African American	2.1%
Other	17.0%
Position	
Physician	55.3%
Nurse	12.8%
Other	31.9%
Perform LPs?	51.1%

Preliminary Results – III.

- Perception of LPs:

Value of LPs performed for AD research (Not valuable = 1, Extremely valuable = 6)	5.7 ± 0.5
Discomfort caused to participants undergoing an LP for AD research (No discomfort = 1, Extreme discomfort = 6)	2.3 ± 0.6
Discomfort experienced by participants undergoing an LP compared to colonoscopy (Much less for LP = 1, Much more for LP = 6)	2.3 ± 1.3
Frequency of complications among participants undergoing an LP compared to colonoscopy (Much less for LP = 1, Much more for LP = 6)	2.0 ± 1.1
Relevance of published data on CSF A β ₄₂ and tau levels for presymptomatic of early stage dementia diagnosis/prognosis (Not relevant = 1, Extremely relevant= 6)	5.1 ± 1.2

Points of Note

- Number of Patient forms still below original goal → keep submitting through September 1st, 2013!
- Missing Patient/Follow-up forms
 - Intended to be completed within 2 weeks of the LP
- Number of Requestor forms also below original goal → additional/new people at your ADC?
- Decision made not to ask for ADC Experience form or Requestor forms again at 1 year
 - Focus efforts on Patient forms and new Requestor forms
- General questions: Krista Moulder (moulderk@abraxas.wustl.edu)
- Website access questions: Elizabeth Robichaud (erobi@uw.edu) or Duane Beekly (beekly@uw.edu)