



AD Lumbar Puncture Survey: Preliminary Results

Krista L. Moulder, PhD
Associate Executive Director
Knight ADRC

KnightADRC
Alzheimer's Disease Research Center

WASHINGTON
UNIVERSITY
ST. LOUIS



Beginnings

- Success rates for lumbar puncture (LP) for research and/or 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?
- Build on multi-center study (Europe), led by Dr. Kaj Blennow (University of Goteborg)
- Two-year US study launched in Fall, 2011
 - Led by Drs. John Morris (Wash U) and Bud Kukull (UW)
 - Funding provided by the Alzheimer's Association



Survey Design

Survey Component	Completed by:	Completed when:
ADC LP Experience	One designated individual per ADC (limited to the Director, Administrator, or the Clinical Core Leader)	<ul style="list-style-type: none"> Initially
LP Requestor	Any and all ADC personnel who are responsible for explaining the LP procedure to patients/research volunteers	<ul style="list-style-type: none"> Initially In the event of a new requestor
Patient LP Experience	One designated patient coordinator (nurse, social worker, or other health professional) per site who has knowledge of the LP procedures of patients/research volunteers	<ul style="list-style-type: none"> Just after the patient/research volunteer is requested to undergo LP (for the entire two years of the study)
Patient LP Experience – Follow-up	Same person who completed the Patient LP Experience form	<ul style="list-style-type: none"> One week after LP (for the entire two years of the study)

Summary Numbers

- ADC LP Experience completed by all 27 ADCs!
- Patient surveys submitted by 18 ADCs
- Totals:
 - 64 LP Requestor surveys
 - 606 Patient–Initial surveys
 - 462 agreed to LP (76%)
 - 144 refused LP
 - 424 Patient–Follow-up surveys
- Leading ADCs:

LP Requestor	Patient–Initial	Patient–Follow-up
Wash U	UC Irvine	UC Irvine/Penn (tie)
Columbia	Penn	Wash U
OHSU/UW (tie)	Wash U	Mayo

Requestors

- 55% of LP requestors were physicians, 12% nurses, and 33% other staff (e.g., social worker)
- Perception of the value of LPs performed for AD research (1 = "not valuable" → 6 = "extremely valuable"): 5.5 ± 0.5
- Perception of the discomfort caused to patients undergoing an LP for AD research (1 = "no discomfort" → 6 = "extreme discomfort"): 2.4 ± 0.4

What Influences Agreement to Undergo LP?

- Previous LP
 - 89.5% of participants who had a previous LP agreed to LP compared to only 72.2% of participants without a previous LP ($p < 0.0001$)
- Previous LP complication
 - Participants who had a previous LP with headache agreed to LP at a similar rate as those who had a previous LP without complication (92.3 % vs. 91.3%), but only 73.1% of participants with other previous LP complications* agreed to LP ($p < 0.03$)

*Examples: back pain, neck stiffness, nerve root pain



Frequency of Complications

- Type of needle (Quincke vs. Sprotte)

N/D; $p < 0.28$

N/D; $p < 0.69$

Gravity wins!

25.2% incidence of complication vs. 35.3%

Hemorrhage is bad. ($p < 0.03$)

45.9% incidence of complication vs. 27.4%

Less rest is better (?!) ($p < 0.02$)

24.0% incidence of complication with < 1 hr rest vs. 38.8% with ≥ 1 hr ($p < 0.002$)

Limitations

- How were participants selected to contribute to survey collection?
 - ADC form averaged 35% agreement to LP, but 84% of Patient-Initial forms indicated agreement to LP
 - Not all participants eligible for LP were asked to participate in the survey at some ADCs
- Missing follow-up forms
- Unequal contribution across ADCs

Thank You!!

- All contributing ADCs, their coordinators, LP requestors, and participants
- Alzheimer's Association (Dr. Maria Carrillo)
- Drs. John Morris and Bud Kukull
- The NACC team
 - Maggie Dean
 - Elizabeth Robichaud
 - Lilah Besser
 - Sarah Monsell
 - Duane Beekly