Exploring the Impact of Low Health Literacy on Participant Attrition in Clinical Research Studies

Laura M Curtis, MS

November 2, 2015





Acknowledgements

Northwestern University

- Michael S Wolf, PhD MPH
- Rachel O'Conor, MPH
- Stephen Persell, MD MPH
- Elisha Friesmema, BA

Mt. Sinai

- Alex Federman, MD MPH
- Melissa Martynenko, MPH





Retention is challenging in longitudinal studies





- Retention is challenging in longitudinal studies
- Associations with patient-level characteristics could bias results (Hernan et. al. 2004)





- Retention is challenging in longitudinal studies
- Associations with patient-level characteristics could bias results (Hernan et. al. 2004)
- □ Research to date (Chatfield 2006, Salthouse 2014)
 - Cognitive Functioning
 - Age





- Retention is challenging in longitudinal studies
- Associations with patient-level characteristics could bias results (Hernan et. al. 2004)
- Research to date (Chatfield 2006, Salthouse 2014)
 - Cognitive Functioning
 - Age
- Health literacy (HL) has not been examined







To explore differences in study retention rates by literacy level across 6 large-scale, federally funded projects





- Convenience sample
- Federally funded (NIH or AHRQ)
- \Box Longitudinal data with ~1 year follow-up
- Include a validated measure of health literacy





Study	Population	Location	# of time points: Timing of follow-up
LitCog	826 primary care, 55-74	Chicago, IL	3: Every 2.5-3 years





Study	Population	Location	# of time points: Timing of follow-up
LitCog	826 primary care, 55-74	Chicago, IL	3: Every 2.5-3 years
CHIRAH	353 with asthma, 18+	Chicago, IL	7: Every 3 mos
ABLE	452 with asthma, 60+	New York, NY Chicago, IL	5: 3, 12, 18, 24 mos





Study	Population	Location	# of time points: Timing of follow-up
LitCog	826 primary care, 55-74	Chicago, IL	3: Every 2.5-3 years
CHIRAH	353 with asthma, 18+	Chicago, IL	7: Every 3 mos
ABLE	452 with asthma, 60+	New York, NY Chicago, IL	5: 3, 12, 18, 24 mos
COPD	393 with COPD, 55+	New York, NY Chicago, IL	5: Every 6 mos





Study	Population	Location	# of time points: Timing of follow-up
LitCog	826 primary care, 55-74	Chicago, IL	3: Every 2.5-3 years
CHIRAH	353 with asthma, 18+	Chicago, IL	7: Every 3 mos
ABLE	452 with asthma, 60+	New York, NY Chicago, IL	5: 3, 12, 18, 24 mos
COPD	393 with COPD, 55+	New York, NY Chicago, IL	5: Every 6 mos
UMS	845 on 2+ meds, 30+	Northern VA	3: 3, 9 mos
MTM	920 with diabetes, 18+	Chicago, IL	3: 6, 12 mos





Methods: Measures

□ Interview completion status

Attrition: Not completing at least 1 interviewRetention: Completing all interviews





Methods: Measures

□ Interview completion status

Attrition: Not completing at least 1 interviewRetention: Completing all interviews

Health literacy measures

	Low	Marginal	Adequate
TOFHLA	0-59	70-74	75-100
S-TOFHLA	0-53	54-66	67-100
REALM	0-44	45-60	61-66
NVS	0-1	2-4	5-6





Methods: Measures

□ Interview completion status

Attrition: Not completing at least 1 interviewRetention: Completing all interviews

Health literacy measures

	Low	Marginal	Adequate				
TOFHLA	0-59	70-74	75-100				
S-TOFHLA	0-53	54-66	67-100				
REALM	0-44	45-60	61-66				
NVS	0-1	2-4	5-6				
Limited							





Study	Ν	Age		Race/Ethnicity		Education	Health	Literacy
		Mean (SD)	Range	% AA	% H/L	% ≤HS	Measure	% Limited
LitCog	826	63.1 (5.5)	55-74	43	3	27	TOFHLA REALM NVS	30 25 52
CHIRAH	347	30.9 (6.1)	18-41	58	27	50	REALM	32
ABLE	433	67.4 (6.8)	60-98	30	39	52	S-TOFHLA	36
COPD	337	68.1 (8.4)	55-91	44	17	48	S-TOFHLA	31
UMS	842	52.4 (9.2)	30-84	23	50	68	REALM	37
MTM	920	52.3 (9.7)	20-81	87	5	67	NVS	81





Study	Ν	Age		Race/E	hnicity	Education	Health	Literacy
		Mean (SD)	Range	% AA	% H/L	% ≤HS	Measure	% Limited
LitCog	826	63.1 (5.5)	55-74	43	3	27	TOFHLA REALM NVS	30 25 52
CHIRAH	347	30.9 (6.1)	18-41	58	27	50	REALM	32
ABLE	433	67.4 (6.8)	60-98	30	39	52	S-TOFHLA	36
COPD	337	68.1 (8.4)	55-91	44	17	48	S-TOFHLA	31
UMS	842	52.4 (9.2)	30-84	23	50	68	REALM	37
MTM	920	52.3 (9.7)	20-81	87	5	67	NVS	81

NORTHWESTERN UNIVERSITY

SCHOOL OF MEDICINE



Study	Ν	Age		Race/E	hnicity	Education	Health	Literacy
		Mean (SD)	Range	% AA	% H/L	% ≤HS	Measure	% Limited
LitCog	826	63.1 (5.5)	55-74	43	3	27	TOFHLA REALM NVS	30 25 52
CHIRAH	347	30.9 (6.1)	18-41	58	27	50	REALM	32
ABLE	433	67.4 (6.8)	60-98	30	39	52	S-TOFHLA	36
COPD	337	68.1 (8.4)	55-91	44	17	48	S-TOFHLA	31
UMS	842	52.4 (9.2)	30-84	23	50	68	REALM	37
MTM	920	52.3 (9.7)	20-81	87	5	67	NVS	81





Study	Ν	Age		Race/Ethnicity		Education	Health Literacy	
		Mean (SD)	Range	% AA	% H/L	% ≤HS	Measure	% Limited
LitCog	826	63.1 (5.5)	55-74	43	3	27	TOFHLA REALM NVS	30 25 52
CHIRAH	347	30.9 (6.1)	18-41	58	27	50	REALM	32
ABLE	433	67.4 (6.8)	60-98	30	39	52	S-TOFHLA	36
COPD	337	68.1 (8.4)	55-91	44	17	48	S-TOFHLA	31
UMS	842	52.4 (9.2)	30-84	23	50	68	REALM	37
MTM	920	52.3 (9.7)	20-81	87	5	67	NVS	81





Results

Proportion with complete interviews by literacy







*Results nearly identical for REALM and NVS

Results

Proportion with complete interviews by literacy



■Limited ■Adequate



*Results nearly identical for REALM and NVS



Results

Proportion with complete interviews by literacy



■Low ■Marginal ■Adequate





*Results similar for REALM and NVS

Conclusions

Differing attrition rates by literacy level in 4 studies
 Those with limited literacy more likely to drop out
 Gradient effect





Conclusions

- Differing attrition rates by literacy level in 4 studies
 Those with limited literacy more likely to drop out
 Gradient effect
- □ Similar attrition rates by literacy level in 2 studies
 - Randomized controlled trials
 - Shorter follow-up
 - 1 high rate of limited literacy





Limitations

- □ Sample of studies
 - Convenience sample
 - Still on-going/short follow-up time





Limitations

- □ Sample of studies
 - Convenience sample
 - Still on-going, short follow-up time
- Definition of Attrition
 - Missing at least 1 interview
 - Did not consider reasons for drop out (e.g., death, active decline, unable to reach)





Limitations

- Sample of studies
 - Convenience sample
 - Still on-going, short follow-up time
- Definition of Attrition
 - Missing at least 1 interview
 - Did not consider reasons for drop out (e.g., death, active decline, unable to reach)
- Other factors related to health literacy may explain associations





Recognize disparities in attrition could bias results





- Recognize disparities in attrition could bias results
- Potential strategies exist to prevent dropout
 Multiple modes of contact
 - Update contact information
 - Periodic communication
 - Proper incentives





Methods to account for attrition in analyses

Multiple imputation





Methods to account for attrition in analyses

Multiple imputation

Pattern mixture models (Little 1996, Rabbitt 2008)





Methods to account for attrition in analyses

Multiple imputation

Pattern mixture models (Little 1996, Rabbitt 2008)

Inverse Probability Weighting (IPW) (Hernan et.al. 2000, Seaman & White 2011)

Applied to attrition (IPAW) (Weuve 2012, Gottesman 2014)





Laura M. Curtis, MS Research Assistant Professor Division of General Internal Medicine Northwestern University Feinberg School of Medicine 750 N. Lake Shore Drive, 10th Floor Chicago, IL 60611 (312) 503 – 5538 I-curtis@northwestern.edu

