



UNIVERSITY OF  
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# Assessing the Impact of Lay Patient Advocate Training in Tribal Communities

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# Background

- Health Literacy – a key factor for effective patient advocacy and of the Social Determinants of Health.
- Defined:
  - “The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Healthy People, 2010).
- It involves knowledge, motivation and activation.
- Coulter and Ellis (2006) – “Health Literacy is fundamental to patient engagement.”

# Health Literacy and Disparities among Minority Populations

- Adult American Indians (AI) and Black Americans are twice as likely to have limited health literacy compared with white peers – Hispanic Americans 3X (Androulis and Brach, 2007).
- In South Dakota – 86% of AI students entering the adult education system have basic academic skills lower than 9<sup>th</sup> grade (State of South Dakota, 2013) – lack of health literacy is a greater barrier.

# Research Gaps

- Coulter and Ellis (2006) – establish most effective ways of delivering health information and education, particularly to those with low literacy, and to hard-to-reach, and disadvantaged groups.
- Nutbeam (2008) – the research base surrounding health literacy as a personal asset (rooted in health promotion, adult education theory, and literacy) is not well developed.
- Nutbeam recommended research using more personal forms of communication and community-based educational interventions.
- Little to no research base related to health literacy interventions among AI populations.

# Project Significance

- Assessed a new community-based method of delivering a health literacy intervention within tribal communities.
- Assessed a novel evaluation model combining measures of behavioral intention and patient activation to project impact of the training intervention.
- Utilized adult education specialists to deliver the curriculum, therefore, combining the content area expertise of health professionals with the specialized instructional expertise of adult educators.

# Three Project Aims

1. Develop Health Literacy/Self-Advocacy Training Curriculum for Laypersons in AI communities.
2. Deliver Training Curriculum via Classroom Integration in Pilot Community Adult Education Programs.
3. Deploy Novel Evaluation Model to Assess Training Curriculum Impact on Patient Activation.

- Rather than creating another centralized service organization – invested in individuals in community.
- Individuals also advocate for family members.
- Improve advocacy in “extended family unit” – the AI community.

# The Curriculum

- Curriculum Committee
- American Indian Advisory Board
- Modules

1: Becoming an Advocate

2: Medication Administration and Prescription Drugs

3: Maintaining Your Balance: Healthy Eating

4: Maintaining Your Balance: Physical Activity





# South Dakota Association for Lifelong Learning (SDALL)

- Professional association for adult educators in SD
- 67 members
- 13 organizations
- Mission: Promoting and providing professional growth and development for adult educators in South Dakota

# SDALL Members

- Program administrators and classroom teachers
- Small percentage with formal science training
- Little time for writing curricula
- Pool of students with identified needs

# Implementation

- Sites

- Sisseton-Wahpeton-Oyate
- Enemy Swim
- Eagle Butte
- Pine Ridge

- Challenges



Method

# Conceptual Framework

- Theory of Reasoned Action (Fishbein & Ajzen, 1975) beliefs, attitudes, intention, and behavior
- Technology Acceptance Model (Davis, 1986; Giger et al., 2014) usefulness (PU) , ease of use (PE), and behavioral intention (BI)
- Patient Activation Measure (Hibbard, Stockard, Mahoney, & Tusler, 2004) active participation in one's care, illness/disease self-management (PAM)

# Delivery Framework

- Community-based participatory research (Giger 2010; Hacker, 2013)
  - Community advisory board
  - Adult education leaders
  - Iterative process

# Hypothesis

Laypersons in American Indian (AI) communities participating in health literacy and self-advocacy training will demonstrate increased levels of patient activation over the baseline.

- Collaborative approach
  - SD American Indian Tribes
  - Adult Education
  - USD SSOM and SHS
- Three repeated measures using validated scales
- Existing health literacy materials in the public domain



## Construct

## Instrument

**Patient Activation**  
(Primary Outcome Measure)

Patient Activation Measure Short Form (Hibbard et al., 2005) is a 13 item measure that assesses patient knowledge, skill, and confidence for health self-management (collected at pretest-posttest and follow-up).

**Technology (Innovation) Acceptance**  
(Secondary Outcome Measure)

Technology Acceptance Model (Davis, 1989; Venkatesh & Davis, 2000) is a 10 item measure that predicts a person's behavioral intention to use an innovation. The model includes two primary predictor variables, perceived ease of use (EU) and perceived usefulness (U), and the dependent variable, behavioral intention (BI) (collected at pretest-posttest and follow-up).

Descriptive Measures (only collected at baseline)

# Participants

- The participant pool was derived from adult education students from the various pilot sites.
- Participants read and signed a consent form indicating their willingness to participate in the study.
- The consent form fully described the study details, including possible risks and plans to protect participants against these risks.
- The consent form fully described the data to be collected, how the data would be used, and how the data would be secured.

# Participants

- The consent form indicated that participants had the right to leave the study at any time.
- Participants received incentives upon completing various phases of the study.
- Each participant received \$25 following completion of the training curriculum (and the preceding baseline assessment), \$25 following completion of the 30 day follow-up assessment, and \$25 following completion of the 90 day follow-up assessment.
- Incentives came in the form of prepaid debit cards to provide enhanced controls and security prior to disbursement.

# Data Collection

- Quantitative outcome data were collected by staff to study our research questions at three points in time: pretest or baseline, posttest, and follow-up.
- The TC intervention was delivered 14 days after our pretest assessment.
- TC was delivered by our collaborators at SD ALL via classroom integration.
- Instructors from these locations were trained in curriculum delivery by the Lead Trainer and received any necessary materials and instructional support from the research team.
- The following table shows primary and secondary outcome measures that were collected to evaluate TC effectiveness and our evaluation model.

Findings

- Descriptives and Frequency Statistics
- Intercorrelation
- Hierarchical Regression
- Fixed and Random Effect Models
- Anecdotal Data

# Descriptives and Frequencies

**Table 1 – Characteristics of the Participants (n = 220)**

<b>Characteristic</b>	<b>n</b>	<b>%</b>	<b>M (SD)</b>	<b>Mdn</b>	<b>Raw Min-Max</b>	<b>Range</b>
<b>Age</b>	216	--	36.44 (12.98)	35	18-75	57
<b>Patient/Participant Activation</b>	213	--	62.41 (14.08)	63.10	34.20-100	65.80
<b>Behavioral Intention</b>	213	--	3.70 (.90)	4	1-5	4
<b>Usefulness</b>	214	--	15.90 (3.03)	16	4-20	16
<b>Ease of Use</b>	213	--	15.18 (3.00)	15	4-20	16

# Descriptives and Frequencies

**Table 1 (Continued) – Characteristics of the Participants (n = 220)**

Characteristic	n	%	M (SD)	Mdn	Raw Min-Max	Range
<b>Gender</b>						
Female	119	54.1	--	--	--	--
Male	96	43.6	--	--	--	--
<b>Residence</b>						
Rent	63	28.6	--	--	--	--
Own a home	31	14.1	--	--	--	--
Live with family	82	37.3	--	--	--	--
Live with friends	12	5.5	--	--	--	--
Other	21	9.5	--	--	--	--
<b>Work</b>						
Full time employee	30	13.6	--	--	--	--
Part time employee	21	9.5	--	--	--	--
Unemployed, actively looking for employment	79	35.9	--	--	--	--
Unemployed, not actively looking for employment	14	6.4	--	--	--	--
Stay-at-home parent	10	4.5	--	--	--	--
Not working, retired	5	2.3	--	--	--	--
Not working, other	57	25.9	--	--	--	--



# Descriptives and Frequencies

Table 1 (Continued) – Characteristics of the Participants (n = 220)

Characteristic	n	%	M (SD)	Mdn	Raw Min-Max	Range
<b>Race</b>						
American Indian	206	93.6	--	--	--	--
White	3	1.4	--	--	--	--
Other	1	.5	--	--	--	--
<b>Education level</b>						
≤ 12 <sup>th</sup> Grade, no diploma	79	35.9	--	--	--	--
GED or equivalent			--	--	--	--
High school graduate	42	19.1	--	--	--	--
Some college, no degree	26	11.8	--	--	--	--
≥ Associate degree	38	17.3	--	--	--	--
	31	14.0				

*Note:* Percentages do not equal 100% to due to rounding and missing data. Theoretical patient activation scores range from 0-100. Higher scores mean higher activation. Theoretical behavioral intention scores range from 1-5. Higher scores mean stronger intention to use the curriculum. Theoretical usefulness scores range from 4-20. Higher scores mean stronger usefulness perceptions toward the curriculum. Theoretical ease of use scores range from 4-20. Higher scores mean stronger ease of use perceptions toward the curriculum.

# Intercorrelations

**Table 2 - Intercorrelations among Key Theoretical Variables**

Measure	PAM	BI	PU	PE
1. PAM	--			
2. BI	.27***	--		
3. PU	.23**	.53***	--	
4. PE	.33***	.45***	.63***	--

Note: \* =  $p \leq .05$ , \*\* =  $p \leq .01$ , \*\*\* =  $p \leq .001$ . Baseline correlations are reported.

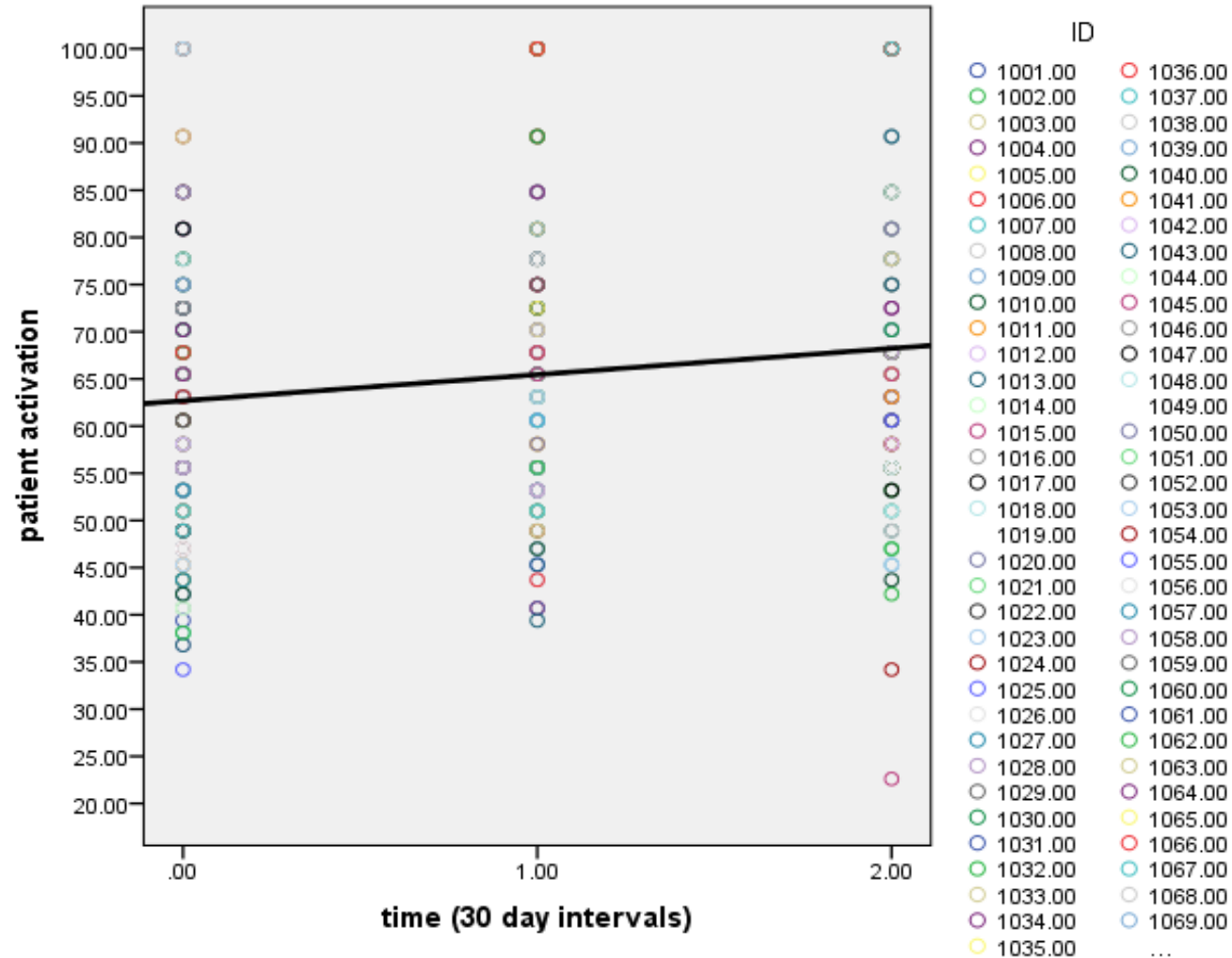
# Predicting Activation

**Table 3 - Hierarchical Regression Analysis Summary for Acceptance Variables Predicting Patient Activation**

Step and predictor variables	<i>B</i>	<i>SE B</i>	<i>B</i>	<i>R</i> <sup>2</sup>	$\Delta R^2$
<b>Step 1:</b> Age Gender	.11 <sup>ns</sup> .70 <sup>ns</sup>	.07 1.92	.10 .03	.01	
<b>Step 2:</b> Age Gender PU PE	.07 <sup>ns</sup> -.41 <sup>ns</sup> .11 <sup>ns</sup> 1.44***	.07 1.84 .39 .39	.06 -.02 .02 .31	.11	.10
<b>Step 3:</b> Age Gender PU PE BI	.06 <sup>ns</sup> -.92 <sup>ns</sup> -.17 <sup>ns</sup> 1.30*** 2.46*	.07 1.84 .41 .39 1.21	.06 -.03 -.04 .28 .16	.13	.02

**Note: Gender (1 = male, 2 = female). \* =  $p \leq .05$ , \*\* =  $p \leq .01$ , \*\*\* =  $p \leq .001$ . Baseline Regressions are reported.**

# Fixed Effects Over Time



# Time Effects and Activation Growth

Table 4 - Estimated Effects of Time on Patient Activation

Fixed Parameter	$b$	$SE_b$	$df$	$t$	95% CI
Intercept	62.66***	.93	215.80	67.20	60.82, 64.50
Time	2.73***	.62	176.10	4.38	1.50, 3.97

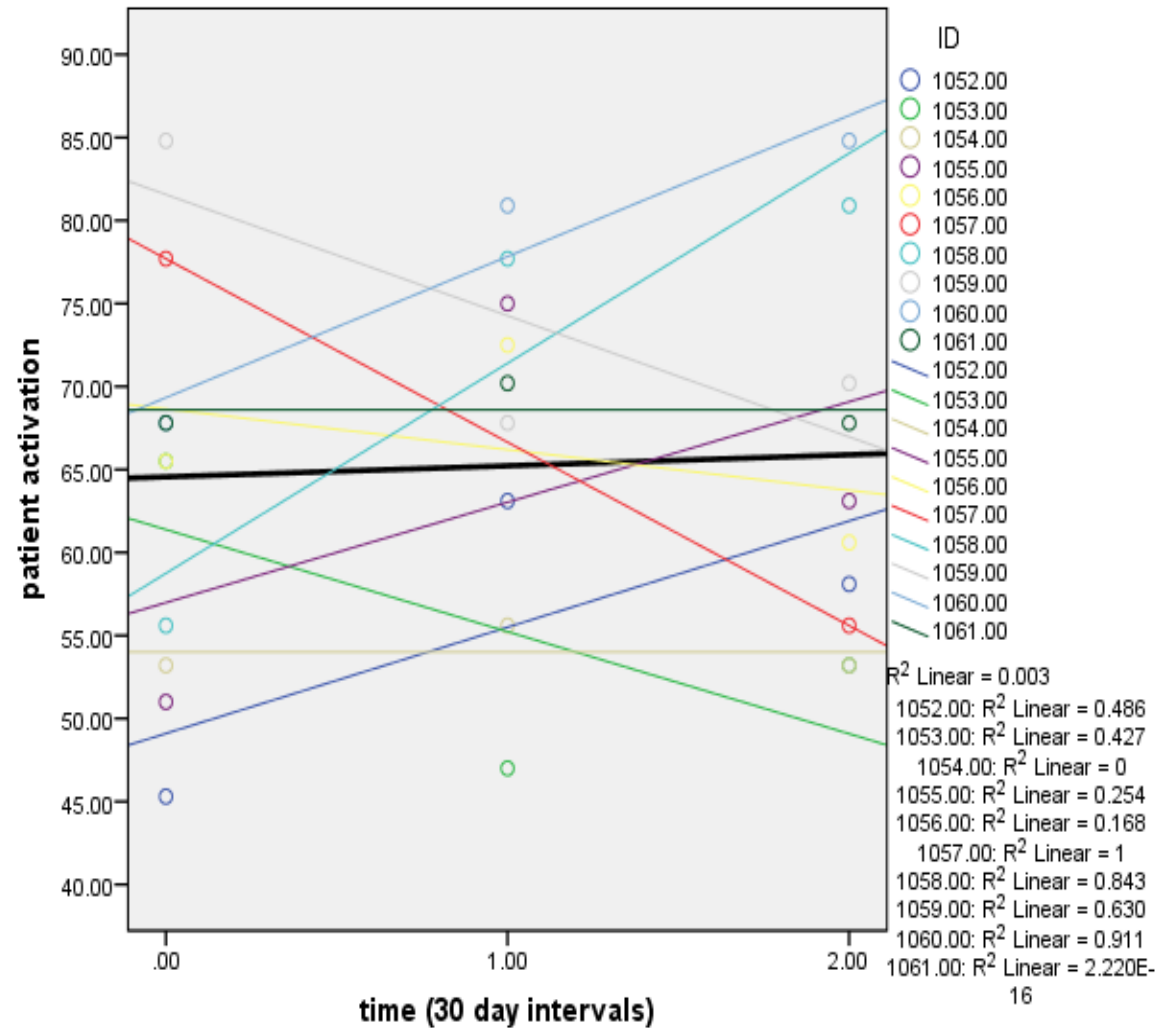
Note: \*\*\* =  $p \leq .001$ .

**Table 5 - Rate of Change in Patient Activation Over Time**

<b>Random Parameters</b>	<i>b</i>	<i>SE<sub>b</sub></i>	<i>df</i>	<i>t</i>	<i>95% CI</i>
<b>Var (<math>u_{0j}</math>)</b>	110.18***	20.10	--	--	77.06, 157.52
<b>Var (<math>u_{1j}</math>)</b>	22.40*	9.27	--	--	9.96, 50.42
<b>Cov (<math>u_{0j}, u_{1j}</math>)</b>	-.02 <sup>ns</sup>	.21	--	--	-.40, .36

**Note:** \* =  $p \leq .05$ , \*\*\* =  $p \leq .001$ . <sup>ns</sup> = not significant. Time was centered to 0.

# Random Effects Over Time ( $n = 10$ )



# Anecdotal Data

- “Advocate training is something that our reservation is lacking. Many of our elderly people need someone to go and talk for them as they don't have family living around them.”
- “It's a good concept, I never asked my provider questions because I thought he/she was supposed to be an expert but now I know that nobody knows me like I do.”
- “Receiving this training gives the knowledge us outspoken people need to help others as opposed to being in the dark and not knowing what to say or ask.”
- “I feel knowledge is power, the more we know about our health and our rights to better health, the more active we will be. Better awareness of our physical & mental needs can be nothing but beneficial for everybody in the community, this is a good thing.”
- “Since taking your class, I went on a personal diet. I've lost 21 pounds total and was able to consult my doctor on options. Would have never known otherwise if I didn't take this course.”
- “I have learned some awesome information on how to be a great advocate for myself and as well as my new baby I am expecting in July 2014.”



# Discussion

## Bottom Line

- The data supported our hypothesis.
- This approach can/does work.
- Our educational model holds the potential for a significant positive impact on long-term individual and group health outcomes.
- Our evaluation model expands the available analytic methods for assessing the impact of a training intervention.

# Presentations at Professional Meetings

- CRCAIH presentation in Bemidji, Minnesota
- National AHEC Organization presentation in Charlotte, North Carolina
- Accepted presentation at the Commission on Adult Basic Education (COABE) meeting in Denver, Colorado, April 2015
- Abstract submitted to the 40<sup>th</sup> Annual National Institute for Social Work and Human Services in Rural Areas (ANISWHSRA) Conference in Vermillion, South Dakota, July 2015.
- Abstract submitted to the Annual Program Meeting of the Council on Social Work Education (CSWE) in Denver, Colorado, October 2015

Lessons Learned

- Account for contextual factors such as training site.
- Secure commitment of all key stakeholders
- Gift card distribution logistics.
- Include more content geared toward visual learners.
- Build in formal qualitative assessment.
- Expect the unexpected.

Next Steps

# Expand the Project

- Develop partnership with the American Indian Institute and the School of Social Work at the University of Oklahoma
- Develop partnership with the University of Kansas
- Develop partnership with the University of Nebraska – Omaha
- Seek funding from the NIH for a 3-4 state project with 3-4 sites in each state
- Study other populations (e.g., Latino/Latina, African Americans)
- Develop other partnerships

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