Methodology and Approaches to
Creating Community Center Health Care:
Leveraging 'Ohana (Friends/Family)
Support and Information Technology in
Chronic Disease Management

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Research Motivation

Motivated by my work in rural areas in Hawai`i and the Pacific Islands

Challenged by the complexity of chronic disease management

Interested in how to leverage and maximize limited resources in under resourced low SES communities

Statement of the Problem

Burden of Chronic Disease

- Worldwide chronic disease epidemic responsible for 38 million deaths each year (WHO, 2015)

- Approximately half of the adults in the United States have one or more chronic disease (Gerteis et al., 2010)

- Accounts for 86% of America's health care expenditures (Gerteis et al., 2010)

Statement of the Problem

Disparities

- Disproportionately affects low- and middle- income countries 75% deaths (28 million) (WHO, 2015)

- SES such as income, education, and social capital, is a driving force of health care disparities; lower SES directly relates to higher levels of disease (Link & Phelan, 1995)

- The majority of premature deaths related to chronic diseases are preventable (Link & Phelan, 1995)

Research Objective

Problem: Burden of Chronic Disease, impact on low SES communities, and need for individual healthy lifestyle support

Objective: To understand how to improve diabetes self-management outcomes within the context of a low SES and small community in Molokaʻi by:

- Improving cooperation among the patient, ʻohana and health care providers

- Leveraging Information Technology

Study Setting - Island of Moloka'i

- Small and remote island population of approximately 7,345 (Population Estimates, July 1, 2015)

- Among the highest poverty levels in the State of Hawaii at 21% of families below the poverty line compared to 11% (overall state poverty levels) (Molokai Community Plan Update: Planning Department, 2015).

- Prevalence rate of diabetes – 17.5% (State average 10.9%) (Hawai'i State Department of Health, 2017)

Moloka'i 'Ohana Diabetes Program

Program Aims

- **Resources** - Support Improved Diabetes Self-Management (DSM)

- **Knowledge** – Provide Information About Diabetes & Effective DSM

- **Behavior** – Support Patient & 'Ohana Behavioral Change to improve DSM

Program Components

✓ **DSM Diabetes Resource Center** (Health Insurance Funded)

  - (3) DSM Group Classes Delivered by Video Teleconference

  - (1) 1-Hour Individual Consultations with CDE personalized information

  - (1) 1-Hour Consultation w/ Dietician/Nutritionist personalized Information

  - New Blood Glucose Monitor (OneTouch VerioSync) & Database Access

✓ **2 Additional Classes by Video Teleconference:** Goal Setting, Technology, Motivational Interview, Chronic Kidney Disease, P-P Testimonies

✓ **3-Month Period of Support by Text Message**

Data Collection: Instruments & Methods

Data Collection: Instruments & Methods

- **Pre-/Post- Health Status Survey (Patient)** Perceived Competence for Diabetes Scale (Williams GC, Freedman ZR, et al.) 1998); Patient Health Questionnaire (PHQ-9) (Kroenke K, Spitzer, R, et al., 2001)

- **Pre-/Post- Diabetes Social Support Survey (Patient & `Ohana)** Diabetes Social Support Questionnaire, Author – Annette M. La Greca, PhD

- **Pre-/Post- Diabetes Knowledge Assessment (Patient & `Ohana)** Spoken Knowledge in Low Literacy in Diabetes (SKILLD) Knowledge Assessment Scale (Rothman et al., 2005)

- **Pre/Post- Telehealth Technology and Content Survey**

- **Participant Interviews**

- **Field Notes, Text and Email Messages, & Observations**

Analysis

Quantitative Data - descriptive analysis due to small sample size

Qualitative Data - rich contextual data and details of participant actions, behaviors interactions.

Clinical Data

- **A1c Data - Patient Provided Lab Results**

- **Blood Glucose Data –Monitors and Database**
  - Tracks Frequency of Tests, BG Levels
  - Calculated averages, color coded trends over specified reporting periods (e.g., 30, 60, 90-days
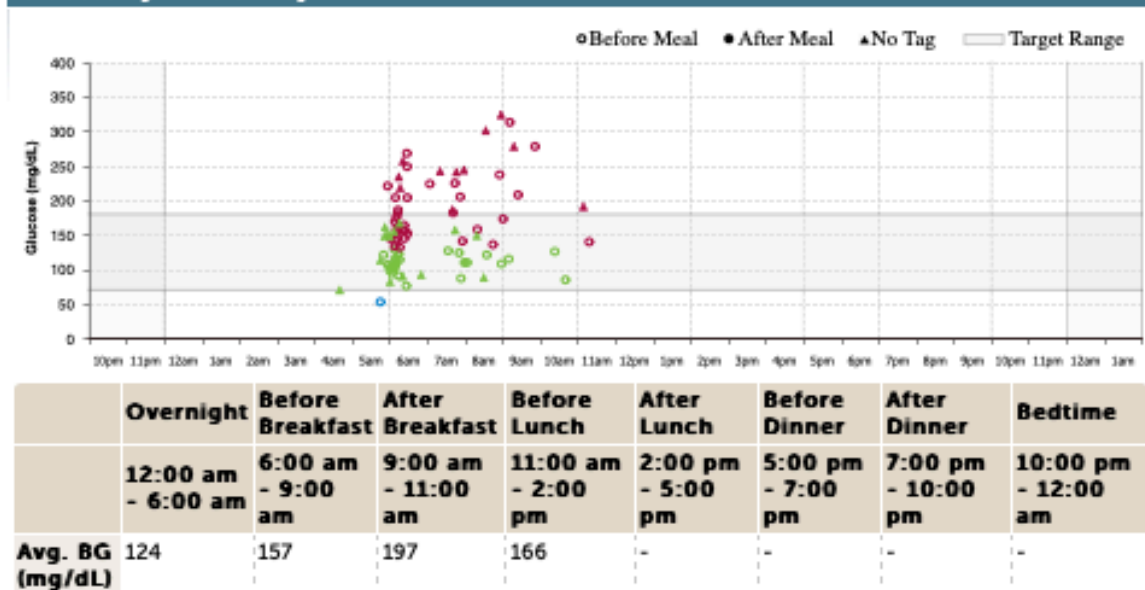 - Standard summary report: average highs/ lows, time of day; adherence to goals

Comparative Statistics

	Current Date Range	Previous Date Range	
	9/2/2018 – 11/30/2018	6/4/2018 – 9/1/2018	Change▵
Blood Glucose (SMBG)			
Overall Avg.	157 mg/dL	164 mg/dL	-4.1%
Standard Deviation	59 mg/dL	63 mg/dL	-4.9%
No. of Readings	89	91	-2.2%
Avg. No. of Readings per day	1.0	1.0	-2.2%
% of Readings w/ Meal Tags	70.8%	85.7%	-17.4%
Before Meal Avg.	149 mg/dL	164 mg/dL	-9.1%
After Meal Avg.	- mg/dL	105 mg/dL	

Glucose Excursions

	Below Target	Above Target	% Below Target	% In Range	% Above Target
No. of Excursions (SMBG)	1	46	1.1%	47.2%	51.7%
Tagged Before Meal	1	35	1.6%	42.9%	55.6%
Tagged After Meal	0	0			
Severe	0	0			
Lowest / Highest Readings	53 mg/dL	324 mg/dL			

Glucose by Time of Day

○ Before Meal ● After Meal ▲ No Tag ▭ Target Range

	Overnight	Before Breakfast	After Breakfast	Before Lunch	After Lunch	Before Dinner	After Dinner	Bedtime
	12:00 am – 6:00 am	6:00 am – 9:00 am	9:00 am – 11:00 am	11:00 am – 2:00 pm	2:00 pm – 5:00 pm	5:00 pm – 7:00 pm	7:00 pm – 10:00 pm	10:00 pm – 12:00 am
Avg. BG (mg/dL)	124	157	197	166	-	-	-	-

Health Status Outcomes: A1c Measures

A1c% -Pre and -Post Study

Participant	Delta -Pre and -Post	Post- Study	Pre- Study
MODP-002_P	0	7.1	7.1
MODP-006_P	-0.1	8.4	8.5
MODP-007_P	-0.3	7	7.3
MODP-003_P*	-0.33	5.83	6.16
MODP-004_P	-1.3	9.7	11
MODP-008_P	-1.6	8	9.6
MODP-005_P	-2	8.2	10.2

Legend: ▮ Delta -Pre and -Post ▮ Post- Study ▮ Pre- Study
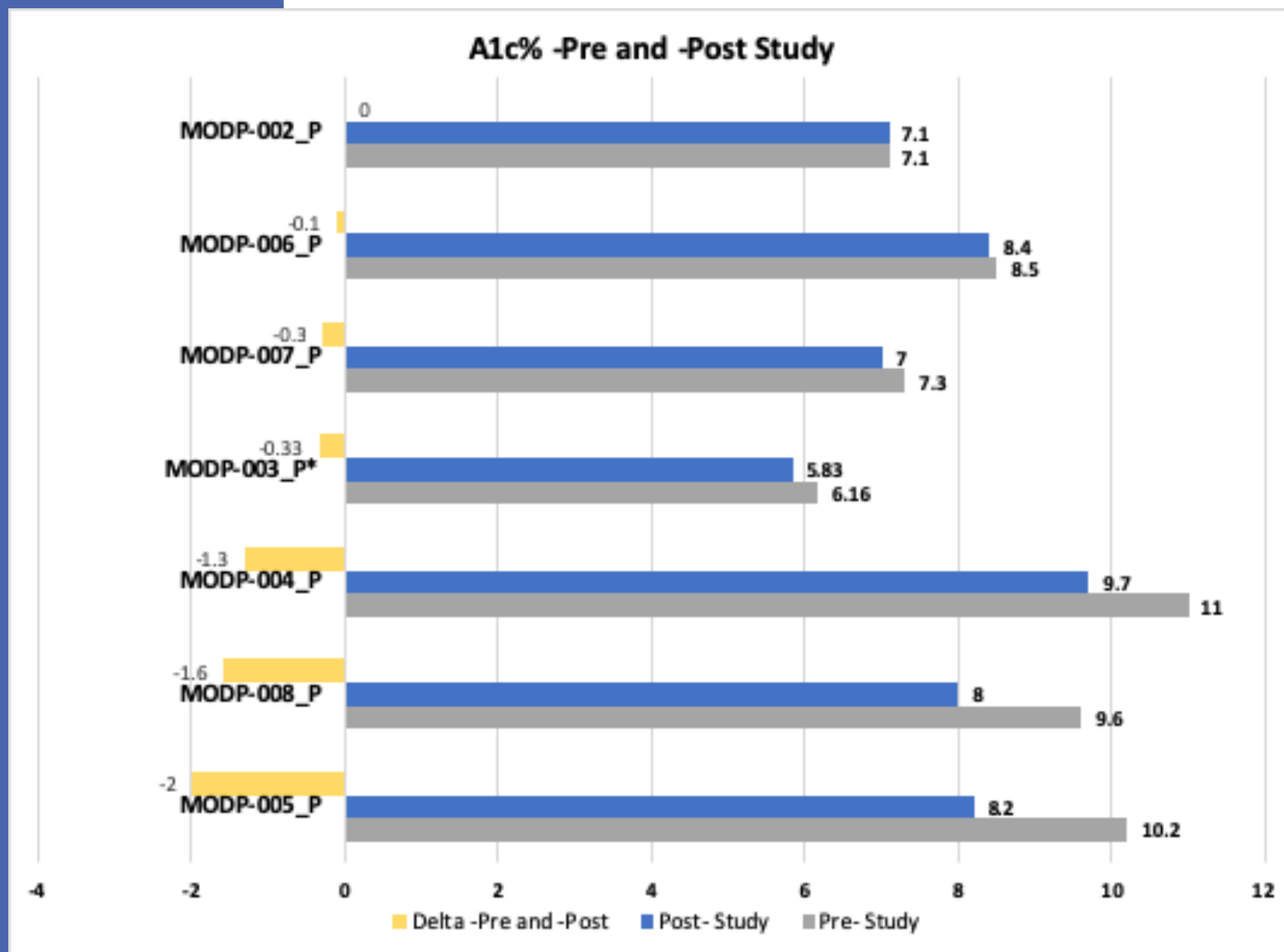
1% decrease in A1c% is significant associated with dramatic reduction in risk for heart attack, eyes, kidney, feet and nerve problems, and death (Kilpatrick, Rigby, & Atkin, 2008).

Change in DSM Activities

DSM Activity	Pre-Study	Post-Study
Blood Glucose Testing	2 Tested Regularly	All 7 Tested Regularly
Medication	2 Did Not Take as Prescribed	All 7 Took at Prescribed
Foot Checks	2 Checked Daily	1 does not check, 1- weekly, 5-daily
Follow Meal Plan	3 Did Not, 4 Did	1 Does Not, 2 Same, 4 Improved
Exercise	4 Did Not At all, 3 Did Sometimes	1 Does Not, 2 Decreased, 4 Improved

Participant	Clinical	DSM Activities									
	A1c	Medication		Blood Test		Foot Checks		Follow Meal Plan		Exercise	
	Delta Pre & Post	Pre-Study	Post-Study	Pre-Study	Last Quarter	Pre-Study	Post-Study	Pre-Study	Post-Study	Pre-Study	Post-Study
MODP-003	-.330	Daily	Daily	0x day	2x day	No	1x Week	No	Yes, 5 of 7 days	4 of 7 days	2 of 7 days
MODP-002	0	Daily	Daily	0x day	.7 to 1.7x day	Daily	Daily	No	No	0 of 7 days	0 of 7 days
MODP-006	-0.1	Daily	Daily	1x day	.7 to 1.1x day*	Daily	Daily	Somewhat	Yes, 2 of 7 days	5 of 7 days	7 of 7 days
MODP-007	-0.3	2 of 7 days	Daily	0x day	.9 to 1x day	No	No	Somewhat	Yes, 6 of 7 days	0 min/ 0 days	45-60 min/ day
MODP-008	-1.6	Daily	Daily	1x day	1 to 1.7x day	No	Daily	Somewhat	Some, 2-3 of 7 day	0 min/ week	150 min/ week
MODP-004	-1.3	6 of 7 days	Daily	0x day	.1 to .6x day	No	Daily	No	Yes, 5 of 7 days	4 of 7 days	2 of 7 days
MODP-005	-2	Daily*	Daily	0x day	.4 to 1.2x day	No	Daily	Somewhat	Yes, 7 of 7 days	0 of 7 days	7 of 7 days

*Started taking medication at start of program
*Self-Reported 2x day, OneTouch less
*Survey Question: How many times did you test BG in the last week? Vs OneTouch Data

Integrating IT Resources Into Practices

Video Teleconference
- Brought new resources to the community
  - Enabled participation from home
  - Low-Cost

Text Messaging
- A few participants learned how to text message (after 3-months)
- Help to maintain relationships (e.g., texting CHW BG numbers)
- Challenges
  - Inconvenient Messaging Time (e.g., 5:30PM – 6:30 PM)
  - Group Texting Issue - Frustration
  - Dyad Issues – Sensitive Topics
- Purchase a Text Message System
  - Schedule, automate group texts
  - Intelligence to decide when to text whom?

Integrating IT Resources Into Practices

Bluetooth Enabled Blood Glucose Monitor and Database

Patients
- Convenient – much easier than paper logs
- Easy and Informative –color codes/ graphs
- Preferred viewing data on mobile phone (vs. online database)
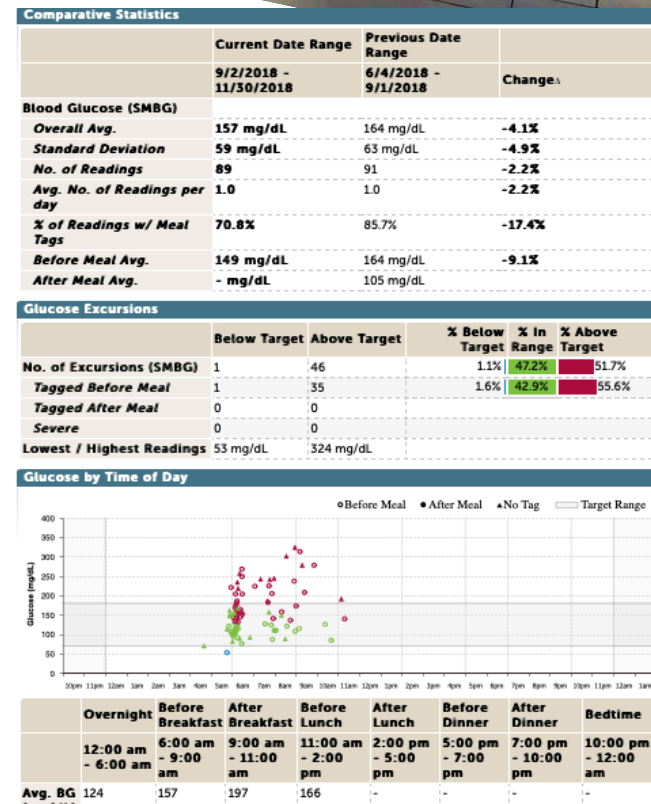- Did not integrate all health app data

'Ohana
- Did not use online database. Viewed data on mobile phone or patient texted BGs
- (New behavior asking about BG numbers)

MOD-P Staff
- Ease of data collection and analysis
- Provided specific patient information used for personalized check-in and education (improved patient accountability, felt that CHWs cared)

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Integrating 'Ohana Support Resources

Roles and Relationships

Support Person Selection & Family Preference (expectation)

- Formalizing Informal Relationships
  - Spouse often default "informal support"
  - Labeled "The Support Person" made it "formal"
  - When formalizing the informal roles - found need to define responsibilities, expectations and provide information
- Selected family over friend - to not inconvenience, trouble, or worry
- However, a friend or co-worker might be more patient, understanding and helpful with stress reduction

Acknowledge Support Does Not Come from One Person

- Clusters of co-worker support developed among Participants

Communication Support Style Preference - Varies

No Single Profile

- Diabetes Police: Strict, Relentless
- Nurturing: Encouraging, Supportive

Fine line between Caring and Nagging (received as)

Integrating 'Ohana Support Resources

Motivation

- Need to identify source of motivation and integrate into the program structure and offering:
  - Diabetics' DSM Goals
  - 'Ohana Life Goals
  - Propositions of Value

Key Lesson Learned

- It is important to empower patient AND 'ohana with information about Diabetes etiology and DSM Activities
- There is no formula for perfect support person because of the varying nature of interpersonal relationships, instead we needed to focus on:
  - Basic Interpersonal Communication skill development and should have more time on Motivational Interview techniques (personalized)

Implications for Technology

Synchronous information delivered when and where needed.

- **Video Teleconference:** Introduced new resources and enabled participation from the home

- **Bluetooth Blood Glucose Monitor:** Preference for mobile application over computer access

- **Text Messaging:** Beneficial continuous routines

Technology supported the reinforcement of learning by enabling the delivery of information that was:

- Timely
- Personalized
- Succinct and Easier to Absorb
- Shared with patient and 'ohana simultaneously

- Easier Adoption than Expected
- Adopted in a way to honor how people communicate
- Used to enhance and maintain personal relationships (Text BG vs. Check Online)

Way Forward –

Research and Theory
- Future Interdisciplinary Study of the Unique Subtleties in Relationships between a Person with Diabetes and 'Ohana for DSM or CC support (e.g., theory-based relationship science or research on family routines)

Application and Practice
- Opportunities for Further Advancement of Diabetes Management Technologies (e.g., Continuous Blood Glucose Monitors)
- Integrate Diabetes Management Health Applications
- Updates in Diabetes Guidelines - more Individualized and payment for value reform will demand better health outcomes, presents opportunity for similar, cost effective programs, to support the patient and 'ohana