January 25, 2012

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Agency for Healthcare Research and Quality

Presenters:
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Carl Stepnowsky
Lygeia Ricciardi
A National Web Conference on Evaluation of Personal Health Record (PHR) Systems and Their Impact on Chronic Disease

January 25, 2012

There are no financial, personal, or professional conflicts of interest to disclose for the speakers or myself.
Implementing PHRs for Patients with Chronic Disease: Lessons Learned

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Objectives

- Describe implementation barriers
- Summarize results of our trial of hypertensive patients
- Compare patient and provider perceptions of strengths and concerns about personal health record (PHR) systems
- Suggest strategies to overcome barriers and enable effective PHR use
**Study Design**

- Cluster randomized effectiveness trial
  - 24 physicians (11 control and 13 PHR)

- 443 of 1,646 approached patients consented (26.4%)

- Patient groups
  - 250 patients received the PHR
    - 207 remained at visit 4 (82.8%)
  - 193 patients received no PHR
    - 119 control patients remained at visit 4 (61.6%)
Outcome Measures

- Primary patient outcome was blood pressure
- Secondary patient outcomes
  - Health beliefs and activation
  - Evaluation of care
  - Medical utilization
- Adherence to treatment guidelines as documented in medical record
- Changes in patient, provider, and staff views of PHR potential
Before We Started We Got Reactions . . .

- From providers
  - Too much time
  - Not secure
  - Patients don’t need information
  - I’ll get sued

- From patients
  - Don’t know what anything means
  - I’m not technologically savvy
  - Good to have my doctor always checking on me
Information technology staff
- More work
- Not enough time to get ready
- Interoperability
- Security

Leadership
- Need to form committees
- Cost
- Legal risks and potential liability
Our PHR at Time of Trial

- Modified by two cycles of patient and expert PHR utilization and suggestions
- PHR elements
  - Messaging and scheduling
  - Blood pressure (BP) tracking
  - EMR tethered: lab and medications
  - Secure, patient-controlled access
  - Links to educational materials
My HealthLink

Inbox
Stay connected with my healthcare providers
You currently have no new messages in your Inbox.

Health Record
My life, my health
To view your health record, click a section:
- Allergies
- Clinical Results
- Health Issues
- Immunizations
- Medications
- Notes
- Surgeries/Procedures

Quick Links
- Health Information
- Schedule Appointment
- Directions
- Physician Directory

Alarm
Reminder
Open 11:49 AM
Schedule Appointment
- Request a Medication Refill

Manage My Health
- Upload Values to My Diabetes Diary
- Immunization Schedules

Manage My Account
- Change My Password
- Update My Email Address
- Add a Family Member to My Account
- Grant My Physician Access

My HealthLink
your care, your way. MCGHealth

MCG Info Help Logoff
My HealthLink

Hypertension Center
Managing Made Easy.

Hypertension is usually a chronic disease. That means it's a long-term condition that tends to gradually become worse. By the time someone is diagnosed, chances are... Read more...

Medication Schedule

The following medications cannot be included in your Medication Schedule because frequency and dosing are required:

- Warfarin

<table>
<thead>
<tr>
<th>Time</th>
<th>Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 AM</td>
<td>Topamax</td>
</tr>
<tr>
<td></td>
<td>Valelease</td>
</tr>
<tr>
<td>10:00 AM</td>
<td>Warfarin</td>
</tr>
<tr>
<td></td>
<td>Zocor</td>
</tr>
<tr>
<td>7:00 PM</td>
<td>Topamax</td>
</tr>
</tbody>
</table>
Main analysis

- Intraclass correlations were calculated with patients nested within physicians who were nested within clinic.

- General linear mixed models were used to compare improvement with time (V1 to V4) with visit 1 data as a covariate.

- Models were conducted for blood pressure, other biological markers, patient activation, patient assessment of chronic care, and satisfaction with care independently.
Secondary Analysis

- Within the PHR group only
  - Logistic regression of use vs. no-use groups to determine predictors of PHR utilization
  - Analysis of covariance models to compare frequency of use as related to patient change from V1 to V4
    - Adjusted for multiple comparisons
Although there were statistical differences, we detected no clinically significant differences between the PHR and no-PHR groups in

- Blood pressure
- Patient activation
- Patient perception of chronic care
- Patient satisfaction with care
## Results—Main Analysis

<table>
<thead>
<tr>
<th>Outcome Measure</th>
<th>PHR</th>
<th>No PHR</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>SBP</td>
<td>129.7</td>
<td>129.3</td>
<td>0.62</td>
</tr>
<tr>
<td>DBP</td>
<td>77.3</td>
<td>75.6</td>
<td>0.288</td>
</tr>
<tr>
<td>Patient Activation Measure</td>
<td>71.4</td>
<td>69.1</td>
<td>0.49</td>
</tr>
<tr>
<td>Patient Empowerment Scale</td>
<td>41.2</td>
<td>40.1</td>
<td>0.02*</td>
</tr>
<tr>
<td>CAHPS Global Doctor Rating</td>
<td>9.39</td>
<td>9.43</td>
<td>0.001*</td>
</tr>
<tr>
<td>CAHPS Physician Communication Score</td>
<td>5.68</td>
<td>5.77</td>
<td>0.001*</td>
</tr>
<tr>
<td>CAHPS HIT Helpfulness Score (exploratory)</td>
<td>3.72</td>
<td>3.68</td>
<td>0.59</td>
</tr>
<tr>
<td>Patient Perception of Chronic Care</td>
<td>70.7</td>
<td>72.1</td>
<td>0.82</td>
</tr>
</tbody>
</table>
Results—Infrequent PHR Use

- No Use: N=43 (31%)
- Low Use: N=32 (23%)
- Medium Use: N=29 (21%)
- Frequent Use: N=36 (26%)
Changes Observed in Frequent Users

- Reduction in systolic blood pressure: 3.97 points
- Reduction in diastolic blood pressure: 5.25 points
- CAHPS global doctor rating and communication score: decreased slightly
- Patient perception of health IT helpfulness decreased slightly
What Predicts Frequent Use?

- Younger age: 4.7 years
- Access and technology skills: self-rated skill and access (83% no use vs. 91% high use)
- Salient clinical need: higher initial BP scores
- Patient activation: initially higher
- Patient-provider relationship: higher CAHPS scores
- System variables: continuity and technology experience evidenced in Family Medicine clinic
Post-Study Perceptions

- Patient Empowerment Scale (PES): effect on patients of provider sharing outpatient medical record
- Interviews and focus groups: based on Technology Acceptance Model
### Results—Benefits

**Post-Study PES**

<table>
<thead>
<tr>
<th>Statement: Patients would . . .</th>
<th>Patients</th>
<th>Providers</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have an increased sense of control</td>
<td>81%</td>
<td>86%</td>
<td>0.52</td>
</tr>
<tr>
<td>Be better prepared for visits</td>
<td>78%</td>
<td>79%</td>
<td>0.89</td>
</tr>
<tr>
<td>Be reassured</td>
<td>78%</td>
<td>62%</td>
<td>0.06</td>
</tr>
<tr>
<td>Improve understanding of their medical condition</td>
<td>78%</td>
<td>59%</td>
<td>0.04*</td>
</tr>
<tr>
<td>Identify errors in the record</td>
<td>76%</td>
<td>83%</td>
<td>0.44</td>
</tr>
<tr>
<td>Improve adherence to provider recommendations</td>
<td>75%</td>
<td>72%</td>
<td>0.74</td>
</tr>
<tr>
<td>Be more satisfied with their care</td>
<td>72%</td>
<td>62%</td>
<td>0.29</td>
</tr>
<tr>
<td>Improve understanding of provider’s instructions</td>
<td>71%</td>
<td>79%</td>
<td>0.38</td>
</tr>
<tr>
<td>Trust their providers more</td>
<td>70%</td>
<td>72%</td>
<td>0.78</td>
</tr>
</tbody>
</table>
### Results—Risks Post-Study PES

<table>
<thead>
<tr>
<th>Statement: Patients would . . .</th>
<th>Patients</th>
<th>Providers</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have more questions between visits</td>
<td>45%</td>
<td>72%</td>
<td>0.0080*</td>
</tr>
<tr>
<td>Be confused by test results</td>
<td>36%</td>
<td>93%</td>
<td>&lt;0.0001*</td>
</tr>
<tr>
<td>Be confused by provider notes</td>
<td>26%</td>
<td>52%</td>
<td>0.0068*</td>
</tr>
<tr>
<td>Worry more</td>
<td>24%</td>
<td>83%</td>
<td>&lt;0.0001*</td>
</tr>
<tr>
<td>Be offended by some things in their record</td>
<td>12%</td>
<td>69%</td>
<td>&lt;0.0001*</td>
</tr>
</tbody>
</table>
Post-Study Interviews and Focus Groups

- 122 patients; 29 providers
- 80% of the patients (N=98) were from Family Medicine; 20% (N=24) from Internal Medicine
- 74% female and 25% male
- 55% white; 40% black; 5% other
- 79% had some college, a degree, or postgraduate work
- 45% physicians (N=13); 55% nursing staff (N=16)
Patient Perceptions of Outcomes

- “I think the ability to send messages directly to my health care team would probably be the most useful thing.”

- “It was just the ability to go back and review certain items, and to be observant—any discrepancies or anything, you make the changes.”

- “I used it with the blood pressure and with my diabetes so when I put my information in, I could always go back and refer to it in case I forgot or need to write it down for my doctor.”
Provider Perceptions of Outcomes

■ “So I think it would give them the opportunity to review information and then know how to ask questions in the future.”

■ “... if they can see their medicine list and allergies, I think they’re more aware of that and then likely to reduce medication errors.”

■ “I think to a large degree knowledge is power. I think it empowers the patients to take more control of their health care. I think they become more invested in their health problems and it leads to more compliance.”
“Because the wording that’s used in the health care record can be very confusing and they can take it to mean something totally different. I think if you’re going to allow patients to have access, there’s got to be a place where someone puts it in layman’s terms.”

“So I think there’s a time constraint issue that could overwhelm a physician. . . It’s going to create more time that’s going to have to be spent with the patient to educate them—to kind of bring them to cross that bridge. And I don’t know who’s going to do all that.”
Other Patient Beliefs about the PHR

- “I believe it keeps the doctor more informed. I could see if I was doing what the doctor said.”

- “I think that as a patient I have a right to know . . .”

- “They should make it to where you can get into your whole . . . you should be able to gain access to all that stuff.”
Other Provider Beliefs about the PHR

- “It would be a help, and not a hindrance, to [establish] rapport between patient and physician.”
- “... there are medical and legal ramifications giving patients access to their charts ... Security has to not only be external but it also has to be protected within the home itself.”
- “There’s the justice aspect ... some patients aren’t able to access records. I don’t mean not having the capacity to do it but they just don’t have access to that technology and so you’re denying them this way of working ... There’s already the disparity along socioeconomic lines so it further widens the gap.”
“Well I guess it’ll come back to time … extra staff … If every time you log into a chart, it takes an extra, even 2 minutes to get into the PHR, that’s a lot of time … the time would be the most preventive piece.”

“I think there would have to be guidelines on how fast a physician would get back to [patients] … it would be an opportunity for them to just write an autobiography.”
Summary: Encouraging PHR Use in Patients

- We need
  - A philosophical shift that increases partnering in care delivery
  - Emphasis on longitudinal patient-physician relationships
  - Increased patient-centeredness in PHR design
  - Better PHR design and usability
  - To not disappoint patient expectations about health IT
  - Increased patient access to technology
Summary: Encouraging PHR Use in Providers

We need:

- Clarity around ownership of personal health information (PHI)
- Increased acceptance and use of existing interoperability between EMRs and PHRs
- Young, tech-savvy providers to be the earliest adopters
- Guidelines and research to establish best practices for incorporating PHRs into the office visit
- Methods to manage workload
- Professional and technical society support
Contact Information

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- (864) 455-9881
Effect of an Internet Intervention on CPAP Adherence

Carl J. Stepnowsky, Jr., Ph.D.

Health Services Research & Development Unit, Veterans Affairs San Diego Healthcare System & Department of Medicine, University of California, San Diego

AHRQ Webinar, January 2012
Introduction to OSA

- OSA = obstructive sleep apnea
  - Repetitive cessations of breath during sleep
  - Consists of apneas and hypopneas
  - AHI = apneas + hypopneas/hour of sleep

- OSA is associated with serious cardiovascular and psychosocial comorbidities and with increased rates of mortality

- More than 80% of all sleep clinic diagnoses are OSA

- OSA is a prevalent chronic disease
  - 2–4% middle-aged adults; 30–40% older adults
Introduction to CPAP

- CPAP = continuous positive airway pressure therapy
- Consists of flow generator, hose, and mask
- Prescribed for use whenever asleep
- Gold-standard therapy
Obstructive sleep apnea historically has been underdiagnosed

Large emphasis on diagnosis
- Many factors (increased awareness, increased capacity) resulting in increased numbers of OSA patients

Evolving emphasis on treatment initialization and follow-up

Medicare 90-day rule has had large influence

Stepnowsky & Moore, 2004; Flemons et al., 2004
CPAP Adherence Rates

- Continuous positive airway pressure (CPAP) therapy adherence rates generally considered suboptimal
  - 75–80% of OSA patients give CPAP a try
  - About 50% continue to use at 1 year
  - Of those that continue to use, 50% use CPAP

- CPAP prescribed for use all night, every night, including naps

- Most patients engaging in partial use patterns
Interventional Studies

- Educational
  - Provision of pamphlets, group education

- Clinical support
  - Provision of additional telephone/clinic visits with focus on therapeutic changes/advice

- Behavioral change
  - Motivational enhancement, cognitive-behavioral therapy, self-management

- Health information technology
  - Telemedicine, telephone-linked care
Health Buddy

- Home telehealth device
- Intervention consisted of branching questions:
  - Symptom management
  - Health behavior
  - Knowledge
- No difference in adherence
  - 4.2 vs. 4.3 hours per night

Health Buddy Appliance, Health Hero Network, Palo Alto, CA

Taylor et al., 2006
Video Teleconferencing (VTC)

- Sample: nonadherent patients over prior 3 months
- Randomized to VTC or control (vitamin placebo)
- VTC group had higher adherence (90% vs. 44%; p=0.03)
- >4hrs/night on >9 out of 14 nights

Smith et al., 2006
Interactive Voice Response: TLC-CPAP

- Full-scale study
  - Incorporation of motivational enhancement
  - RCT of Telephone-linked Care (TLC)-CPAP vs. attention control
    - n=100+ per group
  - Weekly phone calls in 1 month; monthly thereafter
  - 12-month study, with assessment at 6 mos.
  - 2.4 vs. 1.5 hrs/night at 6 mos

- Of concern: magnitude of use

Sparrow et al., 2010
Examined effect of CPAP telemonitoring

- Provider had daily access to CPAP data
- Could act proactively
- No intervention on patient side

20 participants per group were followed for 2 months

Adherence rates: $4.1 \pm 1.8$ vs. $2.8 \pm 2.2$

($p=0.07; d=0.65$)

Stepnowsky et al., 2007
Current Study Objective

- Develop and evaluate a CPAP adherence intervention using the Internet. Key features:
  - Telemonitoring of CPAP adherence and efficacy data
  - Feeding that data back to both patients and providers
  - Creating online resource for participants
Methods

- Randomized, controlled trial comparing two groups:
  - Usual Care (UC)
  - Patient-Centered Collaborative Care (PC3)
- 120 patients per group
- Recruited from UCSD Sleep Clinic
  - Supplemented by word-of-mouth referrals
- Inclusion criteria: AHI≥10
Comparison of UC Vs. PC3

UC vs. PC3

Clinical Process

- OSA Diagnosis
  - (+)
    - CPAP Prescription Ordered

Usual Care (UC)

- CPAP Set-up
  - Introduction to CPAP CPAP set-up
  - Follow-up #1
    - 1 week Phone Call
  - Follow-up #2
    - 1 month Clinic Visit Data download
  - Follow-up #3
    - 2 month Clinic Visit Data download

Patient-Centered Collaborative Care (PC3)

- CPAP Set-up
  - Introduction to CPAP CPAP set-up
  - Follow-up #1
    - 1 week Phone Call
  - Follow-up #2
    - 1 month Clinic Visit Data download
  - Follow-up #3
    - 2 month Clinic Visit Data download

Provider access to monthly data
Provider access to daily data
PC3 Based in Large Part on CCM
CPAP Telemonitoring System

Resmed AutoSet Spirit + ResTraxx wireless module = AutoSet + ResTraxx

Data transmitted via pager/cell network next day in store & forward manner
Provider Side: CPAP
Telemonitoring Using ResTraxx
Data Center (RDC):

- Demographics: background data
- Prescription: allows for setting of thresholds
- Monitoring: calendar format reporting of data
- Compliance
- All for provider access (i.e., no patient access)
# ResTraxx Data Center—Compliance

![Image of a table showing patient monitoring data](image.png)

<table>
<thead>
<tr>
<th>Report Date</th>
<th>September 21, 2005</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Name</td>
<td></td>
</tr>
<tr>
<td>Monitoring Start Date</td>
<td>May 23, 2005</td>
</tr>
<tr>
<td>Monitoring End Date</td>
<td>July 25, 2005</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Physician</th>
<th>Date Of Birth</th>
<th>Total Days Monitored</th>
<th>Compliance Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>63</td>
<td>87.3 %</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sunday</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
<th>Saturday</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>22</td>
<td></td>
<td></td>
<td>23 Rx</td>
<td>24</td>
<td>25</td>
<td>26</td>
<td>27</td>
</tr>
<tr>
<td>07:53 hrs</td>
<td>08:19 hrs</td>
<td>10:14 hrs</td>
<td>10.42 hrs</td>
<td>07:52 hrs</td>
<td>08:42 hrs</td>
<td>01:39 hrs</td>
<td>66.7 %</td>
</tr>
<tr>
<td>10.6 e/hr</td>
<td>8.7 e/hr</td>
<td>10.7 e/hr</td>
<td>11.7 e/hr</td>
<td>11.9 e/hr</td>
<td>11.7 e/hr</td>
<td>8.4 e/hr</td>
<td>11 e/hr</td>
</tr>
<tr>
<td>0.2 l/sec</td>
<td>0.1 l/sec</td>
<td>0.1 l/sec</td>
<td>0.1 l/sec</td>
<td>0.1 l/sec</td>
<td>0.2 l/sec</td>
<td>0.1 l/sec</td>
<td>0.1 l/sec</td>
</tr>
</tbody>
</table>

| 30 | 31 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 | 16 | 17 | 18 | 19 | 20 | 21 | 22 | 23 | 24 | 25 |
|----|----|---|---|---|---|---|---|---|---|---|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|
| 08:27 hrs | 08:22 hrs | 09:32 hrs | 09:32 hrs | 09:49 hrs | 08:29 hrs | 07:11 hrs | 09:10 hrs | 08:36 hrs | 09:30 hrs | 08:47 hrs | 00:00 hrs | 00:00 hrs | 00:00 hrs | 00:00 hrs | 00:00 hrs | 00:00 hrs | 09:15 hrs | 09:28 hrs | 09:26 hrs | 09:28 hrs | 09:26 hrs | 09:28 hrs | 09:26 hrs | 09:28 hrs | 09:26 hrs |
| 13.2 e/hr   | 10.6 e/hr  | 11.5 e/hr | 7.3 e/hr  | 10 e/hr   | 7 e/hr   | 7 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    | 0 e/hr    |
| 0.1 l/sec    | 0.1 l/sec | 3.1 l/sec | 0.2 l/sec | 0.1 l/sec | 0.1 l/sec | 0.2 l/sec | 0.1 l/sec | 0.2 l/sec | 0.1 l/sec | 0.1 l/sec | 0.2 l/sec | 0.1 l/sec | 0.2 l/sec | 0.1 l/sec | 0.2 l/sec | 0.1 l/sec | 0.2 l/sec | 0.1 l/sec | 0.2 l/sec | 0.1 l/sec | 0.2 l/sec | 0.1 l/sec | 0.2 l/sec | 0.1 l/sec |

| Monitoring Summary: Days Monitored: 63
| Compliance: 87.3% |
Provider Treatment Algorithm:

Green/green pathway
Provider Treatment Algorithm: Red/yellow pathway
Patient Side: PC3 Website

- Interactive website designed to offload those tasks that tend to be repetitive to provider:
  - Learning Center – OSA and CPAP
  - Reference Manual

- Add interactive components:
  - My Charts
  - Troubleshooting Guide
PC3 Website Login

Welcome!

The University of California at San Diego’s Department of Medicine and the California Institute for Telecommunications and Information Technology have developed this website, called The Virtual CPAP Clinic, designed specifically for sleep apnea sufferers who want to control their disease and improve their lives. We invite you to come in, explore the site, and discover for yourself how you can make a positive difference in your health.

We invite you to come in, explore the site, and discover for yourself how you can make a positive difference in your health.

Please Sign In

User Name: 
Password: 
Remember me next time. 

Sign in

Sponsored by
VA San Diego Medical Center
The California Institute for Telecommunications and Information Technology

Contact Us
Welcome carl!

Thank you for signing in today, Friday, June 10, 2011

It looks as though you have not yet completed your Baseline assessment. Please click here to begin your baseline assessment.

Click here to view your latest CPAP data.
Learning Center

The Learning Center

Part 1: Obstructive Sleep Apnea
Lesson 1: What is Obstructive Sleep Apnea?
Lesson 2: Why Sleep Apnea is not just snoring
Lesson 3: How you know you have Sleep Apnea
Lesson 4: What Sleep Apnea feels like
Lesson 5: Sleep Apnea being a vicious cycle
Lesson 6: How Sleep Apnea affects your body
Lesson 7: Why you have Sleep Apnea

Part 2: CPAP
Lesson 1: CPAP
Lesson 2: What CPAP looks and feels like
Lesson 3: How to use CPAP
Lesson 4: Adjusting to CPAP
Lesson 5: How CPAP benefits you
The data on this page displays the average values of your CPAP data since the start of treatment. The average values are a general indication of how your treatment is progressing.

**Nightly Average to Date**

- Usage (hours): 5:40
- AHI (events/hour): 4.37
- Leak (liters/sec): .12

You may drill further into the data by selecting the links on the right.
CPAP Adherence Data

Virtual CPAP Clinic Home > My Charts > My Usage Chart

Nightly CPAP Usage

- Usage is the amount of time CPAP is in use during a single night
- The recommended nightly minimum usage is 4 hours (shown in green)

Next Done

Sponsored by VA San Diego Medical Center
CPAP Residual AHI Data

Nightly Apnea/Hypopnea Index

- The Apnea-Hypopnea Index (AHI) is the number of apneas+hypopneas occurring per hour of CPAP use.
- An AHI below 10 events/hour is considered 'normal'.
- An AHI above 10 events/hour indicates a need for additional CPAP management.
CPAP Leak Data

Nightly Average Leak

- Average leak is an indication of much air is escaping from your mask per hour of CPAP use.
- Average leak less than 0.4 liters/sec is considered "normal".
- Average leak above 0.4 liters/sec is an indication that your mask or fittings may require attention.
We hope that you aren't experiencing any problems with your CPAP treatment, but in case you are, this is the part of the website where you can look up solutions for some commonly experienced problems. As you will see, most of the corrections can be done by you at home. Some, however, require that you contact your care provider. If contact is necessary we will help you do so.

*Note: If you would like to print out a complete list of problems and their possible corrections included in this section, simply click on the icon "Full List of Troubleshooting" below and print the page. You can post this list near where you sleep in case you experience some of these problems.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Both Groups Mean ± SD</th>
<th>PC3 * (N=126) Mean ± SD</th>
<th>Usual Care* (N=114) Mean ± SD</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>52.1 ± 13.3</td>
<td>52.2 ± 13.0</td>
<td>51.9 ± 13.6</td>
<td>NS</td>
</tr>
<tr>
<td>Body Mass Index (kg/m²)</td>
<td>32.4 ± 8.0</td>
<td>32.1 ± 8.3</td>
<td>32.8 ± 7.8</td>
<td>NS</td>
</tr>
<tr>
<td>Apnea-Hypopnea Index (AHI)</td>
<td>36.5 ± 25.9</td>
<td>36.3 ± 24.9</td>
<td>36.6 ± 27.0</td>
<td>NS</td>
</tr>
<tr>
<td>Epworth Sleepiness Scale</td>
<td>10.6 ± 5.3</td>
<td>10.7 ± 5.2</td>
<td>10.5 ± 5.4</td>
<td>NS</td>
</tr>
</tbody>
</table>

* No significant differences between UC and PC3 groups.
CPAP Adherence Level (in hrs/nt) Between UC and PC3 at 2 Months

p-value=.016; d-index = 0.34
CPAP Adherence Level (in hrs/nt)
Between UC and PC3 at 4 Months

p-value=.016; d-index = 0.34
Nightly Use Rates over First 90 Days
# Outcome Measures: 2 Months

<table>
<thead>
<tr>
<th>Variable</th>
<th>Both Groups Mean ± SD</th>
<th>PC3 (N=126) Mean ± SD</th>
<th>Usual Care (N=114) Mean ± SD</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epworth Sleepiness Scale</td>
<td>8.5 ± 5.4</td>
<td>8.9 ± 5.3</td>
<td>8.1 ± 5.5</td>
<td>NS</td>
</tr>
<tr>
<td>Sleep Apnea Quality of Life</td>
<td>2.4 ± 1.1</td>
<td>2.5 ± 1.0</td>
<td>2.4 ± 1.2</td>
<td>NS</td>
</tr>
<tr>
<td>CES-D</td>
<td>8.5 ± 5.4</td>
<td>8.9 ± 5.3</td>
<td>8.1 ± 5.5</td>
<td>NS</td>
</tr>
<tr>
<td>Patient Satisfaction</td>
<td>1.7 ± 1.2</td>
<td>1.7 ± 1.1</td>
<td>1.8 ± 1.3</td>
<td>NS</td>
</tr>
</tbody>
</table>

CES-D = Center for Epidemiological Studies-Depression; PACIC = Patient Assessment of Chronic Illness Care
## Outcome Measures: 4 Months

<table>
<thead>
<tr>
<th>Variable</th>
<th>Both Groups Mean ± SD</th>
<th>PC3 (N=126) Mean ± SD</th>
<th>Usual Care (N=114) Mean ± SD</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epworth Sleepiness Scale</td>
<td>6.5 ± 4.2</td>
<td>7.1 ± 4.5</td>
<td>5.7 ± 3.6</td>
<td>NS</td>
</tr>
<tr>
<td>Sleep Apnea Quality of Life</td>
<td>2.3 ± 1.1</td>
<td>2.4 ± 1.1</td>
<td>2.2 ± 1.2</td>
<td>NS</td>
</tr>
<tr>
<td>CES-D</td>
<td>7.9 ± 5.2</td>
<td>8.6 ± 5.5</td>
<td>7.1 ± 4.9</td>
<td>NS</td>
</tr>
<tr>
<td>Patient Satisfaction</td>
<td>1.8 ± 1.2</td>
<td>1.7 ± 1.1</td>
<td>1.9 ± 1.3</td>
<td>NS</td>
</tr>
</tbody>
</table>

CES-D = Center for Epidemiological Studies-Depression; PACIC = Patient Assessment of Chronic Illness Care
Conclusions

- The PC3 intervention has the potential to help improve CPAP adherence in clinical settings.
- The 1-hour-per-night difference held at both 2-month and 4-month time points.
- No differences were seen between the groups on outcome measures at 2 or 4 months.
Conclusions

- CPAP adherence interventions based on health IT have potential to be cost effective relative to more labor-intensive interventions.
- May be useful as part of stepped care plan.
- Patient engagement with health IT tools is variable; consideration of incentives/rewards.
- Future studies would do well to include forums and other peer support, as well as electronic communication with provider.
Acknowledgements

- Project team and colleagues:
  - Christine Edwards, B.A.
  - Tania Zamora, B.A.
  - Zia Agha, M.D.
  - Sonia Ancoli-Israel, Ph.D.
  - Jose Loredo, M.D.
  - Matt Marler, Ph.D.
  - Phil Rios, B.S.
  - Karen Bartku

- UCSD Sleep Clinic Staff

- AHRQ 1R18HS017426-01; VA San Diego Research Service; Veterans Medical Research Foundation.
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ONC’s Consumer E-Health Program Strategy

Lygeia Ricciardi
Senior Advisor
Consumer e-Health
Office of the National Coordinator for Health IT (ONC)
Program Mission

To empower individuals to be partners in their health through information technology.
ONC’s Consumer E-Health Program

Some highlights from program launch in September 2011:

- Participation by 1,400 people including HHS Secretary and Surgeon General
- 30 public and private sector organizations pledged their support for consumer engagement in health via IT
- Release of proposed rules giving consumers direct access to lab data
- Release of extensive online consumer content about health IT at www.healthit.gov
- Released PHR comparison tool for consumers

Group picture of leaders from some participating organizations with Secretary of Health and Human Services and the Surgeon General
Underlying Assumptions

About consumer engagement in health:

- Health engagement includes finding care resources, making good treatment decisions, participating in care regimens, communicating with providers, promoting good health, and other behaviors.

- Actionable information (right info, right place, right time) contributes to individuals’ ability to effectively engage in their health.

- Actionable information for individuals can contribute to the following health outcomes:
  - Increased ability to coordinate care among multiple providers
  - Stronger partnerships with providers in patient-centered care
  - Better self-management
Underlying Assumptions

About consumer engagement in health:

- The goal is effective engagement... not necessarily more engagement.
- Provider and patient attitudes—not just technical and financial considerations—impact individuals’ ability to use information to engage effectively in their health.
- Cultural diversity, the digital divide, and a wide range of literacy levels all need to be addressed to support consumer engagement.
Underlying Assumptions

Powerful “megatrends” support consumer engagement in health:

- Communication technology is getting cheaper and more ubiquitous (e.g., cell phones, smart phones, tablets).
- Online communities are growing and proliferating (e.g., Facebook, Twitter).
- Technology for information collection and analysis is getting cheaper and ubiquitous (e.g., sensors, more powerful computers).
- Trends are toward opportunities for greater consumer engagement in most (other!) aspects of our lives.
- Meaningful Use and other factors are bringing health information held by providers online.
- Market forces are requiring consumers to take greater responsibility for their health and health care.

About roles:
The federal government’s role is to catalyze the change led by other stakeholders and “megatrends.”
Strategic Approach

**Access**
- Give consumers secure, timely access to their personal health information.

**Action**
- Support the development of tools and services that help consumers and providers to take action using their electronic health information.

**Attitude**
- Support the evolution in expectations regarding access to and use of health information to engage more fully in health.
Where AHRQ Fits

Access
- Give consumers secure, timely access to their personal health information.

Action
- Support the development of tools and services that help consumers and providers to take action using their electronic health information.

Attitude
- Support the evolution in expectations regarding access to and use of health information to engage more fully in health.
Example ONC Initiative: Increasing Access

Goal: To recruit and cultivate organizations that touch large numbers of people.

Two types of pledges:

1. **Data holders**: Make it easier for individuals to get secure electronic access to their health info (through Blue Button or Direct), and encourage them to do it.

2. **Non-data holders**: Spread the word about the importance of getting access to health information, and develop tools to make that information actionable.

For more information: [http://www.healthit.gov/pledge/](http://www.healthit.gov/pledge/)
More than 250 organizations have taken the Pledge. Collectively, they will provide access to personal health information to 100 million Americans.
Benefits of Pledge Program

- Public recognition of consumer access to/use of information efforts
- Opportunities to network and partner with other organizations who share a similar goal of greater consumer engagement in health
- A forum to elevate issues and provide input on policy barriers/challenges for the federal government to address
- Input into the development of and access to materials/tools to spread the word
- Opportunities to exchange best practices and learn from leaders in consumer engagement
Example ONC Initiative: Supporting Action

- Healthy Apps Challenge
  - Jointly issued by the Surgeon General and ONC

- Foster development of applications that:
  - Provide users tailored health information
  - Empower users to engage in and enjoy healthy behavior

- Categories:
  - Fitness/exercise
  - Nutrition
  - Integrated health

For more information: [http://sghealthyapps.challenge.gov](http://sghealthyapps.challenge.gov)
Example ONC Initiative: Changing Attitudes
Example ONC Initiative: Changing Attitudes

- Healthy New Year video challenge
- Developing health IT animation
- Goals:
  - Explain value of health IT to general public
  - Foster greater consumer engagement in health
  - Invite public to tell their own stories related to health IT through video.
- Enter the challenge at http://healthynewyear.challenge.gov/
Preparing for the Future: “Frontier Issues”

Better understand (and act on!) policy, technical, and other dimensions of the following areas:

■ Integrating “patient-generated data” into EHRs/clinical care
■ Using social media for health
■ Enabling proxy access to personal data
■ Integrating information about costs/quality of care with clinical info to help consumers understand context
■ Showing how health IT can best support behavior change
Contact Information

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