Studying the use of Information Technology in Home and Hospice Care: Research Findings and Opportunities

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• Introduction
• Studying Information Technology in Hospice
• Technology and Aging in the Home
• Discussion
Hospice Care
Telehospice

The Telehospice Project Research Team is a long-standing interdisciplinary team of researchers committed to intervention research using telehealth technology. We aim to design and test interventions for hospice caregivers that can be delivered through telehealth technologies in an effort to overcome the geographic burden and isolation created through caring for a dying loved one. We are committed to improving caregiver quality of life, lowering caregiver anxiety, improving social support, pain management and problem solving skills.

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http://www.telehospice-project.org
Background

• palliative and passionate care for people in the last phases of a terminal disease and their families, so that they may live with dignity and as fully and comfortably as possible.

• based on the underlying principles of:
  – holistic care; *the patient and their family are the unit of care*
  – self-determination; *it is the patient and family’s beliefs, values, culture and lifestyle that govern decisions pertaining to care.*

• often proxies for clinical decision making given the deteriorating condition of terminal patients.
Background (cont.)

• Caregivers often feel that there is little attention paid to their views and perceptions.
• No specific guidelines for the inclusion of family caregivers in the decision making process or for the assessment of caregivers’ needs and preferences.
• Lack of interventions that are based on an interdisciplinary holistic view of hospice and include caregivers in the ongoing decision making process.
Problem Solving Therapy (PST)

• Problem solving is defined as the self-directed cognitive-behavioral process by which a person attempts to identify or discover effective or adaptive solutions for specific problems encountered in everyday living.

• a conscious, rational, effortful and purposeful activity

• a learning process, a general coping strategy, and a self-control method
Study Rationale

- PST has been found effective in many caregiver populations including hospice.
- Hospice agencies cannot easily adopt cognitive behavioral or psycho-educational interventions that require additional visits.
- Technology has the potential to bridge distance.
- Video can support delivery of non-verbal elements of interventions.
Study Overview

• The aim of this study is to compare the effectiveness of the PST intervention delivered face to face and via videophone to hospice informal caregivers (following a non-inferiority trial approach).

• The underlying hypothesis is that caregivers in the video-based group will report similar levels of post intervention quality of life, problem solving ability and anxiety as compared to caregivers in the face-to-face group.
Subjects

• Two agencies in Seattle, both Medicare and Medicaid certified.
• Inclusion criteria of caregivers were:
  • enrolled as a family/informal caregiver of a hospice patient
  • 18 years or older
  • with access to a standard phone line at home
  • without functional hearing loss or with a hearing aid that allows the participant to conduct telephone conversations
  • no or only mild cognitive impairment
  • with at least a 6th-grade education
Study Design

- Non-inferiority trial
- Random assignment to face to face PST (Group 1) or video PST (Group 2)

<table>
<thead>
<tr>
<th>Visit</th>
<th>Event</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (day 1-3)</td>
<td>Baseline measures</td>
<td>CQLI-R, PSI, STAI, demographic data</td>
</tr>
<tr>
<td>2 (around day 5)</td>
<td>Problem solving Intervention Visit/ Video-Call 1</td>
<td></td>
</tr>
<tr>
<td>3 (around day 11)</td>
<td>Problem solving Intervention Visit/ Video-Call 2</td>
<td></td>
</tr>
<tr>
<td>4 (around day 16)</td>
<td>Problem solving Intervention Visit/ Video-Call 3 (CQLI-R)</td>
<td></td>
</tr>
<tr>
<td>5 (around day 23)</td>
<td>Post-intervention measures</td>
<td>STAI, PSI, Exit interview Via phone</td>
</tr>
</tbody>
</table>
Results

• 138 caregivers referred to the study were contacted by phone
• 8 caregivers refused to participate (lack of time/interest, anticipated travel); 4 were not eligible
• 126 caregivers were randomly assigned to Group 1 (N=77) or Group 2 (N=49)
• Demographics:
  – 6 African American, 7 Asian American, 2 Native Hawaiian/Pacific Islander, 1 American Indian; 110 white/Caucasian.
  – 2% Hispanic; 98% non-Hispanic
• Relationship to patients:
  – 59 adult children; 38 spouse/partner; 4 sibling; 4 grandparent; 5 parents of an adult child; 16 “other”
• 68 caregivers resided with the patients, 58 resided elsewhere.
Results (cont.)

• On average, caregivers reported a higher quality of life and lower level of anxiety post-intervention than at baseline.

• Among participating caregivers, average scores on all PSI subscales showed an improvement in participants’ problem solving skills.

• Of all 126 caregivers, 89 caregivers completed the full study protocol.

• The observed changes in scores were similar for each intervention group and in the expected direction of the scale.
Results (cont.)

• Caregiver quality of life improved and state anxiety decreased under both interventions.
• PST delivered via video was not inferior to face to face delivery.

Subjects’ perceptions

- the convenience of its delivery in one’s home
- opportunity to take the time and reflect on one’s options and strategize/prioritize to prepare for challenging times
- privacy of conversations
- all participants agreed that this intervention should become part of standard hospice services
Subjects’ perceptions-Video

• “a face behind the voice. I really enjoyed it... You were here... It was a personal touch. Although you did make me fix my hair so early in the morning.”

• “At first I thought it would not make a difference... I really liked it more than I thought I would. This made it homey, much more personal. You are here with me and I am talking to you.”
PISCES

- Problem Solving Intervention to Support Caregivers in End of Life Care Settings
- Funded by NIH (R01NR012213)
- Three arm clinical trial
- Clinical Trial Record NCT01444027
Study Design

• Attention control vs intervention group (in person) vs intervention group (via telehealth)
• Flexibility in technology selection
• Bereavement phase
Study Progress

• 4 year trial
• 370 subjects recruited so far
• Overall great levels of acceptance of technology
• Participants suggest other uses for the technology and different timing for the intervention
The ACTIVE Intervention

- Assessing Caregivers in a Team Intervention through Video Encounters
- Funded by the NIH (R01NR011472)
ACTIVE Intervention

• Goal is to test the use of video technology to bring patients and family members into hospice team meetings, measuring the effect of the participation on caregivers’ perception of pain management and patient pain
Findings so far

• Caregivers take an active role in IDT meetings
  – asking questions, expressing concerns, “assertive utterances” (e.g., “I’d like to get your opinion on that)
• Overall, participants (caregivers and hospice staff) expressed support, enthusiasm for project
  – Some concerns originally included staff time, technical quality, handling sensitive topics
  – Many perceived benefits for caregivers (“faces and voices” in decision-making) and staff (new information learned, relationships strengthened/established)
Role of Video Communication

• Explore whether the video-mediated communication facilitates or impedes the communication between teams and caregivers.
• How does videoconferencing quality impact the style and content of communication in team meetings?
• Is there a correlation between the overall audio- and video-quality of video-calls and the themes of communication during these meetings?
## Preliminary work

<table>
<thead>
<tr>
<th>Time Spent On:</th>
<th>Total technical quality score (assessed on site)</th>
<th>Total Video-Quality Sub-score (assessed by the two raters)</th>
<th>Total Audio-Quality Sub-score (assessed by the two raters)</th>
</tr>
</thead>
<tbody>
<tr>
<td>General informal talk</td>
<td>0.63**</td>
<td>0.43**</td>
<td>0.41**</td>
</tr>
<tr>
<td>patient’s clinical status</td>
<td>0.11</td>
<td>0.16</td>
<td>0.14</td>
</tr>
<tr>
<td>pain medication issues</td>
<td>0.11</td>
<td>0.14</td>
<td>0.09</td>
</tr>
<tr>
<td>technical issues</td>
<td>-0.31**</td>
<td>-0.44**</td>
<td>-0.38**</td>
</tr>
<tr>
<td>psycho-social issues</td>
<td>0.43*</td>
<td>0.28*</td>
<td>0.27*</td>
</tr>
<tr>
<td>Caregiver education</td>
<td>0.64*</td>
<td>0.57*</td>
<td>0.62*</td>
</tr>
<tr>
<td>Addressing admin. issues</td>
<td>0.13</td>
<td>0.12</td>
<td>0.11</td>
</tr>
</tbody>
</table>

Correlation Matrix (*p<0.05; **p<0.01; ***p<0.001)
Technology and Aging
HEALTH-E

http://www.health-e.info
Background

• Older adults vary in the development and progression of chronic disease and decline at varying rates in areas of well-being.
• Efforts to date have addressed a single aspect of older adults' wellness.
• Holistic approach to wellness is needed.
• Technology applications have the potential to introduce tools that enable non-obtrusive monitoring and assessment wellness.
Theoretical Framework: Wellness

- Social support and network, perception of isolation
- Vital signs, quality of life, instrumental activities of daily living, gait characteristics
- Social well-being
- Physiological/functional well-being
- Mental/cognitive well-being
- Spiritual well-being
- Spiritual behaviors and beliefs, views on guidance and meaning
- Mood, quality of life, response time, working memory, task shifting, planning

healthoe
home-based environmental assisted living technologies for healthy elders
Study Aims

• test an integrated monitoring system for wellness that utilizes diverse and innovative technologies
• utilize existing hardware systems that can be easily installed in a community setting
• assess issues of acceptance and usability
Subject and Setting

• Eligibility criteria included:
  – age of 62 years or older
  – residents of an independent retirement community
  – independent in activities of daily living (ADL)
  – able to provide written informed consent

• Setting:
  – Community room
Technologies

• Telehealth Kiosk
Technologies (cont.)

• **CogniFit**
  - a brain fitness web-based software solution
  - assessment and over time the improvement of several key cognitive abilities
  - tested for reliability and validity
Procedures

– Initial visit (informed consent, demographic information, baseline assessment)

– Participants come to community room:
  • 3 times a week provide cognitive assessment data (approx. 20 minutes per session)
  • Weekly to use telehealth kiosk

– Exit questionnaires

– Focus group
Methods: Assessment Technologies

- Telehealth kiosk
  - HealthAnywhere database
  - Exported datasets

- Cognitive Function software
  - CogniFit database
  - Exported datasets

Study database

Algorithms for correlations and pattern extraction
My Wellness in October 2011

My Wellness Score Is 81.5/100

My progress over the last 12 months

Messages
Re: Happy Birthday Jane!
27 mins ago
Thanks, Laura :) I am having a wonderful day. Are you coming...
My Wellness in October 2011

Wellness Score 65
Wellness Score 81.5
Wellness Score 74.2

My Age Group

My Community

previous month
October 2011
next month

My wellness progress over the 6 months period

May 2011
Jun 2011
Jul 2011
Aug 2011
Sep 2011
Oct 2011

Overview
Physical
Cognitive
Social
Spiritual
My Wellness in October 2011

Wellness Score
65
Wellness Score
81.5
Wellness Score
74.2

My Age Group
ME
My Community

previous month  October 2011  next month

My wellness progress over the 6 months period


63  53  67.5  73  81  81.5

Doctor’s Note
Results looking good!
Oct 21, 2011
Hi Laura, I just reviewed the CT result and looks good to me...

Calendar
TODAY
Jane’s Birthday
4:30 pm Hair Cut
TOMORROW
6 pm Jane’s Birthday Party

Next Week
MONDAY
10:30 am Doctor’s Appointm...
12 pm Lunch with Paul, Harry...
TUESDAY
7 pm Movies night
THURSDAY
8 pm Happy Hour
FRIDAY
11 am Lunch with Amy, Sam
3 pm Shopping

Messages
Re: Happy Birthday Jane!
27 mins ago
Thanks, Laura :) I am having a wonderful day. Are you comi...
Results: Sample

- 27 subjects
- 9 male and 18 female
- Average age 88.2 years (Range 78-94)
- Educational level:
  - Graduate degree 13 (52%)
  - Undergraduate degree 8 (32%)
  - Community college 3 (12%)
  - High school 1 (4%)
- Experience with computers:
  - Highly comfortable 3 (12%)
  - Moderately comfortable 13 (52%)
  - Slightly comfortable 7 (28%)
  - No experience with computers 2 (8%)
Results: Technology Adaption

- Adjustments needed to maximize usability for participants with various health conditions
- Assistance needed decreased over time; users became independent in short time
- Monthly reports were useful to some participants
- Visualization focus groups revealed diverse preferences for personal wellness records
Results (cont.)

- Increased age was negatively correlated with cognitive tasks associated with divided attention ($r=0.48$, $p=0.029$), planning ($r=0.53$, $p=0.013$), spatial perception ($r=0.718$, $p<0.0005$).
- An increased number of chronic diseases negatively correlated with planning ($r=0.52$, $p=0.016$).
- The number of IADL difficulties was correlated with inhibition ($r=0.46$, $p=0.03$).
Results: Focus Groups

• Positive attitudes towards wellness assessment
• Acceptance of technologies
• Alerts and reports led to changes in individual plans of care
• No privacy concerns
• Some participants self-monitored parameters (e.g. blood pressure, weight) at home prior to enrollment.
• Want to know how they could positively influence wellness on individual level (e.g. specific interventions) and how they compared to peers
Next Phase: Sensor Study

- Stove sensor
- Sensor mat
- Motion sensors
Discussion

• Informatics has the potential not only to enhance home and hospice care but to re-design health care services improving quality of and access to care for stakeholders and facilitate a shift from institution-centric to patient-centric care.
Discussion (cont.)

• Implications for researchers:
  – Residential infrastructure
  – Treatment fidelity
  – Attrition rate
  – Ongoing assessment of technology performance
  – Understand the needs and preferences of the target audience
Contact

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