Comparing Information Needs of Health Care Providers and Older Adults: Findings from a Wellness Study

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Motivation

• Shared decision-making requires information sharing between older adult and health care providers (Demiris, 2009)

• Needs, beliefs, and values of older adults and other stakeholders need to inform the design of technology to support independence (Or et al, 2009)

• Little is known about the similarities, differences and potential discrepancies between the information needs of older adults, HCPs and family members (Keselman et al, 2008)
Preliminary Work

Pilot study- implemented commercially available health monitoring technologies

Enrolled 27 older adults (average age 88.2 years)

Eight week study at independent retirement community
Conceptual model for wellness

- Social support and network, perception of isolation
- Vital signs, quality of life, instrumental activities of daily living, gait characteristics
- Physiological/functional well-being
- Mental/cognitive well-being
- Social 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
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
Data Source for Visualization

My Wellness in October 2011

My Wellness Score Is 81.5/100

My progress over the last 12 months

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 Appointment
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 coming...
My Wellness in October 2011

My Age Group: Wellness Score 65

My Community: Wellness Score 74.2

ME: Wellness Score 81.5

My wellness progress over the 6 months period:

- May 2011: 63
- Jun 2011: 53
- Jul 2011: 67.5
- Aug 2011: 73
- Sep 2011: 81
- Oct 2011: 81.5

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 Appointment
    - 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...
My Wellness in October 2011

- Wellness Score: 65
- Wellness Score: 81.5
- Wellness Score: 74.2

My Age Group: ME
My Community:

Last updated: 5 days ago on Oct 17, 2011

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

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Overview
Physical
Cognitive
Social
Spiritual
Objective

Describe and compare goals, information needs, and preferences for information sharing for older adults and health care providers
Methods - Recruitment

• Older adult participants
  – recruited from an independent retirement community
  – willingness to participate, current resident and at least 62 years of age

• Health care providers
  – recruited through gerontology mailing lists
  – working as a health care provider and experience with older adult care

• IRB approved and consent obtained from participants
Methods – Data Collection

- 4 focus groups with 31 older adults
- 3 focus groups with 10 older adults

Focus group protocol:
- Explanation of a conceptual model of wellness
- Questions about uses, communication, and sharing of health information
- Visualizations of health information used as prompts
Data Analysis

• Seven focus group sessions recorded and transcribed verbatim
• All transcripts independently double-coded by two researchers
• HCP transcripts first and then older adults transcripts with a modified codebook
• Codebooks reviewed for content validity
Results

• 31 older adults (22 female, 9 male)
• 10 HCPs (9 female, 1 male)
• Session duration: 60-75 minutes
• Four themes identified
  – perceived goals of others
  – perceived information needs of others
  – information sharing by older adults
  – role of family members
“I go often, sometimes I don’t go for a while. In between anything can happen and he [physician] wouldn’t know about it. And sometimes you can’t verbalize these problems, raise them.”
“I go often, sometimes I don’t go for a while. In between anything can happen and he [physician] wouldn’t know about it. And sometimes you can’t verbalize these problems, raise them.”

“If we could have some effect on it ourselves, like if it indicated that something we were doing or not doing was causing a drop or rise, we could act appropriately ...”
Theme: Perceived goals of others

• HCP:
  – “A lot of patients would say, ‘I don’t care about my cognitive well-being, what really matters to me is spiritual or social.’”

• In contrast, older adult participant:
  – “Does the health care provider usually take into his overview the social and spiritual well-being?”
Theme: Perceived information needs of others

• HCPs with a greater level of certainty about perceptions of older adult information needs

• HCP:
  – “My hunch is that most patients have their own ideas about what you should track and if you could keep track of that, that would have a lot more meaning for them... if you’re going to put effort somewhere, it would be in finding ways of developing scales that you can agree on with patients and then keeping track of them over time, so that when they come back you can have a meaningful dialogue about how their life is going.”
Theme: Perceived information needs of others

• In contrast, older adult participants expressed uncertainties about providing unsolicited information to their HCPs.
  – “I don’t know if he would be interested.”
Theme: Information sharing by older adults

• Both recognized information sharing by older adults would vary based on the individual
• HCPs noted the potential usefulness of information tools to communicate
• Older adults were open to sharing information with HCPs and family members.
  – Some older adult included friends as substitutes
Theme: Role of family members

• HCPs perceived that family members have goals that differ from their own and their older adult patients.
  – “Family education is, I think, almost more important than patient information.”

• Older adults recognized that not all families are the same.
  – “Some families ask and some families don’t. I don’t think you shove it at them.”
Older Adult Perceptions

Uncertain about use of wellness monitoring data

Questioned ownership of wellness data

Provider Perceptions

Identified multiple use cases for wellness monitoring

Providers would control when and how information is shown

Discussion

• Overall, older adults had less certain ideas about HCP goals and information needs

• Health care providers felt that older adults give high priority to social & spiritual wellness

• Older adults did not necessarily confirm this
  – some older adult participants were concerned with privacy of social and spiritual information
Discussion

- HCPs were open to information from older adult patients

- Older adults felt unsolicited information would be unwelcome

- Shared decision-making may be hindered by conflicting assumptions about information sharing
Limitations

• Older adult participants were of a higher socio-economic status and educational background

• HCP participants represented the disciplines of medicine and nursing.

• Family members not included
Recommendations

• Identify and characterize types of
  – information useful to health care providers, older adults, family members, and others
  – older adults and family members who find consumer health informatics tools acceptable and why

• Design standardized interfaces and tools that are
  – easily tailored to individual patient problems and preferences
  – easily learned by different types of older adults and family members

• Develop communication strategies about
  – potential benefits of consumer health informatics tools for all stakeholders
  – the information that health care providers find useful and are willing to use
Thank you

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