Online Communities and Social Networks: Challenges, Opportunities, and Open Questions

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Agenda

• About My Research
• Online Communities and Social Networks
• Body Listening Project
• Virtual Online Communities for Aging Life Experiences (VOCALE)
• Conclusion and Opportunities for Collaboration
About My Research

Text and Visual Analytics
- Behavioral Health
- Social Media
- Digital Humanities

Information and Knowledge in the Context of Chronic Conditions
- Invisible Conditions
- Complementary and Integrative Health (CIH) aka Complementary and Alternative Medicine (CAM)

Particularly considering:
- Health information quality
- Social construction of illness
- Knowledge representation and belief
- Knowledge collaboration
- Patient experience
Online Communities and Social Networks
Online Communities

• Social technologies are currently being used to connect people and share information about health across geographic boundaries and for a range of health-related issues

• Some exist on generic platforms

  ![Facebook](facebook.png) ![Twitter](twitter.png) ![Reddit](reddit.png)

• Others are more focused on health

  ![PatientsLikeMe](patientslikeme.png) ![MedHelp](medhelp.png) ![DiabetesIQ](diabetesiq.png)
Benefits of Online Communities

• Online communities present great opportunities for persons with health concerns, caregivers, and others to improve their health management

• Empowering outcomes include\(^1,2\):
  – feeling informed
  – increased confidence with physicians
  – increased acceptance and optimism
  – enhanced social well-being


Online Communities Can Provide Different Types of Support

Types of support that we often see:

- Informational support
- Emotional support
- Esteem support
- Network support
- Tangible assistance

The Role that Online Communities Can Play in Health Management

• Patients share executable strategies\(^1\)
• Engage in collaborative problem solving\(^1\)
• People’s use of online communities, along with other information sources, can vary over the course of their condition\(^2\)

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\(^2\)Chen, A. T. (2016). The relationship between health management and information behavior over time: A study of the illness journeys of people living with fibromyalgia. *Journal of Medical Internet Research*, 18(10), e269. [https://doi.org/10.2196/jmir.5309](https://doi.org/10.2196/jmir.5309)
The Value of Information in Online Communities

• Patients have a perspective that is different from clinicians and researchers\(^1\)

• Information from online communities can provide firsthand knowledge of experiences that are not yet well established in an existing body of knowledge

• Patient narratives can be used to augment existing controlled vocabularies\(^2\)

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Challenge and Open Question 1

How do we facilitate engagement?

• In recent years, there has been increased interest in engagement in digital behavioral change interventions¹

• These interventions can have a lot of different components...
  – Apps
  – Modules
  – Social networking components

• How do you identify the active components?

Challenge and Open Question 2

• Patients can have negative encounters in online communities due to:
  – Information redundancy; lack of novelty
  – Negativity
  – Topic drift

• How do we assist patients to find the information that they need?
  – Employ computational means to aggregate information that is similar so that it is more easily retrievable

• How can we mitigate the occurrence of negative interactions in online communities?


Case Examples
The Body Listening Project

LISTEN

schedule
Over the next ten weeks, we will guide participants on an exploration of different topics related to body listening.
GUIDED EXPLORATION

how it works
The content you contribute to this site may be added to a knowledge base for others wishing to learn more about body listening.
LEARN MORE

the hub
We feel strongly about the future of a more participatory web, where everyone can create and discover knowledge.
THINKSPACE

http://bodylisteningproject.org/
Background

• Participatory platform to increase our knowledge of body listening and body awareness

• Body awareness, defined as the ability to recognize subtle body cues, can be helpful in the management of many chronic conditions\(^1\)

• Self-management of chronic illness has been characterized as a dynamic and daily experience\(^2\)

• Three main categories of processes: focusing on illness needs, activating resources, and living with a chronic illness\(^2\)

• There is considerable research on self-management barriers and facilitators, the developmental patterns and sustainability of self-management over time are still unknown\(^3\)

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Participants

• The study was open to anyone over the age of 21 years who was interested in, or wanted to contribute to, knowledge on the phenomenon of “body listening”

• We targeted chronic conditions requiring self-care in which patients might share symptomatology, with a particular focus on chronic pain

• These conditions included chronic pain, fibromyalgia, arthritis, and multiple sclerosis and common comorbidities such as chronic fatigue syndrome and irritable bowel syndrome.
The Plan to Build a Repository

1. Experiences
Over the course of ten weeks, participants will contribute experiences of learning how to listen to their bodies while being guided through the experience by Body Listening Project moderators. Any experiences that you share will be used to build a knowledge repository.
Your voices, experience, and insight are critical to the success of this project!

2. Hashtags
Hashtags are a way to identify a word or group of words to search on them later. Please attach a hashtag (as many as you want) to your contributions.
Your hashtags are one way that you can share with us your ideas for organizing the knowledge that you’re contributing.

3. Steer the Project
In Steer the Project, participate in a discussion about how knowledge about body listening should be organized.
- What categories would you like to see?
- How would you like to search for information?

Guided Exploration
- I noticed that as
- This is what I do when...
- #strategy

Moderators
You

Knowledge Repository

Knowledge Organization

http://bodylisteningproject.org/
# The Guided Exploration

<table>
<thead>
<tr>
<th>Wk</th>
<th>Topic</th>
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<tbody>
<tr>
<td>1</td>
<td>Getting in Touch with Your Body Rhythms</td>
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<td>2</td>
<td>Movement, Energy, and Fatigue</td>
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<td>6</td>
<td>Sense-Making and Conveying What Your Body Tells You in Health Care Contexts</td>
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<td>Mindfulness as a Way to Get in Touch with Your Body</td>
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<tr>
<td>10</td>
<td>The Body as a Vehicle for Self-Growth</td>
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Aim 1. Qualitative analysis to understand the process of body listening


Aim 2. Exploration of the conceptual space of body listening using the tags

- Reviewing tags and developing of a taxonomy
- Text mining and visualization

Learning the Language

Over a chronic condition, participants developed an awareness of their body signals, including how their bodies responded to stimuli:

I learned a lot about my body and its response to stimuli—for a long time I could not drink red wine, have any cured meats, etc.

But it was precisely because I had not been listening to my body that it finally said stop and I had to re-learn how to take care of myself in order to address other less-than-healthy behaviors in my life. (AppleStrudel)
Recognizing and Heeding Limits

not heeding slow-down messages.
(maud)

Exhaustion means I give in, I surrender.
(celestewaters)

Although I know my body will need a full day to recover from even a few hours of activity I find the trade off worth it. (Boboo)
Experiencing Emotional Fatigue and Despair

I’m the manager of all these competing voices and have to coddle them, suppress them, have a talk with them when they get cantankerous, give them attitude adjustments and rewards.

I never wanted to be a manager, no wonder they are burned out all the time! (Zeppelin)
I wonder if we’re too obsessed with the small nuances and signs our body gives us, rather than just feel it, accept it, and let it go. (sgc1203)

I have set a limit on how my condition can affect me. (findjoyagain)
My body is telling me, not now, the suggested dental work needs to wait, you can’t cope with the stress of a root canal on a tooth that isn’t hurting you right now...

My body wants a healer. I am open to facilitation, I am open as well to being my own healer, the right information and support comes to me. (dymond)
The process of body listening in everyday life as a constant conversation.

Understanding the process of body listening can be helpful. But how do we capture and organize this knowledge?
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Guided Exploration

Moderators You

I noticed that as... #strategy

Experiences + Hashtags

Knowledge Repository

Knowledge Organization

http://bodylisteningproject.org/
For me, getting in touch with my body rhythms has taught me that mornings start slow; mid-mornings to early afternoon are somewhat-to-very productive; somewhere between 2-4 p.m. is the roughest/lowest dip of the day; early evening is somewhat productive; anything after 7 p.m. is a miracle; and bedtime is 9-9:30 p.m. but it seems as though I get my second wind as soon as my head hits the pillow.

Regular snacks throughout the day (peanut butter with a banana or celery; nuts; olives; or granola bars) keep me from getting shaky/sweaty/nauseous...

#mostproductivetimes #portablesnacks #planaccordingly #planahead -- MyndiR

Wow!! Whoa! I feel that MyndiR you have written the holy grail synopsis of my life biorhythm!

...this is what I have found majority of my lifetime and have tried to ignore it... I don’t think I ever accepted my rhythm for what it is and narrowed it down like this.

#totallystruckinawe #thanksfortheadvicetoplan -- QnVz
Aim 2. Exploration of the conceptual space of body listening using the tags

• 234 participants contributed 431 posts and 818 tags

• Reviewed tags and developed of a taxonomy\textsuperscript{1,2}

• The taxonomy was comprised of 5 meta-categories and 18 categories

• Text mining and visualization\textsuperscript{2}


Body Listening and Self-Management Taxonomy

- **Health Management Strategies**
  - Treatment or treatment strategy (TM)
    - acupuncture, alexandertechnique, biofeedback, funkplunkmyselfoutside
  - Exercise (E)
    - Adductorstretch, walking, yamunabodyrolling, exercisewithchildren
  - Diet and food (DF)
    - atkinsdiet, eliminationdiet(s)
  - Coping or coping strategies (CS)
    - prayer, affirmations, reframing
  - Supplies or equipment (SE)
    - Netipotforallergies, bodypillow
  - Health management strategy (HMS)
    - Cellphonealarm, taketimetorecover, fulltimebodymanager

Other

Concepts and States

Health-related Information Behavior

Influencers

Green check icon source: https://icon-library.net/icon/green-check-icon-23.html
Body Listening and Self-Management Taxonomy

- **Health Management Strategies**
- **Concepts and States**
  - **General concepts (CN)**
    - Attitude is everything, journey, balance, energy
  - **Positive actions (PA)**
    - Advocating for yourself, transformation, pushing through
  - **Mental states (MS)**
    - Acceptance, compassion, no fear
- **Influencers (IF)**
  - Sick weather changes, four seasons, hot weather, pollen is painful
- **Rhythms and schedules (RS)**
  - Night owl, most productive times

Green check icon source: https://icon-library.net/icon/green-check-icon-23.html
Body Listening and Self-Management Taxonomy

Health-related resources (HR)
Patientexperts, trustedsites

Self-monitoring (SM)
Journaling, symptomtracker, sleepdigestionconnection, bodyclues

Health-related information behaviors (HIB)
Findinghealthinformation

Symptoms, illnesses (IS)
Shakiness, sleepdisorders

Health care-related terms (HC)
doctors, massagetherapists, physicaltherapist

Communication and relationships (CM)
Energyfromothers, supportivebossesrock

Moderator or administrative content (AD)
Useanycoloryoulike, usebothhands
How do the categories from the Body Listening and Self-Management Taxonomy compare to authoritative health knowledge resources?
Prevalence of the Categories of the Body Listening and Self-Management Taxonomy

Concept coverage in the UMLS (Unified Medical Language System) Metathesaurus

Exploring the Conceptual Space of the Tags
The Body Listening and Self-Management Taxonomy as a Network

The Body Listening and Self-Management Taxonomy as a Network

Tags assigned to both Symptoms and Illnesses and Rhythms and Schedules:
#reverseSAD, #daysnightsreversed, and #migraineuponwaking

Reflections on the Taxonomy

- The meta-categories of the taxonomy help us to better understand important aspects of patient self-management, from the patients’ perspective
- Starting point to leverage collective knowledge about health management
- Dimensions of particular value: health management strategies and influencers
- There is great potential to use participatory mechanisms to engage patients in the sharing and curation of health information sources
But there are still issues to work out...

Participants did not contribute as much information about their health information behaviors and health information sources as we hoped.

**Potential solutions:**

- Build clearer avenues for participation, such as structured fields for the contribution of information sources.
- Work with patients to make sure that what we are asking is clear and relevant to their needs.

High lurker population and little sustained participation over time.

**Potential solution:**

- Work with face-to-face support group leaders to build a networked crowdsourcing mechanism.
The Body Listening Project: Conclusion and Implications

• Monitoring and filtering of information from one’s body is difficult work

• We can involve patients in the process of research

• Knowledge of this process can be used in patient education and in the development of tools to support self-management

• The tags that people contribute and manually and automatically created metadata can be used in search and recommender systems, to enhance people’s ability to retrieve relevant information
Virtual Online Communities for Aging Life Experiences (VOCALE)

Discussion
#Week1  #Sleep

This week, we are going to talk about sleep. How well do you sleep? Have your sleep patterns changed over the years? Let’s talk about it! When responding, here are some questions to consider:

- Do you fall asleep easily? Do you experience challenges when falling asleep?
- As time goes on, do you notice any changes in your sleep?
- How have these changes in sleep affected your life?
- How do you manage these changes? Any examples?

Please comment on your experiences below and respond to other participants, even if you get great sleep!

Introduction

Frailty:

• Serious and potentially modifiable geriatric syndrome\(^1\)
• Commonly associated with aging\(^1\)
• Phenotypical manifestations include: weight loss, fatigue, weakness, slowness and inactivity\(^1\)

Objectives and Approach

• Sharing information with peers may facilitate older adults’ development of management strategies for aging-related health changes, including frailty

• We developed the community on Facebook due to its accessibility and high penetrance among older adults\(^1\)

• We set a target group size of 10 for each group, to encourage participation and engagement

Using an innovative discussion platform to give voice to aging-related experiences: A pilot study. Journal of Gerontological Nursing.
Development of the VOCALE Intervention

- **Component:** Training instruction and materials that are friendly to older adults
  - Pilot Test: Red
  - Round 1: Red
  - Round 2: Red
  - Future: Red

- **Component:** Platform that is accessible to older adults
  - Pilot Test: Blue
  - Round 1: Blue
  - Round 2: Blue
  - Future: Blue
  - Facebook linear news feed layout
  - Facebook 'units' layout
  - Discourse topic-level layout

- **Component:** Weekly prompts on differing frailty-related symptoms
  - Pilot Test: Yellow
  - Round 1: Yellow
  - Round 2: Yellow
  - Future: Yellow

- **Component:** Infusion of a more active, skills-based problem solving component
  - Pilot Test: Green
  - Round 1: Green
  - Round 2: Green
  - Future: Green

**Image credit:** Andrew Teng
Training Materials and Support

• Different materials for different device types (computer, cell phone, tablet)
• Two one-on-one in-person Facebook training sessions to ensure that participants were capable of accessing and posting in the group
• Additional in-person booster training sessions were provided as needed

Accessing the Group

3. Click on the group name to go to the group’s discussion page.

You are now on the group discussion/main page.

Even though activities and posts from the secret Facebook group will show up on your News Feed, these activities and posts are not public.

They will NOT appear on your profile and friends will not see this content.
Usability Issues in Round 1

- Topics would be displayed out of order
- Much of the content stays hidden; participants need to click in multiple times to get to content
Units out of order

Welcome to VOCALE - Virtual Online Communities for Aging Life Ex... See More

GROUP TYPE
Social Learning

LOCATION
Seattle, Washington

CREATE NEW GROUPS
Groups make it easier than ever to share with friends, family and teammates.

14 Members

VOCALE
Secret group

About
Discussion
Units
Announcements
Members
Events
Photos
Files
Group Insights

#VOCALE

This week, we will talk about mood. Sometimes our mood fluctuates without any obvious reasons. Sometimes our mood is affected by the

Discussion
#Week7 #Mood

Happy Monday, everyone!
Hope you had a great weekend!
Please see below for this week’s discussion prompt.
Thank you for your participation!

#VOCALE

This week we are going to talk about changes in pace. We may all experience a change in pace in our life. Some people may have a change in pace after a serious illness or life event. Others may experience a gradual slowing down process over time. Let's talk about it! Below are some questions to consider:

- Have you noticed any changes in pace as you age? Does it take

Image credit: Andrew Teng
Units are in order

Hello everyone! Below are the units for each week’s discussion prompt. To find the current discussion prompt, scroll down and find ‘CURRENT WEEK.’ If you are experiencing any troubles, feel free to reach out at vocale@uvu.edu. Thanks and I look forward to an engaging and fruitful discussion with you all!
Welcome to VOCALE - Virtual Online Communities for Aging Life Experiences! The purpose of this private group is to allow us to better understand your age-related bodily experience through the use of moderated online discussions. We will host 8 weekly guided discussions on different topics for you to share thoughts and experiences on. Thank you in advance for your time and contribution!

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<td>3</td>
<td>1m</td>
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<tr>
<td>Week 3: Let’s Talk About ‘Pain’</td>
<td>A S O C</td>
<td>4</td>
<td>1m</td>
</tr>
<tr>
<td>Week 2: Let’s Talk About ‘Physical Activity’</td>
<td>A A</td>
<td>6</td>
<td>1m</td>
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<tr>
<td>Week 1: Let’s Talk About ‘Sleep’</td>
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<td>10</td>
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<tr>
<td>Ice Breaker No. 1</td>
<td>A A S O C</td>
<td>8</td>
<td>21d</td>
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</tbody>
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Image credit: Andrew Teng
Synopsis of Round 1

• Eight older adults (mean age: 82.8; range: 78-90) were enrolled at the start of the study.

• During the ten-week discussion, participants contributed a total of 133 responses.

• Common topics:
  1. *symptoms* (e.g. pain, weakness/tiredness, and sleep difficulties)
  2. *management strategies* (e.g., health behavior changes and psychosocial support)

• Outcomes:
  • Positive trend of change in participants’ average self-reported health and chronic disease management self-efficacy scores

Development of the VOCALE Intervention
Infusion of Problem Solving Therapy

• Problem-solving therapy (PST): cognitive-behavioral intervention focused on the adoption and application of adaptive problem-solving attitudes and skills\(^1\)

• PST is highly flexible \(^1\):
  – can be applied in a variety of formats (e.g. group, individual, telephone)
  – Has been employed with adolescents and their parents, caregivers, in the workplace, among others

• We employed the ADAPT framework\(^2\)
  – Attitude
  – Define
  – Alternatives
  – Predict
  – Try Out


Discussion

#Week6 #Define

This week we’ll be exploring how to define problems, which is an important aspect of the problem solving process. Let’s discuss the problems that Sally is facing below! Here are some questions to consider:
- What are the problems?
- Why is solving these problems important for Sally?
- What are her potential obstacles to solving the problems?

Sally is 75 years old and is experiencing many age-related symptoms including pain, fatigue and trouble sleeping. She recently has been feeling more tired and sore and can no longer walk up or down the stairs.

She has a desire to be more active and exercise, but pain in her back and joints affects her ability to do so, making her frustrated. Furthermore, this pain impacts her ability to have a good night’s sleep. Even when she does fall asleep, she often tosses and turns waking up early.

Her healthcare provider has tried to help her manage the symptoms by prescribing medications, but these treatments are financially taxing and this worries Sally. She and her husband try not to tell their children about their financial concerns because they don’t want to be a burden.

Therefore, her husband often tries to help her out by ensuring that she takes melatonin regularly for sleep and by giving her gentle massages to ease the pain in her joints.
Informal Reflections on Round 2

- Asked more questions amongst themselves; in Round 1 it was primarily between the moderator and participants

- About the PST component:
- Participants gave suggestions instead of performing the task for the week

- How to achieve therapeutic effect
  - Type of moderator (peer, researcher, therapist, etc.)
  - Own problem vs. persona application
  - Homework assignments
Summary of Findings from VOCALE

• This platform can:
  – Facilitate information exchange among older adults
  – Empower older adults to leverage acquired knowledge to promote better health and self-management strategies

• Future research:
  – Conduct a trial on a larger scale to demonstrate differences in health-related quality of life
  – Expand study to focus on other populations including older adults of diverse racial, educational, and cultural backgrounds
Conclusion

• Online communities are important venues for informational and social support
• Two different examples, both having to do with online communities focused on long-term health management:

1. Body Listening Project
• There are ways to learn more about patient experience through narrative experiences, through both traditional and automated qualitative analysis techniques

2. VOCALE
• Iterative design procedures, incorporating user feedback, can assist in designing communities that suit target populations
• Evaluation of the community in terms of usability, user experience, and outcomes
Potential Research Opportunities/Collaborations

Information sharing in the context of chronic illness

Text and visual analytics research to explore user interaction patterns

Building tools for communication of genetics risk information
Family Connection Plan

1. Enlist Family Communicator

2. Train Patient and Communicator

3. Help connect with family

4. Follow up

5. Use DNA and genealogy to find more relatives

6. Help relatives connect with local genetics providers

7. Repeat and grow

Image credit: Dr. Brian Shirts, Department of Laboratory Medicine, University of Washington
Many thanks to:

• Dr. Mike Conway and the Department of Biomedical Informatics, University of Utah

• My collaborators and the participants of:
  – The Body Listening Project
  – Virtual Online Community for Aging Life Experiences (VOCALE)

• My co-authors of a book chapter in progress on online communities and social networks, Drs. Albert Park and Andrea Hartzler
Questions?

(Tai chi anyone?)