# How Can Technology Better Support Spiritual Care?

*Guidance and Future Innovations for Spiritual Care in the Aftermath of the COVID-19 Pandemic*

**Estelle Smith**
Ph.D., Computer Science, University of Minnesota

**Diana Freed**
Ph.D. Candidate, Computing & Information Science, Cornell

**Susan O'Conner-Von**
Ph.D., RN, School of Nursing, University of Minnesota

# Learning Objectives

**[Part I]**      Describe prerequisites of *online* **spiritual support**

**[Part II]**     Discuss **best practices** for helping patients to utilize online spaces for spiritual support

**[Part III]**    Compare and contrast **future tech** possibilities for spiritual care after COVID-19

# Pulse Check: Who's here on Zoom?!

Please complete this brief google form: https://bit.ly/SCA-intro

**Responses will be anonymously displayed to the group in just a moment.**

==**We invite your continual participation during the workshop!**==

- **Ask questions** for the organizers in the **Q&A feature** on Zoom
  - We'll answer them at the end of each section, as time allows
- **Discuss your reflections and ideas** in the **Chat feature** on Zoom

# Introductions

Website | 🐦 @EstelleSmithPhD
c.estelle.smith@colorado.edu

**Current:** Postdoc, CU Boulder, Info. Science
[Now on faculty job market]

**Prior:** PhD in Computer Science (Dec. 2020, MN)

**Diss. topic:** *Computational Spiritual Support*

**Recommended publication:**
What is Spiritual Support and How Should It
Impact the Design of Online Communities? (2021)

Website | 🐦 @diana_freed
dlf92@cornell.edu

**Current:** PhD Candidate, Cornell, Info. Science
[faculty job market June, 2022]

**Prior:** MS in Information Science -Cornell; Clinical
and counseling psychology-Columbia University

**Research:** Digital Health, Privacy and Security,
Human-Computer Interaction, Technology-
facilitated Youth Interpersonal Violence and
Intimate Partner Violence

Susan O'Conner-Von | Website
ocon0025@umn.edu

**Current:** Professor, School of Nursing; Academy
of Distinguished Teachers, University of Minnesota

**Prior:** Estelle's PhD Co-Advisor at MN

**Research & Practice Areas:** Palliative and end of
life care, spiritual care, pediatric pain
management.

1997

CARING
BRIDGE ®

# Evolution of Tech Platforms & Health Policy

**EHRs:** only gov't & big hospitals

More **widespread EHRs:** billing & scheduling

**HIPAA**: Privacy regulation + accountability of insurance

**Office of the National Coordinator for Health Information Technology:** ensure that Americans have EHRs within 10 years

**Nursing Code of Ethics:** provisions on social media

**Federal law:** EHRs *must* be downloadable

**Timeline:** 1876 · 1960s · 1971 · 1990s · 1996 · 1997 · 1998 · 2000 · 2001 · 2003 · 2004 · 2005 · 2006 · 2010 · 2011 · 2015 · 2017 · 2022

First **telephone call:** Bell/AT&T services began in 1880's

First ever **email**

(AOL)
(Hotmail)
(Yahoo Mail)
**CaringBridge**

WebMD

(Cancer Survivors Network)

Wikipedia

(MySpace) LinkedIn

Facebook
Gmail

Reddit
YouTube
LotsaHelpingHands

Twitter

Instagram
MealTrain

SnapChat
Twitch
(GooglePlus)

TikTok

# **Ecosystems** of Tech

## **Patient-Centric**

*Known Identity*

**Journaling:**

- CaringBridge
- ~~CarePages~~

**Coordinating support:**

- GoFundMe
- Lotsahelpinghands
- MealTrain

## **General Social Media**

*Known Identity*

**Personal:**

- Facebook
- Instagram
- TikTok

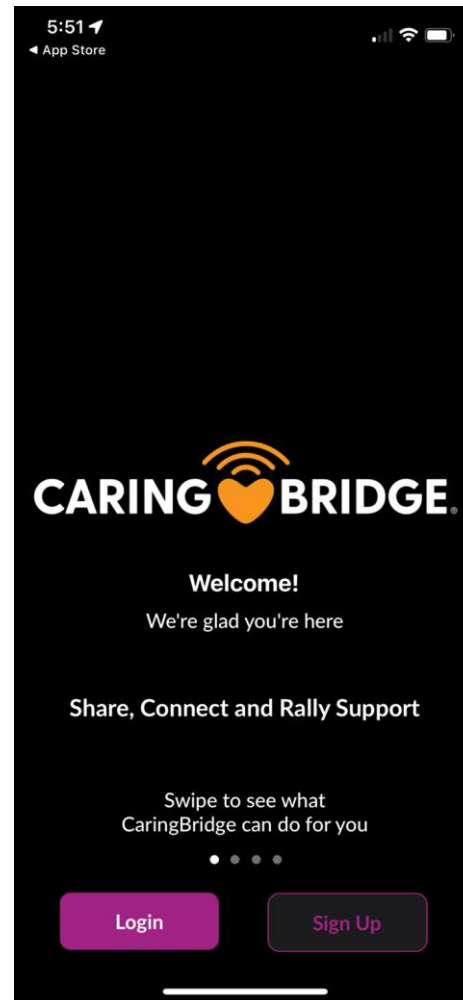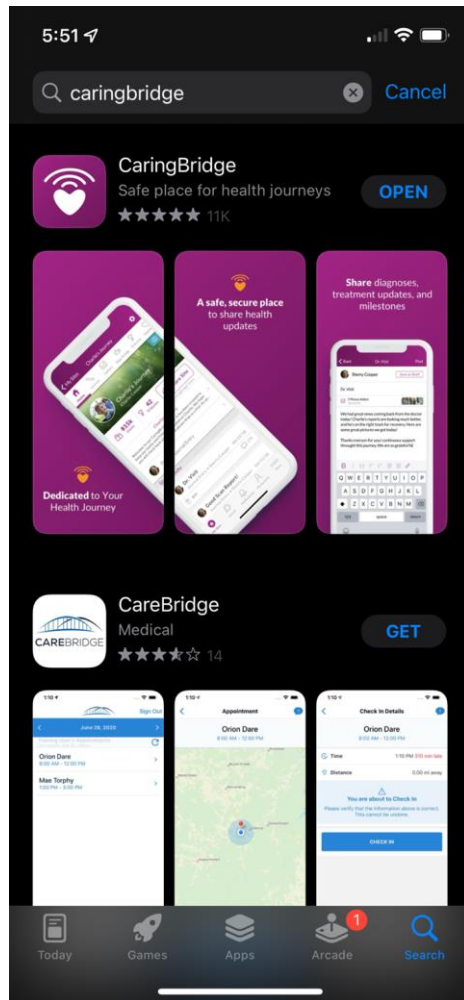**Professional:**

- Twitter
- LinkedIn

*[Pseudo] Anonymous*

**Patient-Specific Platforms:**

- PatientsLikeMe
- Cancer Survivors Network

**Niche Communities on Larger Platforms:**

- Reddit (e.g., r/breastcancer)

# App Store

APR
22
2015

# Sharing Health Updates with Community

## April 22, 2015

Journal entry by ▓▓▓▓▓ — Apr 22, 2015

Welcome to the Caring Bridge site for our friend and sister in Christ, Chris.

I haven't done this before, so if you have any advise for me, let me know!

In March, Chris became sick with abdominal pain and it was discovered that she had a mass on her uterus. She was refered to a specialist in St Paul to remove the tumor at the end of March. The cancer was identified as an Endometrial Stromal Sarcoma. Within a week, she was back in the hospital with complications from the surgery and it was noted that there were some nodules on the base of her lungs. She had further imaging, and biopsy showed that the sarcoma had spread to lungs making this a stage 4 high grade type of cancer. Her doctor was quite concerned because she had 2 separate CT's of the abdomen and pelvis (which includes the base of the lungs) about 3 weeks apart. The second scan showing nodules which were not there previously.

| Jun 9, 2015

Christine please know I am thinking about you and praying that your journey home will be peaceful and painless. You are one of my oldest friends, we met at CCD! We were just 14 and I remember you as a confident, intelligent, and funny girl. and boy could you squeeze a dollar! I still don't know anyone who can stretch a dollar like you! Our lives have gone in different directions but have paralleled in so many ways! I wish your family peace and joy in the knowledge that you will be with God. I will miss you. I love you.

1 Heart     Reply

| Jun 9, 2015 (edited)

Thank you, ___ for creating this journal for Chris.

Reply

| Jun 9, 2015

Chris...may God bring you a miracle. Thanksgiving and Christmas are not the same with out you. Bob Spinharney

3 Hearts     Reply

## Receiving Supportive Communication

| Jun 9, 2015

Chris, we've had so many adventures together! Riding Segways, camp Lebanon, movies and music in the parks, talking about the Church and many, many more. I believe you are personally responsible for teaching the entire Holy Family parish cards! I Love you so much! You are such a great witness to our Faith. You have taught me and many others so much through your actions and prayers. I am praying for you and your family! Peace be with you my dear sister in Christ!!! <3
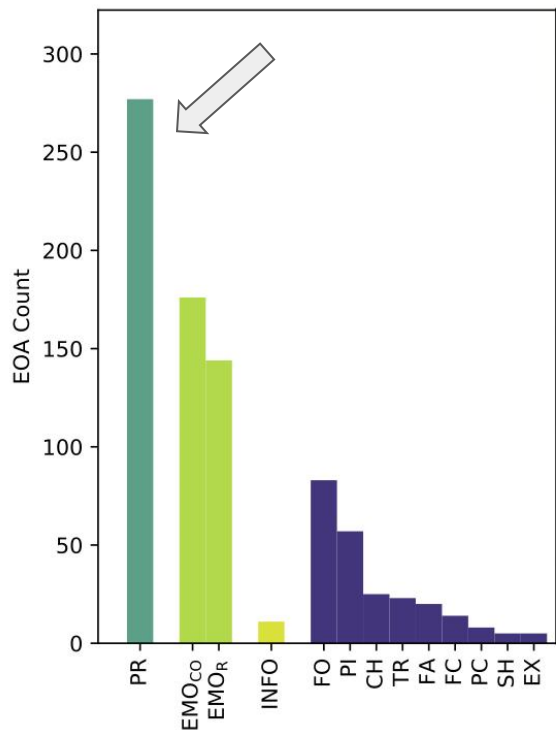
Reply

| Jun 9, 2015

Loving prayers for you Chris.

# Expressions of Appreciation

# Survey (Likert Ratings)



| Support Type | P/CG ($m = 576$) Patients/Caregivers | FFA ($n = 415$) Friends/Family |
|---|---|---|
| Prayer Support (PR) | $M = 3.18$ $SD = 1.14$ | $M = 3.39$ $SD = 1.01$ |
| Remote Emotional Support ($EMO_R$) | $M = 2.87$ $SD = 1.10$ | $M = 3.10$ $SD = 0.94$ |
| Instrumental Support (INSTR) | $M = 2.78$ $SD = 1.19$ | $M = 2.73$ $SD = 1.24$ |
| Co-Located Emotional Support ($EMO_{CO}$) | $M = 2.51$ $SD = 1.14$ | $M = 2.70$ $SD = 1.15$ |
| Informational Support (INFO) | $M = 2.26$ $SD = 1.23$ | $M = 1.88$ $SD = 1.37$ |

C. Estelle Smith, et al. *"I Cannot Do All of this Alone": Exploring Instrumental and Prayer Support in Online Health Communities.* **(TOCHI 2020)**

**Spirituality**

*is the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.*

(Puchalski, 2009)

# Participatory Design Workshops
*CaringBridge Stakeholder Groups*

| CaringBridge Users (n=11) | Spiritual & Religious Leaders (n=6) |
|---|---|
| Healthcare Workers (n=7) | CaringBridge Employees (n=10) |

34 total participants

C. Estelle Smith, et al. *What is ``Spiritual Support'' and How Should It Impact the Design of Online Communities?* **(CSCW 2021)**

What is your group's definition of **spiritual support?**

someone, something or an exper... acting as a catalyst to connect... a person in need to ~~a higher source~~ their perception of a loving spiritual source.

**1. Structured Conversation**

**2. IDEO Group Brainstorm**

# 3. Rapid Prototyping



**Sketching**
*e.g.* "Care m**App**"

**Physical**
*e.g.*
"Therapy Dog
Smart Collar"

> Spiritual support is a **dimension** of social support that **underlies** and can be expressed through all forms of social support.

## Instrumental

## Prayer

## Emotional

## Informational

## Network

## Esteem

Spiritual support forms a **triadic relationship.**

The "Sacred" or "Significant"
*(Transcends specific beliefs)*

A "Provider"
*(e.g. community member, healthcare worker, spiritual leader)*

A "Receiver"
*(e.g. Patient, caregiver, family member)*

Spiritual support is **mutual.**

# **Prerequisites** for Spiritual Support

1. **Adaptability & openness** to support

1. **Discernment & articulation** of spiritual needs

1. **Safe space** for support exchange

# Six **Qualities** of Spiritual Support

| Technology | Presence | Meaning | Location | Relationship | Temporality |
|---|---|---|---|---|---|
| *The degree to which a human invention (e.g., pen & paper, the Internet, smartphones) must be involved for support exchange.* | *A quality of positive, intentional, and attuned presence between a person with themself, others, and/or the significant/sacred.* | *The ability and capacity to make meaning out of pain, suffering, and other challenging circumstances of life & death.* | *Where support is being exchanged, whether in-person (geographic co-location, or remotely (at a distance).* | *The nature of the social relationship between supporter and recipient, and which values or elements of identity are shared (vs. not).* | *When the support exchanged is intended to occur (e.g., now, near or distant future).* |
| Is technology **required** in order for the supportive interaction to exist?<br><br>Is it required that technology be **absent**? | How can supporters cultivate a sense of **genuine, connected presence** with support recipient?<br><br>What might contribute to a sense of **emptiness** or **lack of presence**? *(e.g., "empty" thoughts & prayers)* | What **barriers** are making it hard for the support recipient to make sense of the situation?<br><br>What techniques, tools, and innate qualities help supporter/recipient to express **spiritually healing narratives**? | It is **possible or necessary** for supporter/recipient to be in the same location?<br><br>Is there a **specific** location (geographical or online) where the support needs to take place? | **How well** do these people know each other? *(e.g., spouses, acquaintances, strangers)*<br><br>What **expectations, history, and responsibilities** exist between them, if any? | Is support needed **urgently**, or very soon?<br><br>Is support intended to occur at an unpredictable or predetermined **future moment**? |

# **Q&A / Discussion** [5 min.]

- [L.O.] Describe **prerequisites** of online spiritual support
  - Adaptability/openness
  - Discernment/articulation of needs
  - Safe space

# Part II: Best Practices

[L.O.] Discuss **best practices** for helping patients to utilize online spaces for spiritual support

- Recap **ethical provisions**
- Small group discussions of **case studies**

# Provisions of the Nursing Code of Ethics (2015)

**Provision 1** | The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person.

**Provision 2** | The nurse's primary commitment is to the patient, whether an individual, family, group, community, or population.

**Provision 3** | The nurse promotes, advocates for, and protects the rights, health, and safety of the patient.

**Provision 4** | The nurse has authority, accountability, and responsibility for nursing practice; makes decisions; and takes action consistent with the obligation to promote health and to provide optimal care.

**Provision 5** | The nurse owes the same duties to self as to others, including the responsibility to promote health and safety, preserve wholeness of character and integrity, maintain competence, and continue personal and professional growth.

**Provision 6** | The nurse, through individual and collective effort, establishes, maintains, and improves the ethical environment of the work setting and conditions of employment that are conducive to safe, quality health care.

**Provision 7** | The nurse, in all roles and settings, advances the profession through research and scholarly inquiry, professional standards development, and the generation of both nursing and health policy.

**Provision 8** | The nurse collaborates with other health professionals and the public to protect human rights, promote health diplomacy, and reduce health disparities.

**Provision 9** | The profession of nursing, collectively through its professional organizations, must articulate nursing values, maintain the integrity of the profession, and integrate principles of social justice into nursing and health policy.

# Nursing Ethics [3.1]:
*Protection of the Rights of Privacy & Confidentiality*

**Privacy:**

the right to control access to, and disclosure or nondisclosure of, information pertaining to oneself and to control the circumstances, timing, and extent to which information may be disclosed.

**Confidentiality:**

nondisclosure of personal information that has been communicated within the nurse-patient relationship.

# Nursing Ethics [3.1]:
*Protection of the Rights of Privacy & Confidentiality*

"Because of **rapidly evolving communication technology** and the **porous nature of social media**, nurses must maintain vigilance regarding postings, images, recordings, or commentary that intentionally or unintentionally breaches their obligation to maintain and protect patients' rights to privacy and confidentiality. The patient's well-being could be jeopardized, and the fundamental trust between patient and nurse could be damaged by **unauthorized access to data** or by the **inappropriate or unwanted disclosure of identifiable information**."

# Evaluating Technology: Privacy Considerations for vulnerable populations:

- Personal decision to disclose on social media

- Proxy disclosure - someone shares information about themselves that exposes your personal situation
    (a) 23 and me
    (b) Social media disclosure - [divorce, birth, illness]

- Organizational decisions to "disclose"/provide/sell data externally for profit

- Does the app/ or platform provide clear harm reporting and clear privacy and security features?

- Data Transparency: data mining private conversations without disclosure

    Crisis Text Hotline

    Talk Space

# **Small Group** Activity

- Zoom **breakout rooms** with 4-5 participants
  - **15 Minutes**
  - Same groups for next activity!

- Designate roles:
  - **Note taker**
  - **Presenter**
    - Plan for 1-3 min. summary of key takeaways

- Follow the slides to explore your case study. **Take plentiful notes!**

- Please open this deck in your personal browser now: https://bit.ly/SCA-group

# **Full Group** Discussion

- **10-Minutes**

- **Presenters:** Please share main takeaways (1-3 min.)

# 5-Minute Zoom Break

**PAUSE**

5:00
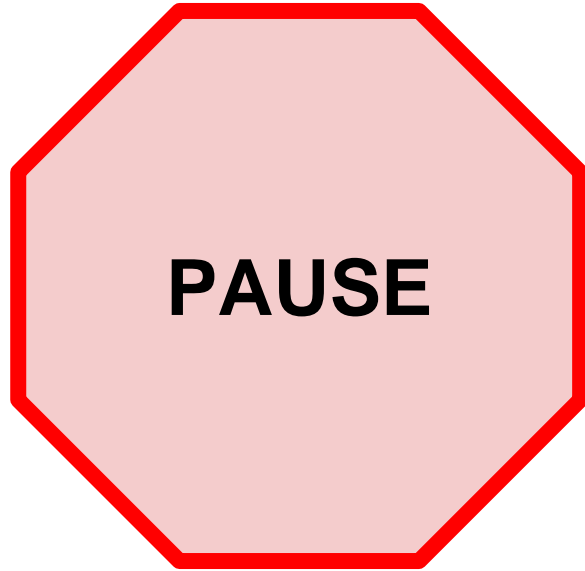
# Part III: Future Tech

[L.O.] Compare and contrast **future tech** possibilities for spiritual care in the aftermath of COVID-19

- Present **prior ideations**
- Return to small groups for **problem-solving & ideation**

# **Ideation** Results

*224 individual ideas, 6 themes*

**62%**

COMMUNITY
& HUMAN
DIGNITY

**22%**

SOUND
& TEXT

**17%**

PRACTICAL
RESOURCES

**12%**

VR / AR

**10%**

ARTIFICIAL
INTELLIGENCE

**7%**

PHYSIOLOGY

# Design Ideas
*for CaringBridge*

## Idea #1: **GodBox**



Choose Your Higher Power
God/Love/Shakti
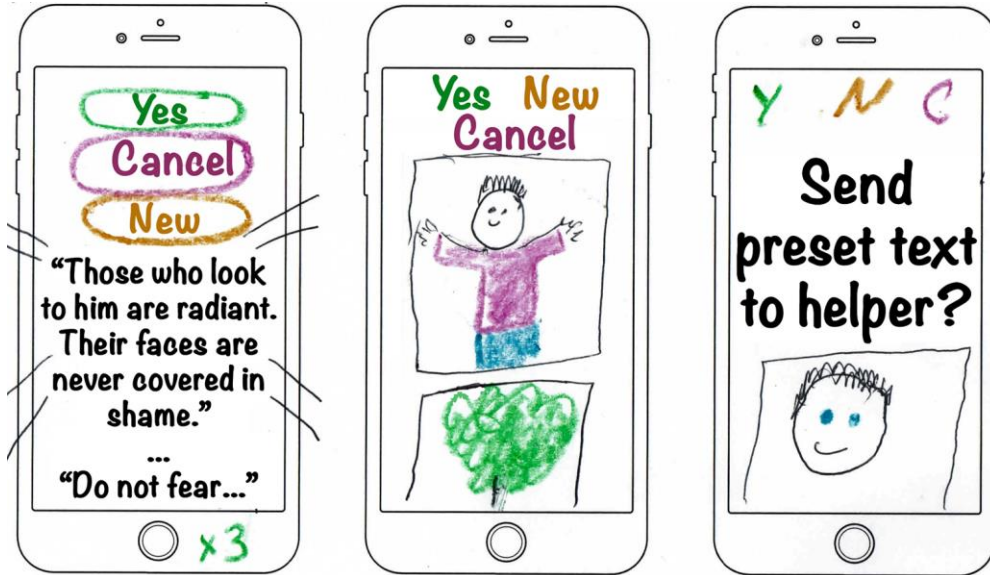
Welcome to GOD BOX

Type your worries into the box.

I am so worried because...

Allow users to select and represent their core beliefs.

# Idea #2: **3Touches**



Provide mechanisms that encourage thought about future events when support will be necessary.

# Idea #3: **AI-Assisted Communication**

Patients and caregivers love hearing from you; add a comment to show your support.

(Current CaringBridge Prompt)

**Post a Comment**

**Estelle Smith**

You are so wonderful

**Post a Comment**

For example:
- Editable text suggestions
- Nudges: what to say or not to say
- Suggestions for scripture or inspirational sayings

# Idea #3: **AI-Assisted Communication**

Watch **_this video_** to learn more about how to say the right thing.

**Post a Comment**

**Estelle Smith**

**Post a Comment**

- Customized training resources embedded in the interface
  - Disease-specific
  - Spiritually-tailored langage
  - Etc.

# Idea #4: **Care mApp**



Visualize support networks and what they have to offer.

*Visualization by
Avleen Kaur, 2020*

# Small Group **Ideation**

During the COVID-19 pandemic:

- What **solutions** (or lack thereof!) did your unit or workplace institute to provide spiritual care remotely?


- How might we **improve** our technologies and practices to better support human dignity & communities as the pandemic continues?

# Small Group **Ideation**

- **10-Minutes**

- You will be returned to the **same Zoom breakout room** as before shortly!

- **All participants:** In the same deck as before, please navigate to slide #19, titled "Small Group Ideation"
  - Here is the link again, in case you closed the tab: https://bit.ly/SCA-group

# Full Group **Discussion**

- **10-Minutes**

- **Presenters:** What were *key takeaways* from your discussion?

# **Thank you** for your time & participation!

Please share your feedback and **ideas for future research**:
https://bit.ly/SCA-feedback

Or email c.estelle.smith@colorado.edu with questions, feedback.