

Meeting Patients Where They're @:

Chaplains' Reflections on Online Spiritual Care Communities

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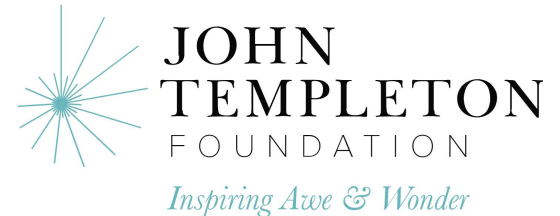


Chaplaincy care can meet patients where they're @



Presentation based on:

- **Workshop paper:**
 - *“On the Challenges of Implementing Online Spiritual Care Communities (OSCCs) in Collaboration with Diverse Healthcare Teams.”*
 - CHI 2024 Conference
 - **Publicly available** on my website (<https://estellesmithphd.com/publications/>)
- **Full journal article submitted July 2, 2024:**
 - *“Meeting Patients Where They're At: Toward the Expansion of Professional Chaplaincy Care into Online Spiritual Care Communities.”*
 - CSCW 2025: A premier journal in human-computer interaction & social computing
 - **Email me** for a copy of the pre-print! (estellesmith@mines.edu)
- This work is funded by the **John Templeton Foundation**
 - *“Expanding Models Of Delivery For Online Spiritual Care”*
 - Project ID 62930



<https://www.templeton.org/grant/expanding-models-of-delivery-for-online-spiritual-care>

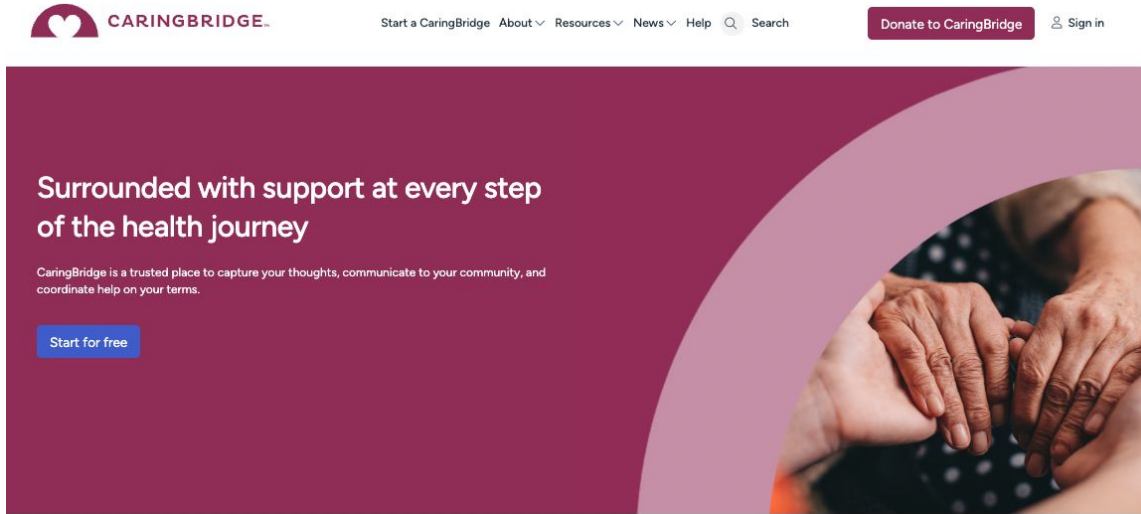
Talk Overview

- Motivation & prior work on **CaringBridge**
- Background on using **Reddit** as a study site
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- **What's Next:** Implications & future work



CaringBridge

- Health blogging platform
- Patients/caregivers write “journals”
- Friends and family subscribe
- Special privacy and safety features
- **45M+ users annually**



The image shows the top portion of the CaringBridge website. At the top left is the CaringBridge logo, which consists of a stylized heart with a white outline and a smaller white heart inside, followed by the text "CARINGBRIDGE." in a dark blue font. To the right of the logo is a navigation menu with links for "Start a CaringBridge", "About", "Resources", "News", "Help", and "Search". The "Search" link is accompanied by a magnifying glass icon. Further right is a dark blue button with white text that says "Donate to CaringBridge". At the far right is a "Sign in" link with a person icon. Below the navigation is a large hero section with a dark blue background. On the right side of this section is a circular inset image showing a close-up of several hands of different ages and skin tones being held together in a supportive grip. The main text in the hero section reads "Surrounded with support at every step of the health journey" in white. Below this is a smaller line of text: "CaringBridge is a trusted place to capture your thoughts, communicate to your community, and coordinate help on your terms." At the bottom left of the hero section is a blue button with white text that says "Start for free".



Communicate

Support that helps you connect.

Communicate to everyone all at once in a safe and private space, relieving the burden of individually updating people.



Capture

Support that helps you process.

The very act of capturing a loved one's health journey improves emotional health and social support.



Coordinate

Support that helps you ask for help.

Making it easy to ask for help, because we know it's often the most difficult thing to ask for.



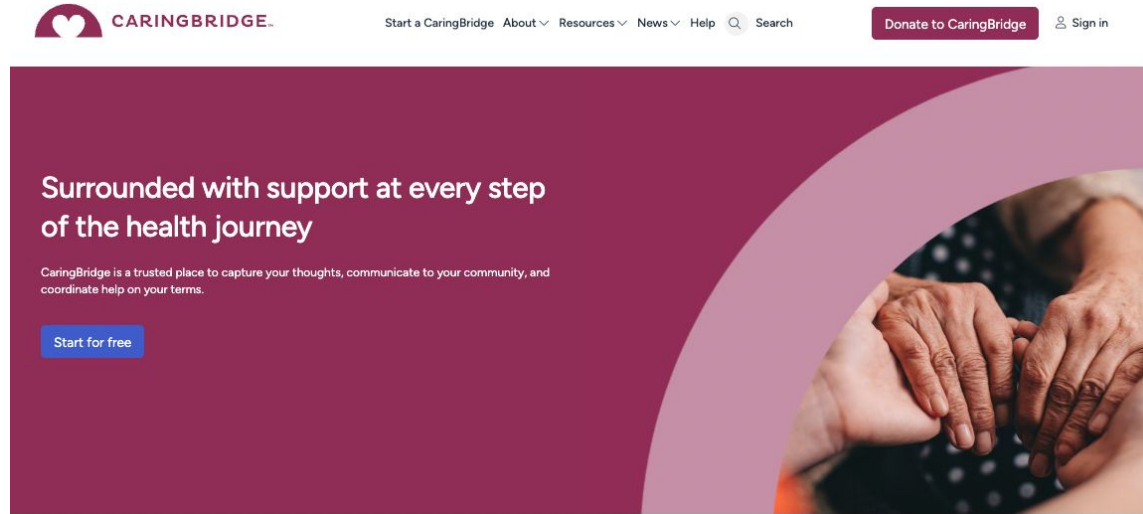
Community

Support that helps you feel less alone.

Bringing together the community of your choice to rally support and connect you with others who have had similar experiences.

Research

- **Human-Computer Interaction (HCI)** researchers frequently study online communities
- I partnered with CaringBridge for my PhD dissertation in Computer Science (6 pubs)



The image shows the top portion of the CaringBridge website. At the top left is the CaringBridge logo, which consists of a stylized heart shape with a white outline and a red fill, followed by the text "CARINGBRIDGE." in a dark blue, sans-serif font. To the right of the logo is a navigation menu with the following items: "Start a CaringBridge", "About", "Resources", "News", "Help", and "Search" (with a magnifying glass icon). Further right is a red button with white text that says "Donate to CaringBridge" and a "Sign in" link with a person icon. Below the navigation is a large hero section with a dark red background. On the right side of this section is a circular inset image showing several hands of different ages and skin tones clasped together in a supportive gesture. The main text in the hero section reads "Surrounded with support at every step of the health journey" in white. Below this is a smaller line of text: "CaringBridge is a trusted place to capture your thoughts, communicate to your community, and coordinate help on your terms." At the bottom left of the hero section is a blue button with white text that says "Start for free".



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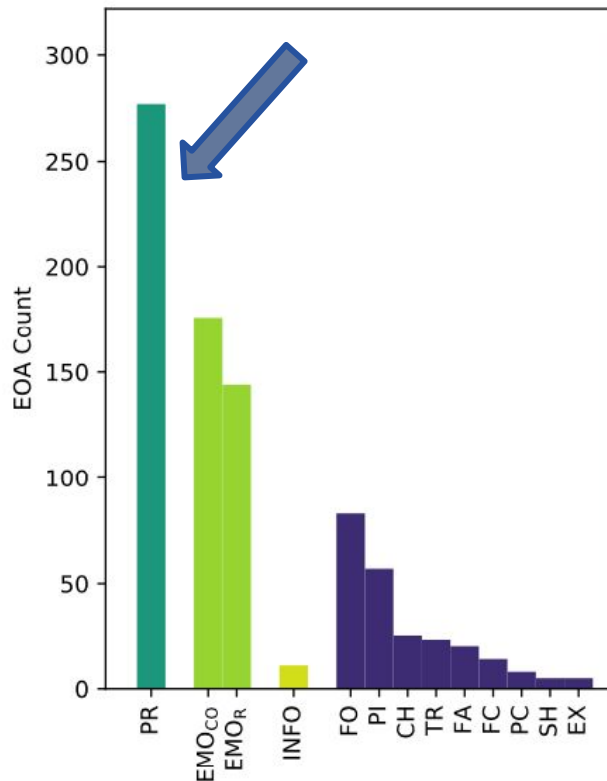
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Expressions of Appreciation

(Counted from behavioral data in CaringBridge Journals)



CARINGBRIDGE™



Ratings (Surveys)

Support Type	P/CG (m = 576)	FFA (n = 415)	Mann-Whitney U
Prayer Support (PR)	M = 3.18 SD = 1.14	M = 3.39 SD = 1.01	U=130617 p = 0.005** CLES=0.546 (d=0.16)
Remote Emotional Support (EMO _R)	M = 2.87 SD = 1.10	M = 3.10 SD = 0.94	U=132131.5 p = 0.003** CLES=0.553 (d=0.19)
Instrumental Support (INSTR)	M = 2.78 SD = 1.19	M = 2.73 SD = 1.24	U=121706.5 p = 0.609 CLES=0.509 (d=0.03)
Co-Located Emotional Support (EMO _{CO})	M = 2.51 SD = 1.14	M = 2.70 SD = 1.15	U=130975 p = 0.008** CLES=0.548 (d=0.17)
Informational Support (INFO)	M = 2.26 SD = 1.23	M = 1.88 SD = 1.37	U=138153.5 p < 0.001*** CLES=0.578 (d=0.27)

Subsequent work

- Multi-stakeholder design workshops to derive a definition of **Spiritual Support** (building on consensus definition of Spirituality from Puchalski 2009)
- New interfaces for **visualizing prayer** (Kaur 2021, Smith 2023)
- Other studies on expressive writing, gratitude, social connections between users, etc.

These results suggest that CaringBridge facilitates online spiritual care

- It's like a "*Prayer Engine*"
 - And that is what's most important to users!
- ...but what about people *without* well-formed support communities? 
- ...or people with *stigmatized* conditions who don't tend to create CaringBridge journals? (e.g., mental rather than physical illness) 

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- Online **forum-based** communities
 - Every imaginable topic under the sun
- **Anonymous** profiles
 - Enables more intimate sensitive disclosures
 - ...but also, all the “bad stuff” that comes with anonymity, as well
- **70M+ unique daily users**



r/lonely

+ Create a post

Join



Hot ▾



Community highlights

Reminder: Do not post your social medias or phone numbers on this subreddit.

1.9K votes · 0 comments



We are here for you :)

A community for all the lonely people. Everyone is welcome here, no matter your age, race, sex, sexuality, relationship status. All that we request is that you be accepting of people, and kind. Any problems at all, please let the moderators know.

389K

Members

112

Online

Top 1%

Rank by size ↻

u/yung-marlboro-420 · 8 hr. ago

Missing out on teenage love

26M here. As the title suggest, I missed out on teenage love due to a shitty childhood leading to socially anxious personality. How do you cope from the fact that you missed your prime years not having a relationship and realizing now it's too late

55

49



Share

u/serpentinexus · 3 hr. ago

Tomorrow is my birthday and all my friends have abandoned me

All my friends have abandoned me. I saw my ex best friend with one of my enemies. My other friend has also blocked me everywhere. I feel so sad and lonely. Only my sister and mom will wish me.

19

35



Share

u/Mysterious-Dust5519 · 3 hr. ago

If I stay home, I isolate and get depressed. If I go out, I see couples and get depressed

I'm 24F, Seriously considering a massage appointment tomorrow just to get touched. Life fucking sucks right

RULES

- 1 No discrimination, sexism or racism ▾
- 2 Please be kind ▾
- 3 No suicide encouragement, glorification, or notes ▾
- 4 Don't post personal information outside of PM's ▾
- 5 No NSFW or posts looking for a relationship ▾
- 6 Don't spam, advertise or push your religion upon others ▾
- 7 Trigger warnings ▾



r/cancer

Hot ▾ ▭ ▾

Community highlights

Welcome to /R/Cancer, sorry you're submitting any posts!

151 votes · 0 comments



u/jazzed-in · 10 hr. ago

Radiation therapy is just as bad as c

I hate it. I hate it. I hate it. No one has ever told me it's not gonna be as bad as chem worst, in my experience at least. I literally can't my mouth that feel like there's a thousand of t swallow food and drink water. I can't even brui time I put something inside my mouth, it leave

Patient

55 ▾ ▾

38



Sha

u/Kremplin7613 · 17 hr. ago

Why does no one tell you about wh:

(This is just a rant) I want to express the diffic adequately explained to me beforehand. The chemotherapy, and the countless painkillers I!



r/hospice

Hot ▾ ▭ ▾



u/ECU_BSN RN, BSN, CHPN; Nurse Mod

Educational Thread: "How long c

How long do we have? Timeline info question

This is, arguably, the most common quest hospice, understand why you are asking! I possible, to understand the timeline of the

41 ▾ ▾

27

Share



u/ECU_BSN MOD RN, BSN, CHPN; Nurse

Featured Community

Caregiver support (advice welcome)

I am grateful for the support and advice a r/CaregiverSupport community. This is a c advice, venting, and letting off steam.

8 ▾ ▾

1

Share



u/jim182182 · 7 hr. ago

Is my sister-in-law eligible for H

My sister-in-law has been unresponsive fr



r/SuicideWatch

Hot ▾ ▭ ▾



u/SQLwitch MOD · 5 yr. ago

New wiki on how to avoid accidentally encouraging suicide, and how to spot covert incitement

We've been seeing a worrying increase in pro-suicide content showing up here and, and also going unreported. This undermines our purpose here, so we wanted to highlight and clarify our guidelines about both direct and indirect incitement of suicide. We've created a wiki that covers these issues. We hope this will be helpful to...

1.8K ▾ ▾

248

Share



u/SQLwitch MOD · 3 yr. ago

Please remember that NO ACTIVISM of any kind is ever allowed here. No matter what day it is.

Activism, i.e. advocating or fundraising for social change or raising awareness of social issues (and suicide is, inescapably, a social issue) is absolutely against the rules here at all times. Please understand that we're all for smart, strategic mental-health and suicide-prevention activism. It's essential to fight against stigma,...

716 ▾ ▾

43

Share



u/funnyhowlifehappens · 12 hr. ago

I'm facing jail time and can't cope

People say own up and deal with your consequences but I can't. I'm not one of those people. I'm being charged with a THC DUI and even fighting it in court is costing me everything. My jobs as a nurse and nurse practitioner. My relationship with an urgent care doctor and that I just started dating off bumble. My apartment that cost \$2 grand a month. Idk how I'll pay for it and become so disrespected by everyone if I can't get it dropped. Which

+ Create a post

Join



Peer support for anyone struggling with suicidal thoughts

Peer support for anyone struggling with suicidal thoughts.

488K

Members

44

Online

RESOURCES

The SW Mod team also maintains r/SWResources.

If you need help for yourself, we've got a directory of voice and chat/text hotline services and FAQs about hotlines, plus selected online resources.

If you're concerned about someone else, you're welcome to post, also check out our talking tips and risk assessment guide. If you're new here and want to help, please read these two posts before diving in.

If you've lost someone to suicide, r/SuicideBereavement is there for you, or you can check out our shared list of bereavement resources.

Note: the Android Reddit app currently has a bug that causes wikis not to work - if links

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Methods: Participants

- $N=22$ professional spiritual care providers
 - Chaplains, Spiritual Directors, Directors of Spiritual Care Units, APCE Educators, Professors, etc.
 - Located coast-to-coast across USA
 - **Highly experienced**, 10+ years experience ($N=15$)
 - **Limited prior experience** with Reddit ($N=13$)
 - Diverse backgrounds (Christian, Jewish, Muslim, Buddhist, Humanism, etc.)
 - 11 female, 10 male, 1 non-binary

Methods: Semi-Structured Interviews

- Day-to-day responsibilities
- Existing use of and opinions toward technology
- Existing knowledge of patients' use of social media

Methods: User Testing Sessions

- Education on Reddit (if relevant)
- Choose 1 or 2 subreddit forums to visit
- Discussion on **observed** behaviors
- Reflections on **what is needed**
 - E.g. Compose a **response** to an existing post
 - Did not submit (i.e. avoid research interference with community)
- Pre- and post-test questions: *Did exposure to Reddit influence their opinions?*



r/ptsd · Posted by u/ [redacted] 18 hours ago

B



How do you handle a traumaversary?

Advice

Hi, I have a tough date coming up—it's the 7-year anniversary of something significant, and I'm dreading it. Usually, I sulk in bed, avoid people, and feel down for a few days before returning to normal. This year, I want to celebrate it as a "look how far I've come" day, but I know I'll still feel low at times. I wish I could forget this day, but I know I'll always remember and mourn it. How do you handle a traumaversary? I need advice and ideas to get through these days. I'd talk to a friend, but I'm worried about burdening them. What should I do?

3 Comments Share Save ...

Comment as [redacted]

[I think that talking to a friend is rarely a bad idea. Our friends often want to be able to help us more than we allow, and being vulnerable with someone is a gift if they are trustworthy.]
Anniversaries hang out in our bodies. The days leading up, as well as the days themselves. I try to "celebrate" too. [take the day off--no plans of any kind. Order food that feeds your soul. Sit outside. Feel alive as much as you can in this body to remind you that you are not in that moment anymore.]

B i @ S <> A ^ ! T ≡ ≡ ≡ 99 ... Markdown Mode Comment



We are a supportive, respectful community for discussion and links of interest for people who have PTSD or have friends, family members, or partners with PTSD. NOTE: We can not diagnose you with PTSD here. If you think you have PTSD, please see a licensed professional.

Created Sep 3, 2008

99.4k Members 141 Online Top 5% Ranked by Size

Join

Demonstrate caring & concern

Share words of hope and inspiration

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Positive reflections toward technology

- Recognized **need** for better technology within & outside of clinic
- **Eye-opening** experience to witness online disclosures
- Online communities perceived as **accessible & scalable**



Chaplaincy care can meet patients where they're @





“Thousands of people are here [online], saying hey, I need support. But my pastor friends are sitting in empty desks.” (P08)

“Similar to what's been known as street ministry, this could be a future opportunity in spiritual care---Reddit ministry. A Reddit chaplain.” (P16)



...but these spaces aren't yet ready for clinical participation





Pre- and post- test questions (1-7 Likert rating)

Minor (non-significant) increase

- Suitability of Reddit for spiritual care (4.82 ± 1.59)
- Personal interest in participating (5.11 ± 1.83)

Significant increase

- Healthcare systems should implement (5.94 ± 0.83)
- Healthcare systems should develop formal training & policies (6.06 ± 1.39)
- (*rated ~1 point higher*)



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Referring online users to standard care

“Encourage to seek support,” e.g., provide direct links, referrals, or resources to connect users with healthcare professionals, hotlines, etc.

Institutionally-Based Formal Care

Traditional care (in-person or virtual). Subject to medical liability, HIPAA constraints, insurance, financial structures, regulatory training.

Platform-Based Community Care

Informal care in online communities. Currently unclear financial accountability & not subject to traditional medical constraints, training, regulation. Requires careful future work.

Recommending patients for
supplementary online community support

E.g., clinicians provide information on trusted online communities and integrating these options into care plans.

Care Loop Benefits

- Increased **patient agency** in initiating care
- Greater **public consciousness** of spiritual care
- Serving more **people in need**

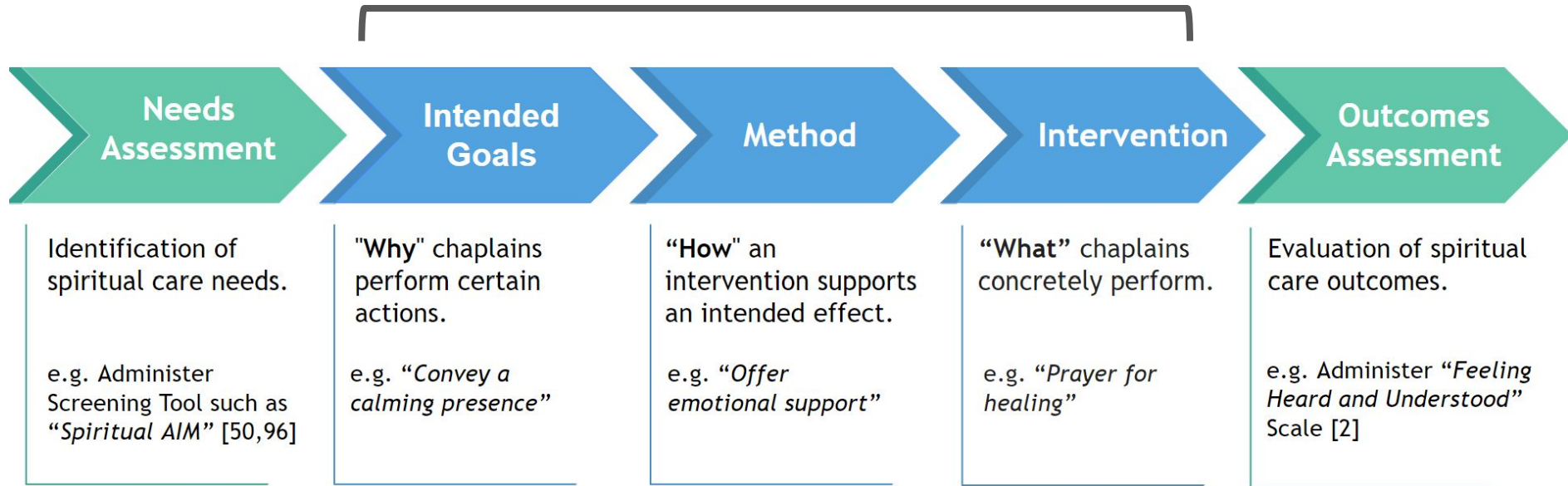
*...but there are numerous **research avenues** ahead*

Open Questions: *How to design for...*

- **Efficacy & safety** in meeting patient needs?
- **Trust & credibility** in the professional spiritual care community?
- **Logistical & pragmatic** feasibility?
- **Financial** models?
- **Organizational** affiliations?

(The list goes on.)

Advocate Health Care Taxonomy of Chaplaincy (Massey 2015)



For example, new interventions like: “Encourage to seek support,” “Educate on reply behaviors,” and “Apologize on behalf of other users.”

Future work

- National surveys
- Co-design workshops

- Maybe someday... real world implementation 🙌

Please be our very first survey participants!



*“Elisa” would appreciate
your opinions enormously*



bit.ly/spiritualcare2024

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[@c-estelle-smith-phd](https://www.linkedin.com/company/@c-estelle-smith-phd)



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Please share the survey, too!

bit.ly/spiritualcare2024

