On the Challenges of Implementing Online Spiritual Care Communities (OSCCs) in Collaboration with Diverse Healthcare Teams

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Spiritual care plays a crucial role in patients' health, particularly in end-of-life and palliative care contexts, yet there is a significant shortage of spiritual care providers to meet the increasing demand. This deficit results in unaddressed spiritual needs and reduced quality of life for patients. However, the increasing prevalence of telehealth and virtual care presents new opportunities for integrating spiritual care into digital spaces. Interdisciplinary collaboration between professional spiritual care practitioners and Human-Computer Interaction (HCI) researchers will be essential to navigating challenges such as lack of awareness about spiritual care, skepticism towards technology adoption, and the appropriate design of safe and effective digital interventions for spiritual care. Our current work focuses on designing Online Spiritual Care Communities (OSCCs) by leveraging insights from existing online support communities and engaging chaplains in design discussions. Preliminary insights suggest that challenges include establishing trust in online moderators, integrating OSCCs into clinical care, and determining the appropriate platform and governance models. We outline considerations for addressing these tensions through collaboration across the design of both sociotechnical and healthcare systems in order to effectively expand models of delivery for online spiritual care.

CCS Concepts: • **Human-centered computing** → **Empirical studies in collaborative and social computing**.

Additional Key Words and Phrases: health care, spiritual care, chaplain, spiritual director, online spiritual care communities, online health communities, intervention, prayer, spirituality, religion, CaringBridge, Reddit

1 AN URGENT NEED FOR SPIRITUAL CARE

Spiritual care, especially in end-of-life and palliative care, has been repeatedly demonstrated to improve important health and Quality of Life (QoL) outcomes [2, 3, 6] while reducing costs of care [1]. However, similarly to mental healthcare [5], there is an urgent deficit of spiritual care providers available to meet rising demand [4]. Medical care routinely neglects to include spiritual care, leading to unaddressed spiritual needs and decreased QoL [3]. There is a serious need for health care systems to innovate new methods for delivering spiritual care, including but not limited to emerging telechaplaincy practices [12, 13].

1.1 New Opportunities for Interdisciplinary Work in Spiritual Care & HCI

Prior work in HCI has established that spiritual support can be exchanged online, such as on the health blogging platform CaringBridge.org [8–11] (see Fig. 1). However, there is virtually no other work in HCI that considers clinically-adjacent spiritual care/chaplaincy. Partially, this is because the professional discipline of spiritual care rejected the adoption of technology before COVID-19 because it was considered antithetical to the practice. Yet the pandemic heightened the urgent need to consider new models of delivery [4], esp. given broader trends in healthcare towards telehealth and virtual services [13]. Consequently, a window of opportunity has very recently opened for interdisciplinary collaboration between professional spiritual care practitioners and HCI researchers. Numerous challenges must be considered while building interdisciplinary teams for online spiritual care: (1) many patients and researchers remain unaware of the existence and nature of spiritual care; (2) some providers may be skeptical of the prospective value and benefit of technology; (3) the metaphysical nature of spiritual or religious experiences can be challenging to study; and (4) there are no known guidelines in HCI for how to design safe and effective digital interventions for spiritual care.
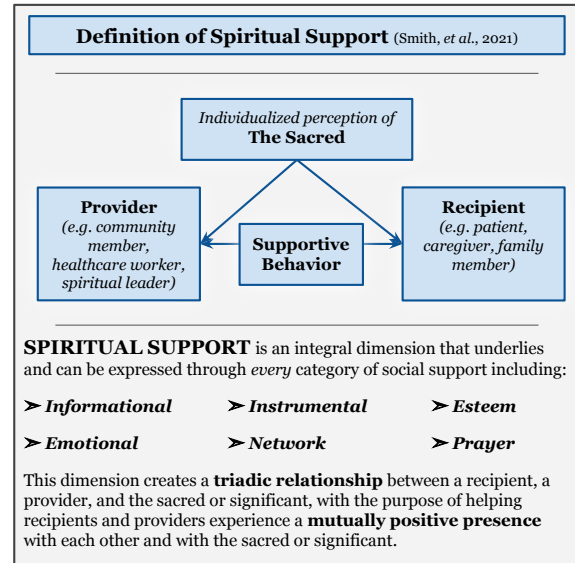

Fig. 1. Definition of Spiritual Support from [9].

1.2 Our Current Work in Online Spiritual Care Communities (OSCCs)

In order to initiate new conversations within the HCI community, this paper describes preliminary insights from our current work. As HCI researchers, we have formed a successful interdisciplinary team including a prominent chaplaincy researcher and a medical sociologist. We attribute the success of our team to extensive prior research experience and excellent communication. Our collaborators collectively bring *decades* of experience in spiritual care. Not only are they guiding our methodological choices, but they are also directly introducing us to excellent, experienced, and diverse participants, thus helping to overcome initial recruitment challenges. Additionally, we look forward to their support in navigating interdisciplinary differences in language/vernacular, paper styles, and publication venues. Our success highlights the importance of including seasoned and well-connected health professionals.

Our study seeks design insights from chaplains on how to design "Online Spiritual Care Communities" (OSCCs). We have previously observed that in "social support" communities on Reddit.com [7], *e.g.,* r/SuicideWatch, r/depression, etc., many anonymous users express serious isolation. We view such spaces as a rich opportunity to improve care for thousands or millions of users who may not have other support available. Reddit *might* be a reasonable site of future OSCC implementation, but we are not committed to Reddit. Rather, we view it as a complex and provocative study site for initial design work for several reasons. First, some subreddits are excessively toxic or abusive; others are wonderfully supportive and caring. There are no perfect safeguards in anonymous online communities, but they can

EMERGING DESIGN INSIGHTS	EXAMPLES OF PARTICIPANT QUOTES
Sociotechnical Requirements for OSCCs: **Trustworthiness:** Establish evidence-based online support communities rooted in current chaplaincy research, starting with pilot programs. **Outcomes:** Evaluate the actual impact of online spiritual support using established assessment frameworks from chaplaincy research and practice. **AI Integration:** Employ AI for various tasks, such as ranking comments based on relevance or quality, improving engagement through automated responses, and enforcing community rules.	*"I guess I'd want to know who the moderators were and who developed it [the OSCC] because, even in the arena of spiritually oriented care, there are certain people I trust and people I am less trustworthy of." -P01* *"[In OSCCs] we need measures that help us assess when is spiritual support helpful, and when it is harmful." -P01* *"Definitely put in keywords for AI to pick up to offer a list of resources that these people can reach out to." -P04*
Training and professional support in OSCCs: **Moderators:** Consider requiring chaplaincy credentials or training for moderators to address the challenges posed online more effectively. **Training Users:** Incorporate educational materials into online communities to offer lightweight training on chaplaincy techniques and best practices, aiming to enhance the quality of support provided. **Professional Support:** Develop online platforms to provide chaplains with professional resources and best practices, including inter-faith resources.	*"[We need to] train people to be moderators like how we clinically train people for group supervision or group therapy." -P01* *"Users might not have the skills to reply, so it's like supporting me with some kind of resource materials that trains me or maybe it could be a video." -P04*
Future HCI Work for Clinical Spiritual Care: **Data Science:** Enhance spiritual support in hospitals by ensuring diversity and inclusion, avoiding referral biases through proactive inquiry of electronic medical record (EMR) data. **Appropriate incorporation of AI/ML Clinical Models:** Predicting terminal diagnoses, length of life remaining, recommendations for palliative and spiritual care services.	*"There's so much more that could be done with the data we have. . . . You don't end up in chaplaincy because of those kinds of [data] skills. So, we're probably behind other fields." -P11* *"Historically what happens is, a hospital takes that information. . . . We're realizing that information is useless if we're not actually integrating it into the care plan." -P10*

Table 1. Emerging Design Insights.

nonetheless cultivate strong norms and potentially expand access to care. Second, patients using Reddit may or may not have clinical oversight, so there is no clear clinical responsibility to users, but users would benefit from evidence-based care. Finally, patients may prefer or benefit more from anonymous care, and many are already on Reddit; it may be possible for chaplains to "meet them where they're at." HIPAA rules, insurance considerations, and payment for care labor apply in clinical settings, but anonymous users online are not governed by codes of ethics or reporting rules; it is unclear whether or how creating clinical bridges to such spaces is feasible.

We are now conducting interviews and user testing sessions with chaplains. We ask about chaplains' prior experiences with social media and then explain Reddit's affordances. Next, we ask chaplains to explore live subreddit(s) of relevance to their patient populations, reflect on their perceptions of the [in]effectiveness of emergent user behaviors, rules, etc., and share about how they might respond to users' posts. We are now analyzing these data to derive design implications for OSCCs, and to understand whether or how we might integrate the recommendation or use of OSCCs in clinical care.

1.3 Preliminary Insights

Table 1 summarizes emerging insights. Given the sensitivity of delivering spiritual care, our data indicate that moderators must be trained; whether they are volunteers or professionals, clinical oversight in training and trust-building is needed. For users in spiritual crisis, basic meaning-making processes must be respected without imposition of others' beliefs on them. Thus, our data likewise suggest that users should receive training on spiritually respectful communication and question-asking before being allowed to interact. We have gathered numerous suggestions on the sociotechnical, digital and UI/UX aspects of OSCCs of anonymous strangers, and how OSCCs might/not fit within the healthcare system. Several tensions and open questions are apparent:

(1) How can we collaborate with clinicians longterm to maintain OSCCs safely, effectively, employing best practices of professional spiritual care?

(2) Should OSCCs be affiliated with hospitals? And how would that fit within existing clinical models, HIPAA, insurance, etc?

(3) Or, should OSCCs be affiliated with geographically situated religious or spiritual organizations? Could mods be leaders or volunteer coordinators vetted by these institutions?

(4) Can we use existing platforms like Reddit, Facebook, *etc.* to host OSCCs? Or do we need to design custom platforms to comply with regulatory or institutional needs of affiliated entities?

2 CONCLUSION

Leveraging HCI research methods and design techniques will be crucial for effectively supporting the emerging expansion of spiritual care online. In our future work, we plan to conduct large surveys of spiritual care providers and patients/caregivers, followed by design workshops to prototype OSCCs. However, OSCCs are not necessarily the only nor the best way to consider clinical spiritual care in HCI. There is important work to be done in supporting spiritual care workers *within* clinical settings, and in taking a design approach centered around spiritual wellbeing in settings beyond disease and illness-states. Our world needs a massive shift and re-focusing toward spiritual wellness, peace, and love: OSCCs represent one step in that direction.

ACKNOWLEDGMENTS

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