Sacred Be Thy Tech: Thoughts (& Prayers) on Integrating Spirituality in Technology for Health & Wellbeing

C. ESTELLE SMITH, University of Colorado Boulder, USA

Spirituality and religion have played fundamental roles in how people have coped with illness, dying, and death since the earliest days of human society. Yet they have also largely been either minimized or omitted from the HCI literature on technology for health and wellness. This omission not only marginalizes fundamental aspects of human identity, healing, and experience, but it also limits the insights and benefits that can be gleaned through human-centered design. In this position paper, I describe the intertwined personal and research narratives that led me to pursue the study of computational spiritual support. I provide an operational definition of spiritual support, a high-level description of how this definition can guide design, and a set of vital questions that should be addressed through future work in this domain.

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

Additional Key Words and Phrases: religion, spirituality, spiritual support, health, wellbeing

ACM Reference Format:


If you’ve ever seen a sensitive health disclosure posted on social media, then you may have also noticed comment responses containing phrases like, “praying for you,” “sending good vibes,” or “let me know how I can help.” [19, 20] Perhaps it’s your favorite-but-oddly-specific support community on Reddit, and one post happened to ride a wave of karma straight to the top of the feed. If you’re on Facebook, that post might receive some 😊, 🙏, and 🙌, but on Twitter, it’s all about the ❤️. On CaringBridge (www.caringbridge.org)—an online health journaling platform that serves over 40M users per year facing life-critical illness—supporters can share kind words or offer 💐 and 🙏, occasionally triggering a wave of viral #prayfor[so-and-so] requests across the Internet [2].

To varying degrees, the language and graphics of these online interactions clearly evoke spiritual or religious connotations. And indeed, since the earliest days of human society, spirituality has been tightly knit within the fabric of our cultures, governance, and health systems—i.e., when people get sick, they turn toward what is most sacred or significant to them to help cope with suffering, and to derive meaning and support. Yet the disciplines of Human-Computer Interaction (HCI) and Social Computing have largely ignored spirituality in computing and technology design [4, 5, 19]. This omission not only marginalizes fundamental aspects of human identity, healing, and experience, but it also limits the insights and benefits that can be gleaned through human-centered design.

After six years of research in online health communities, my interpretation of the support interactions above is that when people are in a state of crisis, they express and respond to each other’s spiritual needs via the sociotechnical mechanisms available to them, whether or not those mechanisms were explicitly designed with spirituality in mind. Yet people often have remarkably different belief systems; this is problematic when a support seeker’s needs clash with their supporters’ responses. Imagine, for example, a post written by an atheist that

Permission to make digital or hard copies of all or part of this work for personal or classroom use is granted without fee provided that copies are not made or distributed for profit or commercial advantage and that copies bear this notice and the full citation on the first page. Copyrights for components of this work owned by others than ACM must be honored. Abstracting with credit is permitted. To copy otherwise, or republish, to post on servers or to redistribute to lists, requires prior specific permission and/or a fee. Request permissions from permissions@acm.org.

Conference acronym ’XX, June 03–05, 2018, Woodstock, NY © 2018 Association for Computing Machinery.

ACM ISBN 978-1-4503-XXXX-X/18/06 ... $15.00

https://doi.org/XXXXXXX.XXXXXXX
receives a bunch of “thoughts and prayers” or reactions. All of humanity is unlikely to agree on the existence of G/god(s), spiritual entities, or life beyond death. My point has nothing to do with the “truth” of any particular beliefs—and everything to do with the fact that everyone holds their own beliefs near and dear in ways that deeply impact their needs and experiences, especially when facing illness. **If we aim to take a truly human-centered approach, we must account for people’s most deeply held spiritual values when designing sociotechnical systems for health and wellbeing.**

In this position paper, I will begin by defining key terms and concepts. Next, I describe the intertwined personal and research trajectories of my doctoral work that have defined and crystallized my interests in **computational spiritual support**. Finally, I share aspirations for future tech design and open questions in this domain.

1 SPIRITUALITY & HEALTH ACROSS MILLENNIA

Religion refers to institutionalized systems of beliefs, practices, rituals and values that vary along denominational and doctrinal characteristics and experiences [15]. Spirituality is a broader construct that can encompass religion [21], as well as non-religious activities like meditation, exploring nature, breathing exercises, or journaling [18]. The following is a commonly used definition of spirituality derived through a national consensus of health experts and faith leaders [17]: "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.”

Although the diversity of human beliefs is endless, most humans become more concerned with spiritual matters when coping with life-threatening illness [17], while spiritual communities often rally to support their ill. For example, in indigenous cultures across the globe, shamans provide leadership and healing rituals to connect their tribes with nature, spirit guides, and ancestors [10]. Ancient Eastern traditions such as Ayurveda (out of India) [12] and Traditional Chinese Medicine [11] emphasize holistically balancing mind, body, and spirit through nature-based foods, medicines, and exercises. In the Abrahamic traditions of Judaism, Christianity, and Islam, clergy assume an intimate role of guidance for congregants facing health crises by performing sacraments or ceremonies, as well as through softer, more social forms of care [13, 16]. It is equally salient to note that religion can have extremely damaging impacts, e.g., manipulation or radicalization of individuals, repression or exclusion of disallowed identities, or Religious Trauma Syndrome (RTS)—a PTSD-like condition resulting from the trauma of abusive or controlling environments, lifestyles, or religious figures [22].

Given the powerful implications of spirituality for human health and wellbeing, a variety of medical conferences now have explicit foci at the intersection of medicine, spirituality, and healing. Yet unmet needs for spiritual care continue to rise, especially in light of the COVID-19 pandemic [9]. Set within a healthcare system that was already insufficiently equipped to meet people’s psychosocial needs, the pandemic triggered not only widespread isolation, and a concerning rise in mental illnesses like depression, anxiety, and PTSD, but millions of families also lost loved ones without the vital ability to visit the hospital, provide caring in-person presence, or even to hold cherished spiritual ceremonies or funerals. Many people died without access to support networks or professional spiritual care, and the spiritual toll taken on both individual and community health has been devastating—yet the expansive body of HCI work on health and healing has largely ignored spirituality.

So, as a fledgling PhD, I wouldn’t have believed you, had you shown me the title of my future dissertation: “Beyond Social Support: Spiritual Support as a Novel Design Dimension in Sociotechnical Systems.” Yet here we are—a world where such a document somehow now exists in the Digital Conservancy of the University of Minnesota. Because my positionality as a researcher is inextricable from the analytical lens I have applied, I want to next share the story of how that came to be.

---

1 E.g., Conference on Medicine and Religion (www.medicineandreligion.com), Annual Conference on Caring for the Human Spirit (www.spiritualcareassociation.org/conference), Annual Assembly of Hospice and Palliative Care (http://aahpm.org/meetings/assembly)
2 AN UNEXPECTED RESEARCH TRAJECTORY

2.1 The Personal Arc

I was raised in a conservative and practicing Catholic household where I was not offered the choice to explore my own beliefs, and I began to experience mental illness around the age of 11. In retrospect, I attribute the origination of these issues to RTS. Leaving the church in my early adulthood was a painful but necessary choice for my personal evolution and healing—and the decision was especially contentious to my mother, whose faith and church were very dear to her. For the next decade, I usually considered myself agnostic, and sometimes atheist, as I struggled to find meaning and cope with my mental illness. Tragically, as I was considering graduate programs in my late 20’s, mom was unexpectedly diagnosed with a rare and aggressive cancer that took her life within 3 months. I was shocked. We all were. It happened so fast.

A few days after mom’s death, I discovered that her close friend had written a CaringBridge journal for her, sharing all the major treatment milestones and situational updates since her diagnosis. No one had told me, but somehow the whole church knew. Given how quickly the cancer had progressed, there were only a handful of posts. But during that tender window of profound grief, it moved me deeply to see that folks had been following along with her, sending love and prayers, and even holding vigil for her synchronously the day she died. When I began my PhD, her death was in the rearview mirror by only about a year. And within a month of starting the program, my co-advisor made an unexpected announcement at weekly lab meeting. A new collaboration had been forming over the past year with a local nonprofit called CaringBridge—were any PhD students interested in joining? ... Well, yes. Yes, I was.

As a scientist, I am committed to empiricism and evidence-based pursuit of fact. Much to my surprise, during graduate school, this empiricism intertwined with my own experiences of grief and mental illness to shape my perspective and beliefs toward a more decidedly spiritual, nature-based, and non-religious view of the world. This sense of spirituality has continuously helped me to survive these past few years of global trauma and chaos; I don’t believe I would have made it out of grad school alive without it. Because my beliefs have changed multiple times during my life, I now tend towards a universalist view that most belief systems point to similar underlying principles, and I do not hold absolute perspectives. Rather, I seek to observe and honor the many ways in which spirituality can support (or harm) our healing processes—and to help align technology development with the greater spiritual flourishing and evolution of humanity. I believe science can, and should, help us to do so.

2.2 The Research Arc

I have read thousands of journal updates and survey responses from CaringBridge users. I have interviewed and conducted design workshops with dozens of stakeholders. Yet one pivotal moment of summer 2017 stands out.

I was working on my second study of CaringBridge at the time. Our first study had shown that, as in my mom’s case, approximately 34% of all journals for cancer patients concluded with patient death. Yet factors like receiving supportive comments, writing expressively, and offering supportive comments to others correlate with sustained use of the journal [14]. But what about the content of these journals? What types of help did CaringBridge users appreciate exchanging during such intense and life-threatening health crises? I was working with a wonderful undergraduate research assistant, Gemma, who was developing our codebook for inductive content analysis. We had begun with conventional social support categories (e.g., informational, emotional, and instrumental support [6]), but we were musing about words like “prayer” and “karma.” A few prior studies had included examples of words like these in their emotional support category, but Gemma and I agreed—the way that users wrote about prayer was different. It was specific, pervasive, and urgent, and it was often tied to mentions of scriptural names or sacred texts. We decided it would best suit the data to break prayer into its own category. This decision didn’t seem like a huge deal at the time, but it became the singular moment that would go on to steer my entire dissertation in a new direction. As it turns out, users not only wrote about matters of prayer or spiritual
support most frequently, but when we later surveyed them, they also rated it more highly than all others [20]. When I first saw the ratings, I had to laugh. It almost felt like mom was striking back from the grave to show me the power of prayer—with the irony being, of course, that I had arrived to this conclusion only through my most rigorous and scientific efforts.

Beyond its frequent linguistic appearances as “prayer,” “healing vibes,” or “good karma,” what does the concept of “spiritual support” truly mean to users? Because of our striking results on prayer support, it became clear to me that something was missing from the literature on health and healing in HCI. Therefore, I next conducted participatory design workshops in order to define spiritual support, and to understand how stakeholders felt it related to the design of online systems and communities. In late 2019, I had the good fortune to conduct these workshops in person with patients, caregivers, spiritual leaders, health care professionals, and CaringBridge employees shortly before the pandemic struck [19]. With an eye toward inclusivity, I worked hard to recruit participants of diverse beliefs, including everyone from atheists and agnostics, to the three major Abrahmics, to yogis and shamans. Through this work, I have derived a set of UI/UX concepts to guide future system development efforts for spiritual care. I will conclude by sharing some of these ideas, and how I hope practitioners and researchers will approach spirituality in design moving forward.

3 TOWARD COMPUTATIONAL SPIRITUAL SUPPORT

Spiritual support is an integral dimension that underlies and can be expressed through every category of social support, including informational, emotional, instrumental, network, esteem, and prayer support. This dimension creates a triadic relationship between a recipient, a provider, and the sacred or significant, with the purpose of helping recipients and providers experience a mutually positive presence with each other, and with the sacred or significant. [19]

Participants described their experiences of spiritual support as moments when they felt deeply connected to themselves, to others, and to what brings their life or suffering a sense of meaning. On the surface, supportive behaviors like dropping off a lasagna (instrumental support) or sharing links to medical resources (informational support) could be considered conventional social support. Yet participants told us that these behaviors are motivated by deeper feelings of spiritual connection, and that the delicacy and sensitivity of how they are executed makes a massive difference in how effectively support is received. Thus, accounting for the spiritual dimension of these behaviors in our studies will honor what is most sacred or significant to users, resulting in a whole-human centered approach that empowers practitioners and researchers to design communities, systems, or interventions that are more attuned to people’s deepest needs during their darkest hours.

In our workshops, we first asked participants to define spiritual support, and then to ideate on how technology could facilitate it. Most ideas (62%) revolved around community and human dignity—either by connecting people with existing support communities, or by providing access to new, safe, and spiritually affirming spaces for healing and support. Many participants emphasized how technology could better serve specific religious or spiritual communities; others pointed toward the basic need to provide people who are suffering with simple kindness and loving presence, detached from specific beliefs. Other (non-mutually exclusive) ideas incorporated: sound and text (22%); practical resources (17%); VR/AR (12%); AI (10%); and physiology (7%). Narrowing the focus to online health communities like CaringBridge, [19] provides design implications for representing spiritual beliefs, technological assistance with supportive communication, advance care planning and digital legacy, and visualization of support networks. I refer readers to the paper to explore those implications in depth, and focus here instead on open-ended questions that can shape future research trajectories.

When is technology the right solution for spiritual support? And when is the better solution to turn all the technology off? A perennial problem in HCI is to “throw some tech at it” when, in fact, technology could make things even worse. [3] A technology like CaringBridge creates opportunities for support and care
that could not exist without it, and which truly do provide focused, meaningful spiritual support. However, participants expressed concerns about how other types of platforms may be more likely to distract from or diminish our capacity to fully realize meaningful human connections during health crises—e.g., endless social media scrolling can provide a too-convenient escape hatch, or a simple reaction might be a too-easy shortcut for more intentional support. One vein of research should explore how to best facilitate spiritual support, while another should explore how to help people eschew the distractions and eliminate technology uses or behaviors that cause more damage than good.

**How can we design interfaces, algorithms, and support mechanisms that honor spirituality within specific spiritual or religious communities, vs. within broader contexts and communities where beliefs can differ extremely?** Religious disagreements have been among the thorniest contentions in human history—causing everything from wars to deathbed familial estrangements. Indeed, people’s spiritual beliefs are always deeply personal, and can vary significantly even when people share the same creed. Future research should explore how to shape support interactions that foster respect and care, even when people disagree on these fundamental issues. Some solutions should be tailored for groups that do generally agree (e.g., a specific temple, church, mosque, or ashram), while others need to confront the reality of heterogeneity of belief systems in online spaces (e.g., online health communities where people of many different beliefs co-occupy the same spaces).

**How can technology support spiritual flourishing and adaptation, rather than repressive or traumatizing adherence to beliefs that are no longer serving an individual?** In my mom’s case, Catholic prayer, rituals, and beliefs were undeniably the most vital and sustaining form of support she received as she died. Yet had I been in her shoes, to impose those same practices upon me would be inhumane. Healthcare workers in my workshops discussed a basic need for humans to have flexibility to explore their own beliefs and adapt them when necessary in light of the new realities of illness; in cases where this flexibility does not exist, they described difficult stories of terrible suffering stemming from problematic beliefs (e.g., “I am dying of cancer because I sinned and am unworthy”). Yet both hierarchical religious structures and online affordances tend to enforce existing practices or norms, which may be damaging or inappropriate in some cases. Future research should draw upon community assets to support people, while also remaining sensitive to individual people’s processes for discerning, articulating, and adapting their spiritual needs.

Many additional questions are also worth exploring, such as:

- How can we collaborate with medical communities to integrate clinically-validated evidence and best practices for spiritual care in sociotechnical systems that extend within and beyond clinical settings?
- What are the roles of AI and automation in the provision of spiritual support? How can we design these effectively and ethically?
- How can we ensure that technologically-mediated forms of spiritual support do not diminish the authenticity, meaningfulness, and quality of supportive interactions and relationships?

4 CONCLUSION

Back in 2013, Buie and Blythe speculated that the discipline of HCI may have historically avoided spirituality and religion due to the difficulty and sensitivity of this line of work, along with concerns about perceived scientific legitimacy, funding opportunities, and professional reputation [5]. However, given that institutions such as the Vatican [8], individual spiritual communities [1], and tech giants like Facebook [7] are now using technology to coordinate spiritual communities and activities, it is absolutely vital that researchers challenge the entrenched status quo and examine spirituality in these contexts. I believe that pursuing questions of the nature described above will empower individuals and communities to provide more sustained, holistic, and humane care with improved patient outcomes. And I look forward to connecting with communities of research and practice who
are ready to adopt a whole-human centered approach, and to pave the path toward the conscientious, respectful, and ethical integration of spirituality in technologies for health and wellness.

REFERENCES


